

EDITORIAL

Methodological challenges in studying the chronically ill elderly: Ethical need to include caregivers

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In low- and middle-income countries, caring for the elderly is a responsibility that is undertaken within households with minimal institutional support from the community or structural support from the state [1,2]. Usually, this responsibility is shared within the home, with the physical and emotional work of caring falling to the one who does not have too many extra-residential responsibilities. The gendered nature of caring responsibility is such that, usually it is women who are not in the formal or informal labour markets who share the responsibility [2,3].

Need to recognise care-giving burden

Care work changes over time, in terms of the nature of care and the work involved. As the elderly person ages further, the responsibilities of the carer increase. But as this increasing carer responsibility is a slow process, the increasing dependence of the elder on the carer is not recognised, even within the household. In addition, with time, as the elderly get confined to limited spaces and may get bed-ridden, due to age or illness, the carer also gets confined to that space [4,5]. In the process, identities and needs of the carer and the person cared for merge. Within a household, the carer gradually becomes the “expert” in care, and therefore, for household efficiency and maximising utility, it suits a household to “enable” this caring role. The demands of the role increase to become a full-time responsibility for the carer. When the care giving role falls to women, as it often does, gendered norms and values prevailing in our communities (and our homes), ensure that women take it on as their routine responsibility. Gradually, a majority of the carers identify with the object of care, the interests of the elderly person, excluding themselves from the frame of reference for well-being; and so do other family members. Often, such carers are not without individual resources or agency. However, as the process of caregiving gets prolonged due to the chronicity of the condition, caregivers may eventually stop recognising their own interests and start prioritising those of the elder they are caring for [6,7]. The caregivers try to satisfy their caring obligation by using their own resources because their caregiver identity is linked to their sense of self-worth. So, they are reluctant to use their social capital in the context of some of their caring responsibilities. It is more likely that the caregiver will not be able to fulfil the reciprocity obligations of any help they receive, because of their caring responsibilities. Thus, they also have a tendency to take on personal care obligations, and this results in longer hours of care burden [8].

Thus, the carer burden tends to leave women, more often than men, with limited time and resources (both material and human) for pursuing personal goals. For the household and community, it is convenient for this person to continue in that caring role and thus optimise household efficiency. This is not without a cost, but the cost to the carer is subsumed within the overall household utility. When one person (usually a woman), takes on the carer’s responsibility, it leaves all others free to work for their own welfare. Thus, collectively, other household members benefit, but the individual carer actually suffers losses. When the carer role is withdrawn due to death or greater mobility of the elder, the carer may have no fulfilling role or identity left to claim as their own. And in the process of becoming an “expert carer”, he/she has no remaining self-identified goals, save those associated with the elder person who was the object of care. It should also be remembered that such carers are also frequently elderly themselves [2,3].

Consequences of excluding social costs of care-giving while examining elder healthcare

The caring role taken on by persons within households and its cost has implications for the methodologies employed to study

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elderly patients of chronic diseases. Their inability to self-manage could be due to the nature of the condition, the cultural factors that facilitate or hinder self-care, the institutional arrangements that they obtain, and the structural factors that operate on the elderly and their care. However, these are subsumed under the broad rubric of expenditure involved in medical and other management, which very often ignores the human costs involved. For instance, examining the elderly patient and their management may require inputs from the primary care giver. Alternatively, the trade-offs among various members of the family may assign specific individuals to take on the role of caregiver. The resources available to the patient and the caregiver to manage care depend on the socio-structural factors such as type of household, household incomes, educational resources available to the patient and the carer. For some chronic conditions, other material resources that can be accessed, such as transport for travel to hospitals, the ability to negotiate the hospital's requirements, are all incumbent upon the accompanying person's ability to manage the required resources.

Research on chronic care involves several layers of complexity. Chronic care comprises the entire care-giving unit which involves the patient, the primary carer, the immediate family, the other social supports and the health system. Therefore, the process of chronic care involves interactions of these members with the patient and among themselves. Most analyses of chronic care tend to overlook the skills, resources and costs to the care-giver and other components of the care-giving unit in the process of caring.

Therefore, information collected from the elderly patient alone may be incomplete or at times even erroneous [9,10]. On the other hand, the resources that the patient utilises may be those that are available to the caregiver and not directly accessible to the patient. The costs of care that go beyond the material may also include opportunity costs incurred by the carers. Therefore, the patient management group needs to be treated as a single unit for analysis and the roles and responsibilities of individuals within it, including the primary caregiver, need to be carefully delineated for any specific analysis. Sometimes the costing of care-giving must also account for all the social capital that it draws upon, including physical, informational, financial and emotional social supports.

Such research needs to treat the intra-household and social exchanges and burdens as variables in the analysis. But often, by individualising the management of care and its costs, the hidden costs to the society, the household and the carer are ignored [11,12]. In such processes, we also tend to ignore the potential for privileging certain types of elderly over other elderly within the society and even within the same household. There could be a potential for economies of scale operating to minimise the care burden, or it is possible that the trade-offs between the privileged elderly and others within a household leave some elderly bereft of appropriate care.

Methodologies that could facilitate the processes of counting the care-giving costs

In most surveys, we tend to select a specific elderly individual using a random selection process and describe their health and healthcare costs [13]. Once one person is selected, all specific details pertain to that selected individual. It is expected that the random selection of individual elderly within households will enable us to capture the varying nature of elderly care and its burden. However, such a process misses out on the intra-household transactions and trade-offs which result in privileging some elderly or depriving some. Not only is this research finding inaccurate, it is also unjust because it fails to represent the experiences of the more vulnerable care givers.

We need to evolve research methods which allow for multiple respondents to report on their contributions to care so that each of these can be counted. To initiate such work, perhaps we can make a start by counting the number of elderly within households and determine their positions in the hierarchies of care and care burdens while examining the health of the elderly and healthcare. Using the theory of dyadic illness management which recognises the interdependence of this team may help to identify the nature of the functioning of the dyad [10]. For example, such an approach may help to identify the carers and their opportunity costs as an important area of research, as these opportunity costs could involve deferred care of the caregiver who may choose to postpone their own much needed care.

The intra-household distribution of care burdens can be accounted for in research. Capturing these burdens cannot be done using conventional surveys of individuals within households but calls for sampling across types of households, elderly burdens and care arrangements. We need to develop methods of data collection and also the means to do so ethically without violating individual rights to privacy and confidentiality. Such research processes are not only methodologically challenging but could also be ethically challenging. For example, how can one collect data on the elderly and the carer if their interests do not converge? The very process of data collection from the caregiver could contribute to alienating them from the household if they are known to report distress due to the caregiving role. The caregiver may not recognise their burdens or may experience extreme guilt in reporting the compromise of their personal interests and comforts. This may either make them undergo emotional trauma, or they may suppress the expression of these experiences for fear of being judged [8,14]. Either way, the research could further burden the caregivers with distress caused by the research process. How does one alert the carer to these

possibilities through the informed consent process? Is it ethical to inform and/or educate the carer, or would it be better to leave them to their own agency to recognise and negotiate their needs? The ethical requirements for such research also need to bear upon the nature and type of methodologies used for data collection and analysis. But, ethical research in this context needs to tread this ground for better understanding of elderly and disabled care burdens to emerge. There are methodologies both analytical [8, 15] and conceptual [10], that are emerging to facilitate such explorations.

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