

Economic Impact of Terminal Illness and the Willingness to Change It

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Abstract

Objective: To gather pilot data on the economic impact of terminal illness on families and on the feasibility of training caregivers as a method of stemming illness-related poverty.

Design: Exploratory, descriptive study involving semistructured interviews with patient and caregiver dyads.

Setting: Pallium India Palliative Care Clinic in Trivandrum, Kerala, India.

Participants: Eleven patient-caregiver dyads (22 individual participants) visiting Pallium India in 2008.

Methods: Trained interviewers conducted face-to-face interviews consisting of 114 questions with the patient and caregiver separately. Questions covered topics of economic impact of illness on household, family, and individual. Questions included if the illness had so impacted families that they needed to sell assets or significantly reduce work and/or schooling.

Results: All families reported that patients were obliged to give up work as a result of illness. In seven families, the caregiver also had to change work habits. All respondents stated illness had forced them to sell assets. Ten households reported that their children were obliged to miss school due to the illness. All respondents indicated they would use trained caregivers to help with the care burden if available. Nine respondents thought that use of trained caregivers would have reduced or prevented some of the household's illness-related change. Nine caregivers said they would be interested in becoming a trained caregiver.

Conclusion: These data indicate that a definitive study would be feasible and would reveal how much assistance caregiver training could lend to household socio-economic resilience.

Introduction

ILLNESS AND POVERTY often go hand in hand. The Commission on Macroeconomics and Health notes that depletion of productive assets leads to an illness-poverty trap at the household level. Households with a terminally ill family member face drastic decreases in income.¹⁻⁴ Patients' families may delay or avoid treatment or use cheaper, often less effective treatments.⁵ The family may sell assets, borrow beyond their ability to repay, and withdraw students from school, pushing the family toward multigenerational poverty.⁶⁻⁸ Medical professionals are not only charged with caring for the terminally ill individual, but also attending to the

families' illness-related suffering, including economic hardship.⁹ Families that are economically disadvantaged are predisposed to further health problems, thus making this a public health concern.

One potential model to help families involves linking economic resilience options with health services.^{10,11} Family caregivers are often given considerable training by hospices and thus could use these skills to re-enter the workforce through formalized caregiver training and certification. Caregivers could gain future employment after being forced by circumstances to truncate their education or quit their jobs on account of illness. They could also help other families avoid poverty by allowing their caregivers to stay in work or school.¹¹

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Accepted March 10, 2010.

Empirical evidence to support proposed solutions to illness and poverty is essential.¹² This pilot study sought to gather data, in an area that could potentially benefit from a caregiver training program, on economic impact of terminal illness on poor households; receptiveness of caregivers and care recipients to training; and feasibility of conducting a larger study to properly explore further details of a training program.

Methods

Design and setting

India has an estimated one sixth of the world's population, with 89% living on less than 92 Rupees (\$2 US) per day.¹³ Pallium India, which provided the study site, is in Trivandrum, Kerala, on the southwest coast. Kerala has a long history of organized health care dating back to the 19th century.¹⁴ Palliative care has been developing throughout India since the mid-1980s. Most palliative care services are in major cities. There is no national palliative care policy, and the training facilities are inadequate for the population's requirements.¹³ Thus, palliative care in India is characterized by an increasing number of home care services that largely rely on unpaid family support and volunteers.^{15,16} Culture and family structure in India are readily accepting of such care since most people in India prefer to live and die at home.¹⁶ Pallium India is a registered charitable trust and provides free care and medication to patients. Most of the trustees have done pioneering work in palliative care in India.

Procedures

The study was approved by the Institutional Review Board at Sree Uthradom Thirunal Hospital affiliated with Pallium India.

A convenience sample consisted of 11 families who were in contact with Pallium India in 2008. Inclusion criteria included: (1) poor, rural families with an ill adult with a prognosis of ≤ 3 months, and (2) families with school-aged children. Exclusion criteria included: (1) patients who were too ill to consent or answer questions, and (2) patients or caregivers who did not speak English or Malayalam.

Participants received a small honorarium (equivalent to the cost of a meal) for completing the survey and were informed that they were free to skip questions, terminate, or not participate, and that it would not affect medical care they were receiving. Interviews were conducted face-to-face in Malayalam or English.

Training on how to conduct surveys was provided to interviewers and translators by Drs. Emanuel and Rajagopal. This training consisted of five sessions followed by mock interviews.

Survey questionnaire

Participants were asked questions taken from established and validated questionnaires including Promise of a Good Death,¹⁷ Health and Retirement Study,¹⁸ Toxicity and Response Criteria,¹⁹ and a questionnaire used in Uganda.²⁰ The questionnaire contained 112 closed-ended questions and two open-ended questions.

Items in the survey included demographics, patient's diagnosis and functional status, number of caregivers and their relationship with patients, education of household members, and household assets before and after diagnosis. Questions

included if the illness had prompted families to sell assets or impacted work and schooling for the patient, caregiver, and/or other members of the household. Open-ended questions included "Is there anything else you would like to say about how this illness has affected the household's economics?" and "Is there anything you think an outside source could do that would help alleviate the hardship caused by this illness?"

Analysis

The open-ended questions were transcribed verbatim by trained study team members. Content analysis was applied to identify common themes and their frequency. Data analysis of these responses was iterative and involved inductive and deductive coding among two team members.^{21,22} Discrepancies in the coding scheme were resolved by consensus and triangulation with a third team member who worked at Pallium India. Responses to the closed-ended questions were recorded, double entered, and analyzed using descriptive analyses in Excel.

Results

Twenty-two surveys were completed (2 per 11 patient-caregiver dyad). The per question response rate ranged from 90% to 100%. Interviews lasted between 23 and 75 minutes.

Demographics and diagnoses

The patients were between 32 and 57 years old; the caregivers, between 30 and 42. Of the patients, 82% were male and 18% female. All primary caregivers were patients' spouses; 82% of caregivers were female, 18% male. Most primary caregivers were sole providers of care. Four of 11 caregivers reported receiving help from family members. Six of 11 patients and 6 of 11 caregivers reported receiving 8+ years of education. Demographic data are in Table 1.

Economic impact

All families had on average a 50,000 Rupees (Rs) (\$1,082 US) debt. Families had spent over 15,000 Rs (\$325 US) on care in the past 2 months. On account of illness, all patients dropped out of the workforce. All families reported inability to work at the same level as before the illness. In nine families, some degree of school was missed, and in two, school was discontinued. Incomes dropped by 200–4000 Rs/month (\$4–\$87 US). All patient-caregiver dyads except two lost all sources of income. All families surveyed sold at least a part of their assets.

Economic circumstances often pressured families to make deleterious life decisions. Four individuals reported feeling pressure to marry on account of the illness. One man took a second wife to care for his first ill wife (polygamy is practiced by certain religions in rural areas). Seven respondents reported feeling pressure to take a job hazardous to their health or resorting to illegal activity. One family had begun producing and selling alcohol illegally to earn money.

Openness to training

When asked about their willingness to serve as trained caregivers for other patients, eight caregivers responded with interest and willingness. Negative responses included feeling

TABLE 1. DEMOGRAPHIC CHARACTERISTICS OF STUDY SAMPLE

	<i>Response</i>	<i>Patient count (%)</i>	<i>Caregiver count (%)</i>
Age (22 responses)	30–40	4 (36)	8 (73)
	41–50	6 (55)	3 (27)
	>51	1 (9)	
Sex (22 responses)	Male	9 (82)	2 (18)
	Female	2 (18)	9 (82)
Religion	Hindu	8 (73)	8 (73)
	Christian	3 (27)	3 (27)
Marital status	Married	11 (100)	11 (100)
Household role	Father	9 (82)	2 (18)
	Mother	2 (18)	9 (82)
Education	<5 years	3 (27)	4 (36)
	5–8 years	3 (27)	2 (18)
	>8 years	5 (45)	5 (45)
Relationship to patient	Wife		9 (82)
	Husband		2 (18)
Patient's diagnosis	Hepatocellular carcinoma	3	
	Oral cancer	4	
	Diabetes	2	
	Leukemia	1	
	Tuberculosis meningitis	1	

under-educated, being unable to afford training, and not wanting to care for another family.

Seven patients thought their caregivers would do well if they obtained training. Four others said they would not like their wives to be trained or leave the house.

All individuals said that if trained caregivers outside of their family had been available, they would have utilized their help. Eighteen respondents postulated such help would have mitigated the impact of illness.

Discussion

Our goal was to gather pilot data on the economic impact of terminal illness on households and to determine feasibility of conducting a larger survey related to building a training program. Consistent with previous data, we found households to be greatly impacted by family illness, which often forced families to accrue large debts and rendered them unable to pay for food or attend even government-funded schools. Some families were forced to make deleterious life decisions and take dangerous jobs.

Regarding a possible caregiver training program, though details and practicalities of training were not specified, we found the majority of caregivers would welcome training.

Regarding provision of care from a nonfamily caregiver, both patients and caregivers indicated they would have used the help. Most thought it would have prevented some sacrifices they had been forced to make.

This study had notable limitations. It was small. All respondents but one spoke Malayalam; translation may have lost some subtleties of language and undermined question validity. Cultural differences and American researchers may have caused response bias. These concerns will need to be addressed in future studies.

Despite these limitations, this is the first survey of its kind in India and the second that addresses in-built economic re-

silience options.²⁰ Importantly, this survey demonstrates feasibility of conducting a larger, more in-depth study to explore details of a potential caregiver training program, including educational content, trainee responsibilities, and time commitments.

Palliative care in and of itself may minimize financial losses; a supplementary caregiver training program responds to financial impact that cannot be prevented. Such a program would be appealing for two main reasons. First, it could help the patients' households. Caregivers could re-enter the workforce by completing and certifying the experience they have begun to acquire. Through semiprofessional caregiving, the household would have augmented income which would relieve some economic hardship. Secondly, trained caregivers could help other patients' households. Outside caregivers could provide respite and relieve tension relief for family caregivers to reduce some of the caregiving burden. Healthcare design that include more people to help deliver health-care services is crucial in countries with high poverty.

Overall, households in this survey were in a position to enter employment as a trained caregiver, supporting the view that such an approach could lend them some economic resilience. There are still many unanswered questions. For instance, would families earn enough to resume children's education? The specifics of a program such as the type of training, type of care they can offer, and how it can be delivered were not determined since a successful training program will not take a "cookie-cutter" approach, but will be customized to the individual trainee and setting. Further research is needed.

Acknowledgments

We greatly appreciate the work of those in Pallium India who arranged for patients to interview, for transportation to and from the interview locations, as well as for our accommodations. We thank Ramadas Gopinath for translating the

surveys as well as Derek Jarvis for his administrative support of this project. This study was funded in part by a grant from the Boston Foundation. While carrying out this research, Tapas Kundu was associated with the Centre of Equality, Social Organization, and Performance (ESOP) at the Department of Economics at the University of Oslo. ESOP is supported by the Research Council of Norway. Melissa Simon is supported by NIH NICHD K12 WRHR HD050121-04.

Author Disclosure Statement

No competing financial interests exist among the authors.

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