Death and Dying in India

Ageing and End-of-Life Care of the Elderly

Suhita Chopra Chatterjee and Jaydeep Sengupta



Death and Dying in India

Most aged in India are experiencing a highly protracted death in hospitals, entangled in tubes and machines. Such 'medicalized death' entails huge psychological, social and financial costs for both patients and their caregivers. There are also many who are dying in abject neglect. However, government response to end-of-life care has been almost negligible, and there is an acute information deficit on dying matters.

This book examines different settings where elderly die, including hospitals, family homes and palliative set-ups. The discourse is set in the backdrop of international attempts to restructure and reconfigure the health delivery system for aging population. It makes critical commentaries on global developments, offers state-of-art reviews of recent advances and substantiates and corroborates facts by personal narratives and case histories. The book overcomes a segmental understanding of the field by weaving various sociological, medical, legal and cultural issues together. Finally, the authors critically examine biomedicine's potential to meet the complex needs of the dying elderly. In an attempt to bring cultural sensitivity in end-of-life care, they explore the lost Indic 'art of dying,' which has the potential to demedicalize death.

Increasing public sensitivity to poor dying conditions of the elderly in India and facilitating changes to improve care systems, this book also demonstrates the limitations of the Western specialization of death. It will be of interest to academics in the field of Medical Sociology/Anthropology, Medicine, palliative care, Public Health and Social Work, Social Policy and Asian Studies.

Suhita Chopra Chatterjee is a Professor in Sociology in the Department of Humanities and Social Sciences, Indian Institute of Technology Kharagpur, India. Her current area of interest is in the field of Death studies. She is the lead editor of Discourses on Ageing and Dying.

Jaydeep Sengupta is a Doctoral candidate at the Indian Institute of Technology Kharagpur, India, and is formally trained in Anthropology and Development Studies. His areas of interest are Public Health and End-of-Life Care.

Routledge Contemporary South Asia

For a full list of titles in this series, please visit www.routledge.com

71 Capitalist Development in India's Informal Economy

Elisabetta Basile

72 Nation, Constitutionalism and Buddhism in Sri Lanka

Roshan de Silva Wijeyeratne

73 Counterinsurgency, Democracy, and the Politics of Identity in India

From warfare to welfare?

Mona Bhan

74 Enterprise Culture in Neoliberal India

Studies in youth, class, work and media *Edited by Nandini Gooptu*

75 The Politics of Economic Restructuring in India

Economic governance and state spatial rescaling *Loraine Kennedy*

76 The Other in South Asian Religion, Literature and Film

Perspectives on Otherism and Otherness *Edited by Diana Dimitrova*

77 Being Bengali

At home and in the world Edited by Mridula Nath Chakraborty

78 The Political Economy of Ethnic Conflict in Sri Lanka

Nikolaos Biziouras

79 Death and Dying in India

Ageing and End-of-Life Care of the Elderly Suhita Chopra Chatterjee and Jaydeep Sengupta

Death and Dying in India

Ageing and End-of-Life Care of the Elderly

Suhita Chopra Chatterjee and Jaydeep Sengupta



First published 2017 by Routledge 2 Park Square, Milton Park, Abingdon, Oxon OX14 4RN

and by Routledge 711 Third Avenue, New York, NY 10017

Routledge is an imprint of the Taylor & Francis Group, an informa business

© 2017 Suhita Chopra Chatterjee and Jaydeep Sengupta

The right of Suhita Chopra Chatterjee and Jaydeep Sengupta to be identified as authors of this work has been asserted by them in accordance with sections 77 and 78 of the Copyright, Designs and Patents Act 1988.

All rights reserved. No part of this book may be reprinted or reproduced or utilised in any form or by any electronic, mechanical, or other means, now known or hereafter invented, including photocopying and recording, or in any information storage or retrieval system, without permission in writing from the publishers.

Trademark notice: Product or corporate names may be trademarks or registered trademarks, and are used only for identification and explanation without intent to infringe.

British Library Cataloguing-in-Publication Data
A catalogue record for this book is available from the British Library

Library of Congress Cataloging-in-Publication Data

Names: Chatterjee, Suhita Chopra, author. | Sengupta, Jaydeep, author.

Title: Death and dying in India: ageing and end-of-life care of the elderly / Suhita Chopra Chatterjee and Jaydeep Sengupta.

Other titles: Routledge contemporary South Asia series; 119.

Description: Abingdon, Oxon; New York, NY: Routledge, 2017.

Series: Routledge contemporary South Asia series; 119 | Includes bibliographical references and index.

Identifiers: LCCN 2017001761 | ISBN 9780415403177 (hbk) |

ISBN 9781315228884 (ebk)

Subjects: LCSH: Death—India. | Aging—India. | Terminal care—India. Classification: LCC BF789.D4 C495 2017 | DDC 306.90954—dc23

LC record available at https://lccn.loc.gov/2017001761

ISBN: 978-0-415-40317-7 (hbk) ISBN: 978-1-315-22888-4 (ebk)

Typeset in Times New Roman by Apex CoVantage, LLC

Contents

	Preface	VI
	Acknowledgments	X
1	Poverty of dying in India: a comparative landscape	1
2	Dying in the homeland	23
3	Are Indian hospitals good places for the dying elderly?	40
4	The rhetoric of dying in home	69
5	Is palliative care the answer to care for the dying elderly in India?	98
6	The failing empirics of biomedicine in dying matters	122
7	End-of-life care: Retrieving death from the zone of obscurity	138
	Index	157

Preface

In the wake of present demographic and epidemiological changes in India, most aged are experiencing highly protracted dying, entangled in tubes and machines in acute care hospitals. Such 'medicalized death' entails huge psychological, social and financial costs for both patients and their caregivers. There are also many who are dying in abject neglect in the absence of adequate social-legal provisions for end-of-life care. Unfortunately, the Indian government's response to end-of-life care has been almost negligible despite it being identified as a global public health priority by the World Health Organization. Serious academic response to death and dying of the elderly has also not been forthcoming due to preoccupation of the scholars with 'active aging' framework. This has led to an information deficit since factors related to improving quality of life in end of life are different from those involved in quality of death and dying. Some recent large scale comparative studies such as the Lien Foundation reports (2010, 2015) suggest that India rates poorly on the quality of dying. These reports set the context for present explorations attempted in this book.

The aim of the book is to improve the evidence base, build public sensitivity to poor dying conditions of the elderly in India, facilitate changes to improve care systems, and make death and dying a public health agenda. It intends to give the reader a comprehensive understanding of international developments in end-of-life care. Yet, the limitations of the 'Western specialization of death' are made fairly evident in order to direct attention to the lost Indic art of dying.

Although the book is primarily about dying of the elderly in India, the discourse is set in the backdrop of international attempts to restructure and reconfigure the health delivery system to meet the recent trend of aging characterized by long-term illnesses and protracted periods of functional decline before death. This is motivated by the understanding that informed decision-making could be assisted by comparing and contrasting care systems around the world. However, different epidemiological and cultural contexts do demand distinct approaches, and each country has to evolve and review its own strategy, especially since even the most efficacious model suffers from several drawbacks. We have tried to make critical commentaries on global developments, substantiated arguments with secondary evidence incorporating up-to-date research and have corroborated facts by personal narratives and case histories. Some issues are distinctly sociological

while others are medical and legal in nature, and demand considerable expertise in interdisciplinary research. We have tried to redress the imbalance stemming from segmental understanding of end-of-life care and have woven under one cover various sociological, medical, legal and cultural issues. To us, this represents a major advancement in the way medical sociologists and anthropologists in India are carving a new niche for themselves within more interdisciplinary forums. However, despite our best intentions, some issues have not been able to command the attention they deserve in end-of-life care because of paucity of data in the Indian context.

The introductory chapter initiates the debate on death and dying by citing Lien Foundation reports (2010, 2015) that depict the poor quality of death and dying in India. As further evidence, the chapter draws attention to the plight of Aruna Shanbaug, who even at the age of 67, failed to evoke an adequate legal response to her long vegetative existence after a brutal rape in her younger days. To assist the reader's understanding of the poor dying conditions of the elderly in India, we have presented a quick but critical overview of end-of-life care strategies adopted by western countries. This is followed by a presentation of the basic end-of-life Health Care environment and availability of related health services for elderly in India. The major arguments centre on a weak public health delivery system which makes coordinated care difficult for the elderly. In addition, limitations of existing government policies and programs for the elderly, which insufficiently address geriatric care, are also briefly covered. The contents prepare the reader for greater appreciation of challenges inherent in different care settings in subsequent chapters.

Three settings – hospitals, homes and palliative settings where elderly die – are examined, and the complexities involved in each of them are addressed in detail. The first setting to be explored is the hospital where most elderly die. Recent developments in end-of-life care, issues and debates – clinical, ethical and social, benefits and harms stemming from innovations involving care pathways, DNR protocols, advance directives and application of bioethical principles are discussed. As one navigates through these, the contrasting and pitiable situation of elderly dying in Indian hospitals becomes distinctly clear. It is evident that service conditions have not been altered to meet the needs of people with chronic and progressively deteriorating conditions. Absence of guidelines for withholding and withdrawing life support, poor prognostication, inadequate admission and discharge policies, all serve to highlight the plight of the elderly. Many are left dying in the 'technological wasteland of intensive care units' which increase their vulnerability to infections. Others are discharged to family homes where paltry care provisions exist and complicate the dying experience.

Family homes are the most common places where the elderly die; however, in India homes are not part of the care continuum and dying at home may be difficult and messy. The fragmented state of home care contrasts with the situation in many industrialised countries which have addressed the role of home and community care in their health delivery system to ease physical and financial pressures on hospitals, lessen dependence on institutional care and respect consumer

preferences for care at home. Many countries have passed national Long Term Care legislations to support ageing and dying at home and to support home carers through various programs. Ancillary support structures like assisted living facilities, nursing homes and hospices take up care tasks when dying at home becomes difficult. In the absence of such integrated home health care management, dying at home in India raises complex problems for aged and their caregivers, many of whom lack skills and resources to deal with dying issues. Absence of palliative networks complicates the situation further.

Palliative care undoubtedly has the potential for meeting end of life needs of the elderly. It has made significant contribution in community care and has become an important aspect of health care worldwide. Recent advances have also been made in Palliative aged care involving the combined expertise of gerontology and geriatric care. Unfortunately, both palliative and geriatric medicine are currently insufficiently developed in India to extend their principles and practices to aged care. Barring a few exceptional success stories in southern India, it has remained limited in scope. By and large, it also reflects a predominantly western approach. A distinct specialty, often at crossroads with mainstream medicine, it appears to us to be strangely co-opted by the field of biomedicine. It is clinical in nature, mostly cancer-specific and has a poor service-mix. Moreover, its link with geriatrics and indigenous medicine has not been well explored. In short, it seems palliative strategies need considerable modification to be congruent to Indian conditions. Government support to palliative medicine in terms of advocacy, organisational strategies, statutory funding policies and linkage with the ongoing National Health Mission also needs improvement.

Finally, attempts at improving quality of death and dying needs to take into account the cultural context. Death though physiological in nature, is imbued with deep cultural meanings. Biomedicine itself is a cultural construction and its trained incapacity to accept death is rooted in western philosophical perspectives on human finitude, body and its destruction. Recent scholarship suggests that its approach is more geared to acute conditions, and alternative responses are needed to meet present demographic changes involving ageing and prolonged dying. Biomedical principles and practices also need considerable modification in cultures such as India which have different notions of ageing, death and dying. Age-specific nuanced meanings of autonomy, choice and dignity among elderly need to be understood and appreciated.

The critical inquiry into biomedicine is likely to set the mood for greater appreciation of Indic approaches to aging and the dying. Some of these approaches incorporate principles of indigenous medicine and spirituality, while others fall outside the medical gaze and have the potential to de-medicalize death. Deep in our hearts, we nurture the need to visualize a program for the aged and the dying in India which does justice to a person's last journey in life, without depending on medically sanctioned methods of tackling illness, disease, suffering and death. We have briefly explored the lost 'art of dying' and tried to figure out how cultural sensitivity may be woven in end-of-life care.

We hope that the book would provide a good reference for policy makers, professional practitioners and academics in the field of medical sociology/anthropology, medicine, palliative care, public health and social work. It can be a good resource for teachers and students alike by providing information and inspiration for future research. We hope that the large number of social and cultural themes addressed in this book are also likely to sustain interests of readers with diverse backgrounds. The overview of advances in end-of-life care in various countries may help provide a comprehensive understanding of complex issues on death and dying of the aged under one single cover. A comparative treatment of the theme, incorporating both western and Indian examples is likely to make comprehension easier. Complex medical issues are presented to the lay reader in simple ways so as to invite public participation on death and dying.

We wish to thank the Ministry of Human Resource Development for funding the project "Improving End-of- Life care of the Elderly through Indic Perspectives." The present work forms the initial theoretical impetus for empirical research we have already initiated in different settings. A special thanks to Prof. Joy Sen who provided the platform to activate such projects under the Science-Technology-Culture-Heritage interface.

Suhita Chopra Chatterjee Jaydeep Sengupta

Acknowledgments

This work is part of SAndhi, a cluster of projects under the Science–Heritage initiative of Indian Institute of Technology Kharagpur supported and funded by experts and representatives of Ministry of Human Resource Development, Government of India. Our thanks to the Ministry and sincere heartfelt gratitude to Prof. Joy Sen, the Principal coordinator of SAndhi for creating an intellectual space for the subproject: "Improving End-of-life care of the elderly through Indic perspectives."

We are thankful to the team of Routledge U.K., who found our effort worthwhile and gave us the opportunity to express our ideas on this complex theme.

1 Poverty of dying in India

A comparative landscape

Indians are dying poorly. Most of us know this from our encounter with human mortality in some way or the other, but it also got an academic confirmation with the Singapore-based Lien Foundation's commissioned study on quality of death. The study based on a survey of 40 countries compared nations under four headings: End-of-Life Healthcare Environment, Availability of End-of-Life Care (EoLC), Cost of End-of-Life Care and Quality of End-of-Life Care, on the implicit assumption that the need of a dying person remains same across different locations. It rated India as the least-preferred nation with a low score on all four indices. India held the last position in the overall Quality of Death index – 39th position in the category of Basic EoLC, 35th position in the Availability of EoLC, 39th position in the Cost of EoLC and 37th in the score for Quality of EoLC. In a more recent study, the country rates as 67th among 80 nations based on a new version of the Index, which expands its scope to take into account global developments in palliative care (The Economist Intelligence Unit, 2015).²

For those wary of statistical evidence, Aruna Shanbaug's case is still fresh in our minds as an illustration. While the battle to legalize euthanasia is highly debated in many discussion forums and the country awaits a deliberated law on the issue, Mumbai's King Edward Memorial (KEM) hospital had been a witness to the slow aging and dying of a bright, young and capable nurse in their own precinct after being raped and brutally strangulated with a dog chain by a sweeper at the same hospital in November 1973. Aruna was 67 when she died with multiple morbidities, brittle bones, rotting gums and a gasping body. Her life indeed was of little worth, but she had some sort of an iconic value for the nursing staff of the hospital, prompting the Supreme Court to rule out euthanasia as a nonpermissible option in the wake of not having a direct indication of Aruna's wishes and views. Meanwhile, many, including her biographer Pinky Virani, had considered it as one of the most gruesome stories of slow, painful dying in a country that has not yet laid down a reasoned plan of action for ensuring a dignified exit. She had filed a petition with the Supreme Court of India pleading for euthanasia as a means to terminate Aruna's life with dignity. After much deliberation, the petition was turned down in 2011, almost a year after it was filed. The rather stoic decision of the court testifies to the nation's inability to grant peaceful exit for a person who had exhausted all possibilities of dignified living. However, the

court permitted passive euthanasia on a case-by-case basis. Recently, in February 2014 the Supreme Court also referred the matter of legalizing euthanasia to a five-bench jury in response to a public interest litigation filed by an NGO in 2008.

Aruna's case would have shocked the conscience of the Indians, as did Karen Ann Quinlan's tragedy in the U.S. way back in 1976.³ But while the 20-year-old Karen in a comatose condition had moved the Americans to plead for euthanasia in the U.S., the deadly silence of a vegetative and semicomatose Aruna Shanbaug for 37 years has as not yet melted the Indian hearts. It was alleged by some that in contrast to the old and decaying Aruna, photographs of her youthful days were widely circulated in media to craftily hide her suffering in a hospital bed for over three decades.

Aruna's story, emotional and sentimental, also smacks of a poor end-of-life care perspective in India. It betrays an overzealous state with little concern for resources on an almost lost case, the never-to-die attitude of the medical establishment that patronizes such cases while remaining ironically immune and even a silent spectator to the agony of innumerable people dying wretched deaths in hospitals, homes and even on streets, seething with pain and nowhere to go. While it tolerates the use of expensive life-extending technologies on frail elderly in the hi-tech, sophisticated, state-of-art ICUs in acute and tertiary care hospitals in India, many young people die for want of simple remedies. However poignant the stories of such 'other' deaths may be, for the time being, we choose to concentrate on end-of-life care for the elderly – a term we reserve for understanding the experience of dying rather than the experience of living with aging. Before we start our explorations in India, a brief contextualization of the issues at the global level would help to appreciate its seriousness and limitations in the homeland.

Dying old in the West

With life expectancy having increased to 76 years for men and 82 for women according to the World Health Statistics, 2014 and replacement fertility rate at only 2.1 births per woman in most of the industrialized nations, dying has become inextricably linked with aging as a result of this demographic shift. Global demographic data indicates that number of people aged 65 years or older is projected to grow from 524 million in 2010 to nearly 1.5 billion in 2050, with most of the increase taking place in developing countries (WHO, 2011). The category of the 'oldest old' constitutes 12 percent in developed nations and 6 percent in less-developed countries. In many countries, the oldest old are now the fastest growing part of the total population. On a global level, the 85-and-over population is projected to increase 351 percent between 2010 and 2050, compared to a 188 percent increase for the population aged 65 or older and a 22 percent increase for the population under age 65. The global number of centenarians is projected to increase 18-fold in 2050 from what was the number 50 years ago (United Nations, 2000). This growth is particularly significant because people accumulate long-term illnesses as they age, creating greater demand for palliative and end-of-life care services.

But care for the dying elderly is not an easy task. Elderly people die following four different trajectories that at times overlap with one another: (1) sudden – like severe stroke, myocardial infarctions or even accidents, (2) terminal illnesses with gradual decline, (3) organ failure and chronic suffering and finally (4) bedridden with frailty(Lunney, Lynn, Foley, Lipsonand Guralnik, 2003). Lengthy chronic illnesses and long periods of functional decline as in trajectory 2, 3 and 4 make dying a protracted affair. It is obvious that dying from various age-related chronic diseases and multisystemic illness, such as ischemic heart disease, cancer, stroke, arthritis, chronic obstructive pulmonary disease, dementia, depression and several others, make dying not only slow but challenging for the caregivers also. It is, as Nuland suggests, a messy affair (Nuland, 1994).

Protracted dving, when in hospitals, makes a disproportionate demand on health resources. Hospitals, which are already under pressure and, according to some observers, may become extinct soon due to escalating cost, are overstrained by the influx of a large population of elderly who are fast approaching their endings. An analysis in the U.K. showed that hospital-bed use increases with age, with those under 65 years using one-fifth of a bed day per year, whilst the average for over 85 years is five bed days per annum. Under such circumstances, calls for more prudent use of medical resources appear quite valid. It was 22 years ago that Daniel Callahan in the U.S. argued that expensive medical care needs to be prudently decided and rationed carefully for elderly patients. As a cofounder and President Emeritus of the Hastings Center – a nonpartisan, nonprofit, independent bioethics research institute in New York, Callahan's highly controversial book Setting Limits: Medical Goals in an Aging Society made the case for limitations of care based on age – a topic that provoked intense, if sometimes hyperbolic, arguments in health care debates (Callahan, 1995). But even earlier, Veatch (1979) had made a strong case in favor of a greater distribution of resources for the young in comparison to the elderly. Since these early warning bells, there is now a growing realization that aging of populations gives rise to new issues related to health and care services for the dying and require fresh perspectives on death and dying.

Improving the experience of dying

In the first place, as mentioned above, since dying has become more expensive, there has been an expressed concern to reconfigure health policy in a way so as to make EoLC a public health agenda. One way of doing so involves strengthening primary care, which has the potential to provide people with a gateway into the health care system and ensure continuity and coordination of care provided by different levels of health system and professionals. Cross-sectional studies show that primary decision aids can be developed for chronic conditions – Type 2 diabetes, osteoporosis, benign prostatic hyperplasia or even mental conditions, and it is this aspect of its proven success in chronic diseases that suggests the need to develop primary centers in order to improve end-of-life care as a public health measure (Legare, 2009). Subsequently, health forums and organizations, such as McMaster Health Forum (2014) and Ottawa Health Research Institute (2014),

4 Poverty of dying in India

have supported patient decision aids to enable them to engage with physicians to prioritize their complex and multiple-care goals.

Many primary health facilities are now equipped to deliver palliative care, which is an approach that improves the quality of life of patients and their families facing problems associated with life-threatening illness. It provides prevention and relief of suffering through early identification, assessment and treatment of pain and other problems – physical, psychosocial and spiritual. In addition, it helps patient autonomy in decision-making. Its multidisciplinary approach has special relevance for the elderly who suffer from chronic ailments and multiple morbidities. Unfortunately, for a long period of time, patients received palliative care only when death was imminent, although it professes to neither hasten nor postpone it. This approach was problematic for the aging population and their families who experienced several difficulties and complexities throughout their illness trajectory, almost on a daily basis. The revised model now suggests initiation of palliative care from the early stages of illness, often along with curative treatment. However, health care systems have to be flexible enough to be able to incorporate it within mainstream health delivery (cf. Davies and Higginson, 2004).

Incidentally, countries where palliative care (and implicitly end-of-life care too) is at the most advanced level of integration with the mainstream service provision, commendable work has been done within public health framework to deliver geriatric care (Alliance and WHO, 2014). In most European and Scandinavian countries, for instance, care for the elderly is addressed through Long Term Care (LTC) program that is provided through hospitals, nursing homes and social care homes. Conceptually, LTC not only addresses issues related to illness but also caters to needs during end-of-life, at least in terms of accessing high-quality medical services. But robust LTC programs can only be designed on the basis of a very viable primary health care system. Silveria and Forman's (2012) field study show how Primary Care Providers (PCPs) in the United Kingdom play an important role during EoLC by maintaining a continuity of care for the patients. They assist in planning advanced treatments and EoLC decisions, attending to patients' emergent needs, bringing flexibility in scheduling appointments, facilitating information-sharing with outside providers and coordinating care within primary care practice to address patients' needs quickly, and even acting on behalf of their patients. However, in recent times, a specialized approach to disease and treatment has undermined the role and significance of PCPs in many places, and many dying elderly continue to rely heavily on hospitals. But empirical research strengthens a widely favored opinion that primary care is the most suitable option for elder care, as it deals with chronic illnesses, lifestyle issues and preventive care. Endorsing this idea, WHO has collaborated with Health Ministries of different countries, both developed as well as developing nations, to produce 'Age-friendly PHC Toolkit.' So far, the toolkit has received support from different agencies and forums like WONCA (World Organization of National Colleges and Academic Associations of General Practitioners/Family Physicians), IAGG (International Association of Gerontology and Geriatrics), IFA (International Federation

on Ageing), HAI (HelpAge International) and the NYAM (New York Academy of Medicine), among others. This venture nurtures the mission to make primary health centers and their caregiver staff aware, sensitive and competent to tackle the growing morbidities of the elderly population. The toolkit suggests comprehensive and integrated care, continuum of care, adequate physical and social environment and upgrading human skills in caring elderly patients as important means to make PHCs age friendly.

In addition to the above measures, these countries are making attempts to cut down hospital expenses for elderly by evolving regulatory measures to curtail use of invasive technologies and by devising care pathways. It may be mentioned that by and large, many governments - even those like Britain - have not paid due attention to formal technology assessments and their distribution among different groups of population. Restrictions on the production, use and distribution of medical technologies are weak in most countries in comparison with policies regulating therapeutic drugs, and are mainly advisory rather than binding. As a result, a technology-oriented, expensive and primarily curative biomedicine has been left with little option other than freeing hospitals from the clutter of old and dying people. This is more problematic in those countries that have centralized national health care systems, or where a sizeable chunk of health expenditure is borne by the State. Many advanced countries have therefore developed improved ways of negotiating and identifying death through protocols like Gold Standards Framework (GSF), which reduce unregulated hospital admissions though not compromising on care. The GSF is considered to be a cornerstone of the United Kingdom's end-of-life care program for letting a person die a 'good death.' It is also recognized as 'best-practice' in other countries outside the U.K., such as the U.S., Australia, the Netherlands and Belgium.

GSF ensures that a high-standard care is delivered. It works through a wellcharted framework extending from primary to tertiary level of care with thrust on coordination of stakeholders at all levels. This essentially includes patients and their family and medical and nonmedical professionals. Uniquely, GSF ensures that out-of-hour care service is available even though it reduces unregulated hospital admissions. It restricts all mindless hospital admissions in the last few weeks of survival and draws all possible resources available at the primary-care level near to the dying persons that are consistent with the persons' needs and wishes. Practicing GSF in community starts with an accurate prognostication of the person's survival, which might be as long as few years to as short as few days only. This is followed by close assessment of the dying persons' pain and other symptoms, and finally, it involves preparation of a care plan considering all risks that might arise in the future. Nationwide audits done periodically to assess the benefits of GSF have shown that it has indeed halved total avoidable hospitalization during end of life while giving maximum care and comfort at the person's preferred place of dying. In one such audit of 2010 covering seven care homes of Scotland, GSF training program has reduced within a span of one year (2007–8) 'avoidable hospitalization' during the last two months of life from 31 percent to 24 percent, 'related days spent in hospitals' from 82 percent to 44 percent and

'total avoidable hospital deaths' from 15 percent to 8 percent (Hockley, Watson, Oxenham and Murray, 2010). The evidence also points out that by reducing hospitalization it has contributed toward cost savings of National Health Services (NHS) as much as £30–40 million/year/care home.

However, the success of EoLC in many countries, particularly the U.K., which figures high in quality of dying, rests on another pivotal structure - the Liverpool Care Pathway (LCP). Overseen by the Marie Curie Palliative Care Institute, LCP is widely accepted as a best possible model of care for dying persons in the last few hours of life. It was developed by the Royal Liverpool Hospital and the Marie Curie Hospice during the late 1990s. With time its popularity grew, LCP was identified as a model of best practice by several organizations: NHS Beacon program in 2001, the Cancer Service Collaborative Project and the National Endof-life Care Program during 2004-7. It was recommended in the National Institute for Health and Clinical Excellence (NICE) guidelines to facilitate supportive and palliative care for patients with cancer in 2004 and also got included in the 'Our Health, Our Care, and Our Say' white paper in 2006 as a strategy worth rolling out across the U.K. Often considered in tandem with GSF, it becomes more important when dying is irreversible. It then sets to review all clinical procedures and aligns them in accordance with the patient's comfort and ease. This might result in discontinuation of forceful feeding (although drip is sometimes allowed on caseby-case basis), symptom control or even life support. Apart from the U.K. where LCP originated, it is practiced in 21 different nations (Murphy, 2011; Constantini, Ottonelli and Canavacci, 2011). Credibility of LCP is, however, questioned by many including Freemantle and Seymour (2012) through their empirical research in three oncology wards of a hospital in England. The case studies that the authors present show how patients suffered at the moment of dying even though the physicians and the nurses of the hospital accepted LCP. Inaccurate assessment and identification of the time of dving, poor orientation among out-of-hours doctors and constrained communication were the chief factors that caused the failure of LCP.

Good end-of-life care in the West also rests heavily on Advanced Directives (ADs), which were developed in the early twentieth century as a means to consider patients' opinions and wishes in medical decision-making. By the middle of the century, when death movement became strong, ADs in the form of 'Living Will' became prominent with consumer rights overtone. ADs have been formulated in different ways in many countries. In the U.S., there are three types of ADs: (1) Power of Attorney, a very strong legal document assigning a person to issue Cheques, handle business or even apply to Medicaid for nursing costs on behalf of the patients, (2) Health Care Surrogates that are exercised in making health care decisions during accidents or disease when the person is unconscious. It gets nullified as soon as the person gains consciousness and (3) 'Living Will' to give authority to a person to make health care decisions in the event of losing cognitive senses. This becomes applicable only if the attending physician ascertains the person to be in a vegetative state.

Apart from these measures, governments in the West developed structures to deinstitutionalize dying. Unable to withstand extreme financial pressures involved

in protracted dying in hospitals, it became imperative to reconfigure the home to make aging and dying-in-place a reality. For this, the home had to be reinstated and reconfigured. Other disciplines like architecture helped to provide necessary modifications and barrier-free designs for frail and disabled older people. These homes were equipped with new technologies in assisted living, which were to substitute somewhat for lack of caregiver support to make people age and die comfortably. Since caregivers were poorly equipped for such complicated dying, and since the social fabric to support such caregiving had already eroded, ancillary structures involving Long Term Care of the elderly were developed. These include Nursing Homes, Assisted Living Facilities (ALF), Continuing-care retirement community and Residential homes for the elderly. In the U.S., the 'National Survey on Residential Care Facilities' by Center for Disease Control and Prevention (CDC) found that there were approximately 31,100 ALFs for elderly contributing roughly 9,72,000 beds for elderly (Park-Lee et al., 2011; Centre for Disease Control and Prevention, 2010).

Many of these serve the elderly till the very end, when distinct institutions for dying – the hospices – take over their caring tasks. Started in 1967 by Cicely Saunders, hospices were, and still do, cater primarily to cancer patients but have recently started expanding their scope to include geriatric population – a move that owes much to the development of geriatric medicine. The latter's holistic approach emphasizes psychological intervention, functional recovery, palliative treatment and hospice care through a multidisciplinary focus involving inputs from gerontology, medicine, sociology, ethics and environmental sciences.

Hospices are known for providing expert medical care, pain management and emotional and spiritual support, which is in accordance with patients' needs and wishes. In most cases, care is provided in the patients' home but may also be provided in freestanding hospice centers, hospitals, nursing homes and other Long Term Care facilities. In 2012, an estimated 1.5 to 1.61 million patients received services from hospices in America (National Hospice and Palliative Organisation, 2013) mostly at patients' place of residence (66 percent), followed by private residence (41.5 percent) and Hospice Inpatient Facility (27.4 percent). However, only 6.6 percent received the facilities in acute care hospitals in 2012. In the U.S., 83.4 percent of hospice patients were 65 years of age or older and more than one-third of all hospice patients were 85 years of age or older. Globally, people aged above 60 years are mostly in need of palliative care (69 percent) in comparison to younger adults (25 percent) and children (6 percent) (Worldwide Palliative Care Alliance, 2014). Surprisingly, only 1 in every 10 persons receives relief from pain and other symptoms. A recent report of 2012 from Muslim majority countries shows the huge unmet need for pain management. Out of 15 countries, only 2 have adequate consumption of opioids; for the other13 countries, the figure is virtually nonexistent. Moreover, whereas the U.K. and the U.S. have 1,397 and 3,300 hospice-palliative care services respectively, Bangladesh, Pakistan, Egypt, Sierra Leon and Saudi Arabia have 1 to 3 of such services. Malaysia is an exception with 35 services catering to a population of 685,000 (Aljawi and Harford, 2012).