

INVOLVING PATIENTS, CARERS AND FAMILIES: AN INTERNATIONAL PERSPECTIVE ON EMERGING PRIORITIES.

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ABSTRACT

Over the past two decades, health care reforms, methodologies and how the system changes as far as the dynamics in family structure and social situation changed has made the health care provision change as well. Are you capable of keeping the pace? This is the question that needs to be addressed.

The budget allocations, the intensity of medications utilized in psychiatry, the availability of the psychological, social and other interventions desired and the involvement of the agency, government and the private sector is significantly disproportionate to the care required and desired by the families and the patients.

We want to highlight some of the important parameters involved in the situation and ways to change these parameters in the best interest of the patients and the families as better outcome and prognosis. Although they might appear to be the same, there are differences in different regions of the world.

The provision of resources is variable in developing countries as compared with the developed countries. Involving the families and care providers is undoubtedly a significant method to get the better outcome and prognosis.

INTRODUCTION

People who are paying to receive the health care and the agencies involved expects differently from the way the health care provision is currently practiced by the professionals¹. The health care professionals perceive that safety and the symptoms removal is the key, however for families and the patients the perspective is to achieve a complete remission and go back to the premorbid level.

To achieve this balance where both the parties are at the same page where the patients and the families are getting what they desire and the health care professionals are providing what is expected; possible can be achieved if certain parameters and domains are fulfilled to create a balance between the two.

DISCUSSION

Considering the amount of money and resources spent this harmony should be achieved, if it won't be then the chaos seen in the hospitals and other facilities is immense and huge amount of resources are

spent to overcome the chaos rather than to provide services. In the end we expect to get the appropriate answers to these questions rather than complicating the situation.

In the beginning we have to address a question; are we doing enough to involve the care givers and the patients in achieving the appropriate outcome? To respond to this questions we have to understand that every family dynamics and the patients are different from each other, so a client coming from London will have different dynamics (Including family) from the one coming from Bombay. The segmentation of the patients is essential in this case. This simply means that one size does not fit all².

The second question is do we involve the caregivers and the patients into health care provision system? In different cultures, communities and countries it is different³. In developing countries there is no option and most of the patients are coming with families and in the developed countries the individuals are responsibilities of the state, like in UK, Canada and Eastern Europe. So an individualized system needs to be developed for each segment again.

The third question is regarding the decision-making. In most of the situation the decision is made by the health care providers and the family and the patients are conveyed the decision⁴. The decisions are discussed, however these decisions are usually one-way traffic and not mutual or two way traffic flow. This means if the diagnosis of the health care provider is wrong everything collapses down.

The fourth question is related to the self-care. This is mostly related to the fact that patients should be involved more and more in preventive aspects rather interventional model. They should be able to understand the importance of health. This can be achieved if the policy makers are involved in provision of health education more and more. The media and the internet have challenged this and most of the patients and the families get the knowledge of the symptoms and the diagnosis after the things are complicated and the health care professionals are involved and by this time they ask questions what to do next⁵. It should be other way round, health education should be part and parcel of each curriculum taught in schools, colleges and universities rather than getting sick and then reading about it. So if the awareness is created at broader levels then prevention and out come both can be improved significantly.

Fifth question is, are we capable of mobilizing appropriate resources at appropriate time? In most of the countries of the world either

developed or underdeveloped, the resources are not properly mobilized at the time they are desired. This mainly is because the health care providers do not consider this issue prior to the interventional strategies; they try to understand the flow and availability of the resources only after the interventions start failing.⁶ We can achieve this target very conveniently by utilizing some human resources to gather the information before the intervention.

Sixth important question again comes as an information strategy; Are our patients and the care givers provided with good information they require or is essential rather than the information desired at that point in time? Usually the consultation is provided which is time barred and we cannot fill up this gap in limited period of time⁷. In developing countries like Pakistan and Bangladesh, the human resource is not very expensive and few people can be deputed to gather the provision of information before the actual consultation is provided. However this remains a question for the health care professional when and who will organize this. This needs to be addressed by the administration of the hospitals or the clinics. It is easy and may give forth valuable outcome.

The seventh question is related to the research and teaching; Do we involve our patients in teaching and research?⁸ This is usually practiced in the teaching universities only, which is provably less than 20 percent of the total health care providers setup across the globe. If we will not start moving in this direction, soon robotics will take over and the situation will get worse than what it is at present.

Do we utilize the assets appropriately in the communities? The assets, which are available, are huge; in most of the Islamic countries huge amounts of donations and affording class does philanthropic work. Same goes for the societies which are usually religiously more inclined. Usually the health care providers are least bothered about these resources and they leave every thing to the administrators and other people involved in care rather focusing and spending some time in understanding the resources available around them to provide to the patients.

The ninth question is, do we incorporate the comments, feedback and appreciation remarks into consideration to form policies and new health care models?⁸ Whenever new projects are made or are implemented we usually do not bother about the recipients' response. Most of the projects are made in closed rooms with out involving the patients, care providers and health care professionals, across the globe. This is the problem never addressed appropriately.

If we incorporate these issues, respond to them and try to understand the dynamics in broader perspective as the emerging trend, this will increase the involvement of the patients and the care providers into health system and policy.

CONCLUSION

The achievable solution and need of this time and times to come is to increase the patients' involvement, activating their participation, and boarding them in the decision making; all models of health care provision should be made with their involvement and participation.

We have to develop a workforce that can reach out to our patients and care providers and be available to engage them, involve them

and make arrangements to respond to their queries and questions with the theme of prevention is better than cure⁶.

The funding, payments and the financial resources available should be tapped, incorporated before the interventional strategies rather tapping them during the treatments.

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