Care of the Dying in the Republic of Moldova

The book **„Care of the Dying in the Republic of Moldova”** was published in the frame of the project **„The End-of-Life Practices in Moldova”** by the National Commission of the Republic of Moldova for UNESCO and the University of BATH of Claverton Down with financial support of the Leverhulme Trust.

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The authors are responsible for the choice and the presentation of the facts contained in this publication and for the opinions expressed therein, which are not necessarily those of UNESCO and do not commit the Organization.

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Care of the Dying in the Republic of Moldova

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CHISINAU

2011

Printed by: Profesional Service

ISBN 978-9975-4240-5-9.

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ACKNOWLEDGEMENTS

We wish to thank the following people and organizations who made this research possible:

- All the families who participated in this research and who generously gave of their time to share with our interviewers their difficult and often painful experiences of care. Without their co-operation, the Republic of Moldova would not hear of their unrecognized plight and we would therefore be less ably equipped to identify and address their current and future needs.

- The National Commission of the Republic of Moldova for UNESCO, and especially to Dr Luminita Drumea for her continual enthusiasm and support, expert project supervision, and her foreword at the beginning of this book.

- The Leverhulme Trust in the United Kingdom for a research grant that made this research possible (grant no. F/00 351/Y). Their support for international end of life care research, such as the one reported here, has been invaluable. This kind of international support ensures that local investigations into emerging health care needs, in countries unable to fund such developments, are nevertheless able to pursue these policy questions with their financial help. Their support is most gratefully acknowledged.

- Syntacta Translating and Interpreting Service in the UK, especially the project manager Krystyna Lenik and the translator Monica Mirescu who handled all the UK-based Romanian to English translations for this project.

- Dr Meinhard Breiling, Mr Dumitru Drumea, and former Minister of the Republic of Moldova Dr Constantin Mihailescu for their support and guidance in developing the initial stages of this research project.

FOREWORD

The project „**The End of Life Practices in Moldova”** was initiated to encourage beneficial changes to future health care policies for care of dying patients in the Republic of Moldova.

The successful implementation of the project, which is embodied in the public release and distribution of the book – „**Care of the Dying in the Republic of Moldova”**, became possible due to efficient cooperation of an extended team of professionals coming from Great Britain and the Republic of Moldova. In this context, the National Commission of the Republic of Moldova for UNESCO expresses its deep gratitude and thanks to Professor Allan Kellehear from Great Britain, the initiator of the project, for raising public awareness in the Republic of Moldova about the issue of caring for suffering people at the end of their lives, for the idea of bringing this study to the Republic of Moldova, as well as for logistic and continuous financial support during the period of the project implementation.

It is also worth mentioning the fact that it is the first time in the Republic of Moldova that the issue of the fate and care of the dying patients is being discussed, this being a very sensitive topic of human existence. Moreover, the implementation of a project of this kind is a first for the National Commission of the Republic of Moldova for UNESCO. The National Commission for UNESCO highly appreciates the contribution of all those who initiated and actively participated in this international project, which is of great importance to the country in general, and to dying people, their families and caregivers in particular.

The National Commission of the Republic of Moldova for UNESCO expresses its acknowledgement and appreciation to The Leverhulme Trust, who offered the needed financial support for the implementation of this very special project.

The National Commission of the Republic of Moldova for UNESCO expresses its highest gratitude to the local team of doctors – Vadim POGONET, Rodica MINDRUTA-STRATAN and Victor GORELCO, who contributed with skillfulness, personal abnegation and a lot of time investment in the implementation of this project, difficult and unique in its problem and its objectives as it was. Without the effective cooperation of this very devoted and professional team, the successful implementation of this project would have been impossible to imagine.

Finally, UNESCO Moldova also expresses cordial thanks to the large team of translators of the English and Romanian texts of this book – Monica Mirescu from Great Britain, Renata Pogonet and Dumitru Drumea from the Republic of Moldova – for the quality of their professional work. It is due to their efforts that the book is accessible to the Romanian-speaking public.

Luminita Drumea, PhD

Deputy Secretary General
National Commission of the Republic of Moldova for UNESCO

CHAPTER 1

Introduction to the Study

The book you are about to read is a study of the personal experiences of how 102 families across the Republic have cared for their dying loved one.

It is a uniformly a study of love and care, but it is also a parallel story of great hardship and suffering. Most importantly, it is an account of *unnecessary* hardship and suffering. Although everyone must die, it is also equally true in this day and age, that most people do not need to suffer in their last weeks, days or hours of life. The care of dying people we love, when it involves the witnessing of great personal hardship and suffering, invariably imparts additional trauma and grief to the caregivers. The toll of suffering for every dying person is therefore also a toll of suffering for those who care for them. This is a toll that is both pitiful to record as it is unnecessary to tolerate in a country with a fully functioning national health care system. Unfortunately however, this appears to be the situation of end of life care in the Republic of Moldova today.

In terms of world history, the human story of death and dying has evolved dramatically in the last century or so (see Kellehear 2007). For about 1.5 million years, most human beings lived a hunting, gathering, and scavenging lifestyle. Life expectancy was short (18-25 years of age) and often came through traumas such as accidents, animal predation, or troublesome childbirth. In the last 10-12,000 years of our history, human beings became farmers, horticulturalists, and pastoralists. People grew crops and kept animals rather than foraging for fruit and vegetables or following the seasonal herds. Communities became more permanent, and villages and even towns began to emerge in these new forms of economy. The keeping of animals, the habit of living with one's own sewerage, and the exigencies of close living meant the rise of infectious diseases. The last thousand years in Asia and Europe, for examples, saw successive waves of the rat-flea infested diseases of the plague. Again, such waves of infectious diseases – plague, tuberculosis, cholera, malaria and so on – led to poor life expectancies and early death. Only in the last 100 years across the affluent countries of Europe, Asia and the Americas have we witnessed the very recent rise of life expectancy common also in the post Soviet Union republics such as the Republic of Moldova. In these places, more and more people have begun to enjoy longer life expectancy – in to the 70s and 80s – and this is typically a modern pattern of health, illness and mortality.

However, there is often an under-recognition that longer life expectancy is associated with a wider prevalence of diseases that were previously uncommon. These are the diseases associated with aging itself – circulatory diseases such as heart diseases and strokes, cancers, and organ failures, especially those associated with the heart, but also the growing dementias. Unlike the infectious diseases of yesteryear, the diseases of old age take a longer time to kill and usually entail a longer lead time of disability and suffering. Whilst the Bubonic plague may take a course of 10 days for its victim to succumb, a cancer or heart failure can take years in plaguing its victim before death comes. During that time, the symptoms can be both troublesome and difficult to manage without consistent professional and personal supports.

The symptoms of chronic and worsening pain, breathlessness, gradual loss of appetite and weight, growing weakness, increasing nausea and vomiting, as well as bleeding, compound other episodic problems such as bowel obstructions, headaches or confusional states. The control and management of such medical symptoms creates other personal problems such as job and income loss – for both the ill person and sometimes a carer who must give up work to care. Social isolation from work can also begin a more general isolation from former co-workers, friends and even family. Because so many families now travel to work – in other towns or villages but also overseas, the traditional source of an extended family may not be a reliable source of support. Drugs and medical equipment can be costly, as can paid carers or nurses to help with caring for someone who is dying. Such resources can be burdensome to obtain or out of reach altogether for many families. The cost of care is both personal and financial for most people in the Republic. This can, and does lead to traumas such as depression, deep grief, and helplessness. It can also lead to anxiety, desperateness, and anger. Such emotions and personal sorrow can last for years, disturbing not only the primary carer but also their family and general ability to cope psychologically and socially in the future. Trauma and grief, as consequences of poor professional and social support, can have terrible and tragic costs to family, and therefore to communities, and ultimately to the general health and wellbeing of a nation.

Just for these epidemiological and social reasons, governments worldwide are now establishing specialized health and social care support for families to care for their dying loved ones. These services are designed around research that shows the type and extent of need in every country that is developing these new services. In the Republic of Moldova, there has been little progress in these kinds of developments. Understanding about end of life care in the Republic is very limited, often based on individual professional opinion and experience. Stories about „what is usual" differ from clinician to clinician based on their own personal experience of families who care and their own (better or worse) recollection of events and experiences. Opinions differ about how involved communities are in assisting with end of life care in families; who takes the brunt of the care – men or women; how widespread are the religious or village customs for end of life care; how effective families cope – or don't – with the burden of end of life care; even, opinions about what families actually need during this difficult and testing time. This book reports the *actual* experiences of 102 families across the Republic. The sampling is representative. We have kept the statistical analysis to a minimum, choosing instead to prioritize the description of experience and need and also to give a general sense of proportion – of how many are effected by what kinds of troubles, customs, or supports.

In this chapter, we report the rationale and design of the study, describe the main study participants, and briefly summarize the overall results. The next four chapters will provide an in-depth description of: (Chapter 2) The Carer’s Experience; (Chapter 3) The Customs for Dying and Death; (Chapter 4) The Dying Person’s Experience; (Chapter 5) Needs of Carers and Dying People; and finally (in Chapter 6) Professional and Policy Recommendations that emerge from our findings.

We begin now with the background to the study.

BACKGROUND

Hospice and palliative care is the medical and nursing care of people in the last stages of life. In the USA, UK, Canada and Australia this kind of care also involves the use of social workers, chaplains, psychologists, family support workers and community volunteers. Most people who receive palliative care have advanced cancer, various forms of organ failure (heart, liver or kidney for examples), AIDS or Motor Neuron Disease (MND). Palliative care is recognized by the World Health Organization (WHO) to be a key and compassionate part of care for the seriously ill when they enter the final phase of their illness, a time when curative treatments are seldom relevant. At this stage, personal comfort, supportive symptom management and quality of life become the primary aims.

Developed in most Western Countries during the 1960s and 70s, palliative care is now spreading across global communities in Africa, Asia, South America and the Pacific regions improving the life of people at the end of life. This kind of work in Eastern Europe and Central Asia is either non-existent or in its infancy.

Most end-of-life care policies are based on elementary information about place of death, existing quality of life data about dying and its care in family and health service contexts, and a general picture of „need”. Such basic information cannot be assumed in much of Eastern Europe, and in national examples such as the Republic of Moldova, are not in evidence at all. Literature on end of life care in Moldova – in English, Romanian or Russian – is not available. Furthermore, countries such as Moldova experience major out-migration of male workers, significant poverty, and poor health service infrastructure, particular in rural areas where the majority of the population reside.

The population of Moldova is approximately 3.5 million though this is a conservative figure. The National Bureau of Statistics in Moldova admits to a 5% „under-coverage" in their estimates due to poor counting methods, community fraud and identity theft, and inestimable illegal emigration (personal communication, Oleg Cara, Deputy-Director, National Bureau of Statistics of the Republic of Moldova, May 2007). Of this total population about 60% live in rural areas of the country and 660,000 live in the capital city of Chisinau.

The national mortality rate is about 12 in every 1000 or 44,689 deaths in the country for the year 2005. The leading causes of death are circulatory, cancer and digestive diseases, followed by accidents, suicides and poisonings. Average life expectancy from birth is about 68 years with men expected to live to 64 years of age and women to 72 years. There is no place of death data.

Palliative care is in its infancy, confined to the capital city of Chisinau. There is only one hospice in the country – in Zubresti, about 40 km from the capital – with a total capacity of 12 beds. In broad health services terms there is no national end of life care service development and currently no national or regional policy or strategy for the development of this health service area/field.

End of life care information beyond these rudimentary demographic or epidemiological remarks is non-existent. Discussions about end of life care behavior, experience or needs are based on personal speculation, anecdotal sources or professional impressions gleaned from experiences within direct service provision. Community customs about the end of life and its care is based on similar guesswork and impressions. The current study is the first systematic piece of health social science research to provide basic empirical data in this area to guide future policy discussions and further research development.

Need for and Significance of this Research

Because very little is known about end of life care practices in Eastern European countries there is a desperate need for even the most basic empirical data to assist in the development of health research and policy development. What little information that is available from Eastern Europe tends to be abstract and demographic (death rates, life expectancies and causes of death as described above) or describes very broad patterns of palliative care service development (see Clark et al 1999). Since many Eastern European countries have modest national budgets for health and social care much of their emphasis and priorities has been in developing acute care interventions and building infrastructure for health. Death, dying and bereavement care has taken a lower priority both in terms of research and health services development. Even palliative care services in these countries tend to service urban populations, their overall impact on dying and its care – at a national level – is minor. This mirrors the wider experience of end of life care in the West in general where most people die in nursing homes or hospitals and not in hospices (Kaufman 2005; Kellehear 2007).

There is a common assumption that communities, guided by old customs and folkways experienced in these verities, adequately address much of their end of life care needs – caring for the terminally ill and bereaved. This pattern of care occurs within the largely rural populations of many Eastern European countries. Although this may have been true in the distant past, and even in the recent Soviet times, there are several observations to make about this assumption.

First, although the idea that communities have assumed most of the care for their dying and bereaved is undoubtedly true, we have very little actual documentation of what that care looks like – who does what for whom, when and how. Collection of even a small national database will enable speculation to be tempered with recent empirical, social indicators.

Secondly, however true this might have been in the distant or recent past, the collapse of the Soviet Union has injected a set of sharp and dramatic changes to the economic and social infrastructures of a host of former satellite countries. In countries such as the Republic of Moldova, there has been massive out-migration by working-age populations between 20 and 50 years of age seeking employment. This subtraction of a major cohort since the early 1990s has important implications for the local economy (eg worker supply and taxation basis for services) but also the informal social economy of the household – who cares for whom. For end of life care circumstances, these demographic and economic changes render households financially and socially vulnerable and this in turn can distort, change or render customs of care irrelevant or impotent. A descriptive database of current end of life care practices in the community will enable an early assessment to be made about these changes. It will also provide baseline data to evaluate future changes – whether end of life care is improving or deteriorating, and at what rates, and due to what kinds of responsible factors.

Thirdly, whatever customs have been important to end of life care experiences in Eastern Europe in general, and Moldova in particular, the fact is we have very little empirical knowledge of these facts and the changes that might be effecting those traditional patterns of care. The absence of this social information limits and compromises future health care policy development, planning and service sector development. A database on community end of life care will provide government, philanthropic interests and AID organizations information that will enable them to build these policies, plans and sector developments with a modicum of certainty about the real community situation whilst providing a further basis for future social research development in this area. Future health and social researchers will be able to build, fine-tune and revise this first database.

Finally, the national and international dissemination of the findings of this study will enable other researchers and policy makers to compare and contrast their own national findings with those of Moldova – especially those in Western Europe and Britain. The potential for mutual exchange and collaboration with other health policy and social researchers will be made possible by the dissemination of these findings, particularly in the international journal literature in medicine and health care more broadly.

Objectives

1. To provide the first representative national survey of community end of life care in the Republic of Moldova.
2. To describe the experiences of ordinary people in their care of a dying family member.
3. To describe any traditional customs that are important to dying and its care and to document any barriers or changes to these customs.
4. To describe the experience of dying from the point of view of their carers.
5. To identify unmet psychological, social and medical needs of the community.
6. To publish the findings in the local and international health care literature.
7. To publish and distribute the final results to health and education authorities and agencies as a national resource.

The Research

Design

A cross-sectional interview-based study was designed. We accessed hospital and polyclinic records of recent deaths that occurred between 6 and 24 months ago. From these records, our clinician-researchers (Drs Vadim Pogonet, Rodica Mindruta-Stratan, & Victor Gorelco) approached the family of the deceased to request permission to interview. Deaths that occurred earlier than 6 months ago were not included in this sample for ethical reasons – mainly to avoid the initial period of bereavement and grief. Permission was obtained to access to these records from the Ministry of Health.

Sample

The sample was carefully drawn from representative geographical and social areas of Moldova. We drew about 15 interviews each from the North (Edinet), South (Cahul & Comrat with Christian and Turkish minorities), and South-East areas (Stefan-Voda). Two interviews were offered by Transnistria inhabitants (at the moment a region with controversial status). About 60 interviews were drawn from the most populated area in Moldova – the Central area including the Orhei region, Leova, and about half of these interviews (30) from the capital Chisinau. In total then, we conducted 102 interviews across the nation as a whole.

Method

Interviews were semi-structured and designed to collect categorical data such as age, sex and occupation as well as year and place of death. The remaining questions sought to document qualitative data – experiences of care, observations of need, attitude and behaviour of the carers and the dying person, all as the interviewees recollect these. The outline of our interview schedule is provided below.

INTERVIEW SCHEDULE FOR PRIMARY CARER

Region Code & Sample Number:
INTERVIEWEE DETAILS:
Age
Sex
Occupation
Relationship to the deceased

DECEASED DETAILS:
Age
Sex
Occupation
Diagnostic category
Month & Year of death
Place of death

The Carer's Situation

1. Please describe the kinds of activities that were involved in your direct care of your dying relative?
2. For what period of time did this level and kind of care last before his or her death?
3. Were other people involved in this care? Who were these people and what was the nature of that care? What did they do and how regularly?
4. How did you feel during this period of care? Please describe how this time was for you?
5. How did this care effect other parts of your life – work? friendships? church? recreational activities? relationships with spouse/children?
6. Please describe what happened in the last 48 hours of your relative's life?
7. Who was directly involved in this last 48 hours? Self? Neighbours? Priests? Medical practitioners? Others?
8. What customs were involved during this last 48hours?
9. Were any customs omitted during this last 48 hours? Why?
10. Were you present at the moment of death? Others?
11. How was that time for you?
12. What kinds of assistance, if any, do you think might have helped you during this period of care (1) overall; (2) in the last 48 hours; (3) after the death ?

The Dying Person's Situation

1. Do you think that the dying person knew that they were dying? For how long before their death?
2. How do you believe that they came to know this – or why did they not know?
3. What kind of overall experience do you think this time was for the dying person?
4. What was the last 48 hours like for them emotionally and socially?
5. How would you describe the severity of their physical suffering in the last 48 hours?
6. How was this suffering addressed, by whom, and how adequately?
7. What psychological, social, and spiritual needs arose and were you (or others) able to address these in the last hours?
8. What needs did you think you could not or did not address for them? Why?
9. Were there any special requests by the dying person during their last days/hours?
10. How were the final physical moments of death for the dying person?
11. How would you describe the dying person's attitude near the end?
12. Were there any unusual events or experiences for the dying person during the final moments of death?
13. What kinds of assistance, if any, do you think might have helped the dying person during the period of dying (1) overall; (2) in the last 48 hours?

The interview questions were designed to act as prompts for the interviewers to enable them to systematically cover the required topic areas. The questions were asked conversationally and in a social manner appropriate to context and with an eye to the logic of the overall social exchange between interviewer and respondent. This is usual for a qualitative approach to interviewing. In this way, these questions are not „survey” questions in the conventional social sense. The clinician-researchers conducted all of the interviews. UNESCO was the project manager of the on-the-ground team of interviewers.

Interviews were transcribed into Romanian and then translated into English. Categorical data was subject to very basic quantitative analysis – frequencies, averaging, t-tests, etc. Qualitative data was analyzed thematically but also subject to a more quantitative-oriented content analysis – checking and noting, for example, for frequency of certain problems, behaviors, customs, or needs. Thematic analysis identified patterns of social organization and care conduct within families, communities or health service relationships. Spiritual or religious attitudes, customs or behaviors were also identified and described from this kind of analysis.

Ethical issues

We have already mentioned that we did not seek to interview respondents for whom a bereavement had occurred with the last six months. This is because we wished to avoid the most difficult and sometimes most traumatic initial period of grief.

Permission was sought to interview the primary carers of the deceased if bereavement was longer than 6 months but within 24 months of a death. Assurances of confidentiality were offered. Respondents were assured of the right to withdraw at any time during the interview. Aftercare for any grief or stress prompted by the interviews was offered by the Moldovan investigators and/or an appropriate referral made. A summary of the final research findings will be offered to all participants as well as to their local health authorities.

Ethical approval was also sought from the University of Bath before the research commenced, mainly to comply with data storage and protection requirements in the UK.

Dissemination of our results

Our dissemination strategy has two equally important aims. First, we wish to publish a series of academic papers in the professional health and medical periodic literature. These papers will summarize important data and will be disseminated in Moldovan and international health services periodicals. These papers are designed to stimulate local and international academic interest in Moldavian end of life care research, especially from health, palliative care and social and policy sciences communities. These papers are designed to signal research interest and activity to the wider national and international academic communities, encouraging their interest and possible future collaboration and or communication.

The second, equally important dissemination aim is to publicize and circulate the results to major health, social care, educational and political authorities within the Republic of Moldova itself. A book-length report as embodied in the volume you are now reading was written that summarizes both quantitative and most of the more lengthy qualitative data, providing overviews of the patterns within the numerical data and extensive vignettes of personal case experiences and need. Our aim in publishing this in a single bilingual (Romanian and English) book under UNESCO authority is to disseminate all our results to the relevant health and social care authorities (incl. hospitals and government departments) as well as schools and public libraries. We view this final aim of our dissemination as a contribution and stimulus to professional and community health education and policy development within the Republic of Moldova.

This book is distributed free of charge in an effort to stimulate community, health services and political discussion and policy development in end of life care in the Republic. This book dissemination strategy is an absolutely vital policy stimulation aim of the project and is designed to maximize the impact of the research results on opinion makers and other research, policy and practice communities in Moldova. We believe that a book is more useful to „non-academic audiences” and will attract more interest from local practitioners and policy-makers if published under the local authority and prestige of the UNESCO organization.

CHARACTERISTICS OF THE STUDY PARTICIPANTS

The majority of people who died in this study died at home (91%) with only 9% of people found to have died in a hospital. The vast majority of all people in this study were cared for by women (82%). Of the overall total number of carers about half of these were daughters (30%) or wives (20%), or daughters-in-law (10%). Other women included sisters and mothers (8%) or step daughters, god daughters, or sister-in-laws. Men accounted for only 18% of all carers and these were mainly sons (13%) Husbands (4%) or fathers (1%). Paid carers, neighbors or friends accounted for only 7% of the total sample.

The median age of carers was 54 years while the median age of those in their care was 68 years. The latter age reflects the world wide prevalence of death and dying occurring to older populations. The youngest carer we interviewed was 20 years of age while the oldest carer was 81. The youngest dying person was only 17 year of age while the oldest was 102 years of age. Most of the dying people in this study also reflected the main diagnostic categories endemic to dying in the modern industrial world. Most people in this study were dying from cancer (60%), from complications derived from a serious cerebral vascular accident („stroke”) (14%) or from various forms of organ failure (13%) – mainly heart and liver failure. Other illnesses included in this study were dementia, paraplegia, asthma, atherosclerosis, astrocytoma, cirrhosis, and hydrocephalis. All these entries, and other similar diseases, numbered less than 1 to 3 cases each. Most people who were dying were retired from work with only a small minority with professional backgrounds and the majority from unskilled or semi-skilled work backgrounds.

The majority of deaths (77%) occurred in the years 2008 (30%) and 2009 (47%). This is to be expected since the study recruitment criterion was to solicit interviews from carers of people who had died some 6 to 18 months beforehand. The study commenced in September 2009 and finished in September 2010. The overwhelming majority of those we interviewed were the primary or main carer (over 95%), and of these, two-thirds were present at the moment of death itself (66%). The median time of care was 26 weeks, or about 6 months. The time of care ranged from one week to several years, especially in the case of long term illnesses such as heart failure, stroke, paraplegia or hydrocephalis.

BRIEF SUMMARY OF RESULTS

Most people who cared for their dying loved one reported that dying people in their charge died with great suffering. Less than 3% of families reported that the dying person's last days were characterized by usual routines and satisfactory mood. The overwhelming majority reported the opposite experience. Most of the dying knew that they were dying (over 86%). Carers reported that these dying people experienced significant or extreme pain (65%) usually accompanied by bleeding, serious constipation, diarrhea, coughing, breathlessness, or vomiting. Often pain, bleeding, diarrhea and vomiting was uncontrolled toward the final hours. Although the final hours were commonly reported to be a time of calmness for some dying people (over 42%) the majority report a diversity of negative emotional and social states ranging from depression to agitation or anger and desperation. About 14% of all dying people were comatose some hours or days before their death. The physical suffering was often extreme and unfortunately for carers – memorable.

> „She was in pain all over, terrible pain, she was groaning, biting her tongue, not swallowing, had to spit out her saliva, she could not taste her food, her body was giving off a heavy smell, she had become thin, she was just a bag of bones, like those people from concentration camps. She had lost her taste, three days before she died she said she would give anything to be able to taste fruits again." (#31)

> „He was in great pain, had lost weight, he threw up blood, there was froth coming out. I would give him injections more often, he was constipated. He was urinating blood.” (#36)

> „She was in a lot of pain and she could not stand it. She was bleeding, losing her consciousness, was really sick, constipated, and had wounds on her back. She was a stout woman. Nobody believed she had that illness and that she would die so quickly.” (#37)

> „Her condition had already been serious for a few weeks. She was in a lot of pain and the injections were not helping anymore. She threw up repeatedly, lost a lot of weight. We called the priest a long time before she died because we did not know how long she had left to live. He heard her confession. On the day that she died, she called the ambulance medic. When he arrived, she said: „Do something so I don’t die”. The doctor encouraged her, he gave her an injection, she calmed down. I think she even fell asleep. She died a few hours later.” (#49)

These experiences of sharp and tragic suffering, reported in this study all too often, make the experience of care for family carers both harrowing and grief-stricken. Over 60% of carers described their time of care as „emotionally hard”, „difficult”, „depressing and upsetting”, or „stressful”. Other terms commonly used in interviews to describe this time include burdensome, painful, sad, terrible, dark, traumatic, lonely, and even nightmarish. Little wonder that well over a third of all carers (42%) interviewed reported that they could have used more social and psychological support, either from family, neighbors, financial support or the services of a psychologist or counselor for their own personal support during this period. As the following respondents illustrate, carer’s experience was extremely difficult.

> „What can you feel in such situations? You know, in the last three weeks he could not even swallow and when he was trying to eat something it was though I were hurting too. When I saw how he suffered I felt as though I could feel what he was feeling. You know, we had a beautiful relationship, he was a decent man and when I

> saw how he suffered I felt strong emotions. I empathized with him. In short, it was a terrible, difficult time." (#43)

> „It was a difficult period for me. There were new concerns, needs. I knew my husband was dying. I felt very sorry for him and that made me withdraw into myself. I could not discuss my problems and difficulties with anyone. I had the feeling that nobody needed me and my problems. I had no shoulder to cry on and I could not talk to strangers about this, so I bottled up all my emotions and problems, as though I could not open my mouth. There was a period when I would talk to myself, I would pity myself so no-one would see me. After he died, I was very stressed, could not work, did not have the strength to do anything. My legs got sore, it was probably related to my nerves. I was probably depressed. You know, when a person close to you dies, it is as though everything is over for you, life is over, nothing makes sense anymore. I was in this state for a long time after he died, more than a month, I could not say exactly. That is how I was emotionally..." (#40)

The main carer for a dying loved one usually shoulders most of the personal care. They spend all their days and nights caring, sometimes with others, often without others. Their duties go beyond feeding and chatting with a sick loved one but become quite medical and nursing in their daily tasks. Much of the work is heavy, physical work and tiredness becomes the norm.

> „I washed, changed him, prepared his colostomy bag (I washed it), changed the napkins. I did everything the doctor prescribed for his treatment especially his medication. Our daughter gave him his injections (Analgin, Papaverine, and others). He refused any opiates till the end. He knew he was ready but he was brave till the end. I made him tea, diet food. For example, I made him oat porridge, to which I added all sorts of ingredients: grated walnuts, sunflower and pumpkin seeds, oranges (he refused to eat them on their own). I also made him soup, dunked bread in it and fed him with a teaspoon. I was always at his disposal, day and night, because he

> was in a lot of pain, had great burning sensations in the spine and other organs, or he would say he could not breath properly. He also had neuralgia, which would regularly get worse (for example when he shaved, or if he somehow touched his cheek). I kept moistening his lips, bottle fed him, and took care of his bedsores – and all this for almost a year." (#42)

Often the experience of dying and caring is difficult to separate. The experiences of the two become almost „symbiotic" – a kind of mutual cycle of anxiety and pain and grief shared by dying person and carer. The actions of one often determine the actions of the other in a ceaseless cycle only ended by death itself. But in all this ceaseless and changing set of challenges the carer is frequently an isolated and lonely figure in the last hours, especially when the dying person enters a final coma or sleep.

> „He was in a lot of pain in the last two months. He was constipated in the last two days. It was different on the last day, I could see he was shivering, sweating. He had a temperature of 40 and was saying he was aching all over. I gave him an injection of Analgin and Dimedrol and his fever disappeared straight away. His sweat became cold and this reminded me of the expression, „the cold sweat of death", but I still did not really think he was actually going to die. I called the ambulance that night, even though he did not want me to…. The ambulance staff gave him an injection, even though I told them I had already given it to him. They then said it was for his heart, even though he refused it. I asked them: were they perhaps taking him to the hospital? But they refused. When they left I saw that he seemed to have cooled and calmed down. I was holding his hand so he could feel he was not alone. I was thinking maybe he was going to die, but I chased that thought away. I could not bear to think he was going to die. I preferred to think that he had fallen asleep, though I was aware that he had received a double dose of Dimedrol. I went to bed about 1^{am}, woke up about 5^{am}. He was still warm. I asked him twice: „Papa, are you dead?". He did not answer. I called the ambulance again and told them about the visit on the previous night and that his stomach was hot and I did not know

> if he had died. The ambulance staff said the body was probably cooling more slowly. They asked me if I wanted them to help me call the morgue.” (#46)

These above accounts, and many more that we will describe and detail in the following chapters, tell us a great deal about a national need for wider social support strategies and professional care policies for the end of life in the Republic. In these coming chapters, we will describe in greater detail the personal costs of care for families caring for their own at the end of life. We will also describe in greater, often tragic detail of the suffering encountered by those at the centre of that love and care, and we will give voice to the almost unanimous cry for more help so often and so regularly described by those who have lived these common and regularly occurring experiences. These are experiences that we will all encounter during our lifetime. As the following respondents put it so eloquently:

> „I think the main thing is that the state should get more involved in these patient’s problems. In fact, in our country there is practically no help from the state. You see, I was able to care for her at home, to give her the right conditions, but I have seen a lot of families who are not able to care for such patients as is appropriate. That is why I think they would feel much better if there were social help, with home visits from specialists, specialized consultations to care for these patients. I also think families’ attitudes toward looking after these patients should change. At the moment, some families with incurable patients at home think only about the will and not about caring for the patient, who, after all, is a close relative, maybe a mother, a father, a grandfather…the state should get involved in the problems of these families who look after incurable patients.” (#48)

And from even a medical practitioner who cared for her own mother:

> „In the past, parents used to live with their children, which meant that they could be better supervised. On the other hand, the elderly benefitted from better care at the end of their lives. They all lived together. Now, at the end of your life, you are left alone and powerless at home. Generally speaking, I think it would be helpful

> if there were a unit where these people who are getting close to death could be cared for – where people at the end of their lives can benefit from the assistance needed. Where they could live, not isolated, but benefitting from specialized care given by well trained staff for this very purpose. I believe a lot of people do not wish to die in hospitals because they cannot benefit from the care required by their situation... As for myself, I personally would have benefitted from a counselor or psychotherapist during the period of care. Special beds would have been useful, on which I could have cared for my mother. One needs special clothes, which can be put on and taken off easily during the period of care, they can be easily handled. One needs special sheets, powders for bedsores, solutions for personal hygiene, special mugs to give water to the sick person to drink. Above all else, one needs carers in these situations, probably more so than priests or doctors.” (#22)

These final comments and observations by two carers are representative of the sentiments and needs of those who have been through a prolonged but typical experience of care. Through their experience they have understood the daily – almost hour by hour – needs of caring for the dying person with complex care needs. Care for those who are passing away is not a simple care characterized by conversation and occasional feeding but a care that is characteristically complex and involving, a care that involves many basic nursing, medical and physical tasks that lone individuals and families are often unprepared for. Even the doctor in the last quotation was surprised to learn what was involved:

> „I felt how incompetent I was. Even though I am a doctor, I did not know how to turn the patient, how to care for her. In hospital, when I tried to do something, the nurse would tell me, „you are not doing this and this right”, and so on. „It must be done differently, so as to prevent bedsores”, and so on. If she had died without my being present or having got involved, maybe I would have felt differently. But because I cared for her I felt terrible. I accused myself of perhaps not having done everything for her.” (#22)

Such comments and observations highlight the desperate need for support for those who care for the dying at home. Nursing the dying can be a complex task that is not easily performed by isolated individuals no matter their previous level of professional education or even their financial resources. The care of bedsores, or turning a patient in bed, are small but important tasks that, wrongly performed, can lower both the quality of life for the dying person as well as the health and safety of those who care for them. A lack of support from other family or neighbors or even health care professionals increases the chances that dying can become degrading and grief-stricken for both the dying and those who care for them. For those with no relatives, friends or neighbors to provide regular care, specialized state-supported services are essential.

This study has shown that the needs of patients at the end of life, as well as those who care for them, are extensive. These needs range from better co-ordination of existing health services and better end of life care training for health professionals, to respite care and financial assistance for families involved in this type of care. There are significant equipment needs, social and psychological support care needs, and major national and community education needs about how to care for loved ones at the end of life. There is also a significant health services planning challenge suggested by the current study.

The health services challenge for the Republic is to design a system of health care to assist people to care for their loved ones at home with medical, nursing and social support. End of life care is yet to develop into a system of care triggered by the event of a patient returning home for the final time. Existing primary care systems – GPs, community nurses and ambulance paramedics – await a model of communication and co-ordination that would permit identification of relevant patients in the community for this kind of care AND the training needed to implement specialized symptom management care for the dying in these situations. For the most isolated or complex cases specialized units for palliative care may need to be developed in strategic regional locations about the country. We will discuss such policy recommendations towards the end of this book.

CHAPTER 2

The Carer's Experience

Life changes dramatically for most people who are caring for a dying loved one. Both the social and physical life of carers change (Kellehear 2009). Many carers are forced to give up paid work while for others heavy physical work becomes a 24/7 arrangement. Most people are forced into developing caring skills they did not have before, such as giving medications and injections, or having to wash and toilet their spouses or parents. The performance of these tasks become necessary because many carers cannot afford paid help or both carers and the dying person do not wish to employ strangers to perform these highly intimate tasks. As the medical condition of the dying person deteriorates, the carer becomes increasingly locked into a total care situation that is both physically and emotionally demanding, testing, and isolating. As more than one carer put it: the care for a dying loved one becomes „a great burden upon the soul." (#36)

The statistical reality of care may be summarized as follows. Although the overwhelming majority of carers claim to take on the bulk of everyday care for their dying loved one most of these have *some* assistance from family. Over 60% of carers have at least one member of the family who assists with care. For 23% of carers several members of the family contribute to everyday care. For the remainder of the 60% it is a sister (13%) daughter (9%) or son (7%) who will help. About 14% of assistance also comes from a spouse. So for most carers, some assistance comes from family or spouse (75%). Family is crucial to end of life care in the Republic. However, there are some other important and worrying trends.

One in five carers claim to have no-one assisting them (21%). For this small but not insignificant group of carers, absolutely all the burden of care comes from them without respite or help from others. All the emotional and physical care is performed by them alone with no-one to care for them in any way at all. Furthermore, and equally of concern to a „traditional country" such as the Republic of Moldova, less than 5% of all direct assistance comes from community or neighbors. Furthermore, less than 3% of respondents in our research claim to have regular assistance from medical practitioners. Alongside this dismal figure for community and neighborhood care is the parallel figure of 13% of carers who had to hire a paid carer or nurse to assist them. One can only conclude from this summary of the pattern of care at the end of life that when family care is unable to meet the challenge of end of life care, unfortunately, community, neighbors and professional services tend to fail to fill the gap left by these omissions. Although doctors, nurses and paramedics play important roles, these professionals tend to operate remotely, intervening from time to time during emergencies or scheduled visits. In terms of the minute to minute and hour to hour daily care, their presence is part of the background rather than the foreground of care.

In this chapter, we will discuss three major aspects of the carers experience. First, we will describe the main tasks involved in caring for a dying loved one. Secondly, we will describe how this relentless daily routine of care emotionally affected the carers in this study. Finally, we will describe the social impact of this lifestyle on the people who are performing this care, especially how spouses, neighbors or other family reacted to the carer's plight. In each of these tasks we will employ voices and descriptions from the carers themselves, that is, we will employ their own words wherever possible. All interview quotes in the following chapters have been made anonymous but for our research records numeric designations in parentheses after each quote refer to a specific interviewee.

The Tasks of Care

Over 95% of respondents in this study claim to be the principal carers. Only 5 people reported that they were not the main carer or that they were simply one who shared the care tasks equally with others. Most people however typically made the following remarks about what was involved in their care duties.

> „I basically did everything necessary for his care: fed him, gave him his medicines, lifted him, treated his ulcers. I did not call the family doctor or nurse because they came themselves anyway.” (#50)

> „I did everything that was needed: prepared the food, fed her, tidied up and looked after the house. I gave her injections twice a day, gave her a quick bath every day.” (#53)

> „I washed him, changed him, prepared his colostomy bag (I washed it), changed the napkins, I did everything the doctor prescribed for his treatment.” (#42)

> „Everything – starting with cleaning, food, injections, 24/7, washing, washing throughout the house, laundry, watching TV, shopping. I did everything she asked for. She was very fussy.” (#23)

> „I did everything – cooked, cleaned. I was the only one who cleaned. I also went with her to see the doctor and called the priest too.” (#65)

> „I did everything possible to help her, encourage her. I cooked for her, fed her, washed her, looked after her hygiene. Toward the end though, she could not even eat or drink. I took her to the doctors, called the family doctor, talked to her, gave her massages, injections, called the medical nurse to put her on a drip.” (#78)

> „I did everything. I washed her, cooked for her, looked after her hygiene, gave her injections, I stayed with her night and day. I tidied up.” (#82)

> „I did everything: I fed her, washed her, gave her the injections prescribed by the doctor, did the dressings for her bedsores daily. I changed her clothes, looked after her hygiene, tidied up her house, chatted with her, washed her clothes, called the doctor at home, bought food and whatever else was needed – everything a person needs to live.” (#80)

> „For as long as he was ill, from the very beginning and then later, when he was in bed, our children and I looked after him. Our daughter, four sons and daughter-in-law did everything. We fed him, prepared the food, did the shopping, tidied up. In the last few months he needed to be supervised, because he did certain unpredictable things. For example, he would go into the kitchen and turn on the cooker, turn on the water, he once tried to throw the fridge out the window…” (#88)

> „I did everything he needed: cook, wash him, dress him, change his diaper regularly, every hour, because he could not control himself.” (#7)

> „I basically did everything that was needed to care for someone. I fed my father, bathed him, changed his clothes, underwear, nappies. I got his medication and gave it to him. I took him to the doctors when needed.” (#94)

> „I did everything in terms of caring for my mother: I bathed her, changed her clothes, gave her intramuscular injections and put her on a drip because, when she started needing care, she could not eat anymore. (#55)

And finally a 59 year old woman who was the daughter-in-law of a 63 year man who was dying of cancer wrapped up her comments in this way:

> „I washed him, changed his clothes, he used to spit into a bottle which I changed. I cooked, looked after the house and yard, tidied up, washed his clothes, buried him.” (#71)

Other respondents went into great detail about the many new and ever multiplying tasks of care. For many of these respondents, the new tasks were complex and challenging. A young wife described her routines in the following way:

> „I would change his nappies, rub oils against bedsores on his body, give him medication, make compresses, give him drops, massages, rub cream including on his face. I did everything, no other hands touched him…when I gave him injections I would also caress him, kiss him, tell him stories and in this way we could reduce the dose of narcotics. I was with him even during the seven courses of chemotherapy, radiography and immunotherapy. I would give him drops, vitamins, do physical exercises with him (even in intensive care, after the operation). I devised a diet and prepared everything according to it. I would make him juices. During the day he would often sleep and at night he wanted to chat, we would play music, watch films or cartoons (to make the fear of the unknown go away)." (#33)

Another carer described her new roles in the following manner:

> „I washed him, cooked fresh meals and on time, I read to him, we watched TV together, talked to him, I tidied up, prepared natural medicines, creams. I took him to the hospital, lit the stove because he was always cold. I would do my best to cheer him up, surprise him; or I would tell him something or prepare him a meal that he liked, or buy him something that he liked when he was healthy. He was a wonderful husband. I prayed that he would live as a long as possible, even though he was sick." (#38)

A 77 year old niece of a dying woman described her work in this way:

> „I would wash my aunt, change her clothes, cook for her and give her food, fixed things in the house (paint, plaster), clean, till her land, bring home the produce from the land, make the fire, spend nights with her." (#27)

Another carer mentioned novels ways to overcome the challenge of caring for a dying person's hygiene needs in the following way.

> „I would wash her in the morning and in the evening, tend to her personal hygiene, change her shirt with a new one every day. I would tear the old one so as not to hurt her and throw it away, do her dressings, clysters (she was constipated), disinfect her hands with surgical spirit, cook the food that she wanted, talk with her, tend to her house and garden, tidy up, pick the land produce, paint the trees, paint around the house, including the fence, call the doctor, sleep over at her house." (#28)

Many carers had to learn new skills, especially simple nursing or medical skills and this was often an unanticipated side to caring for a loved one.

> „Her youngest daughter learned to give her injections, especially since in the last month, my cousin had to be administered morphine twice a day." (#86)

> „In the last month my husband received injections for pain, which I administered myself. Even though I am not a medical worker, I learned how to do them." (#60)

> „Besides household chores, I also had to perform some medical procedures, such as intramuscular or intravenous injections, drops, massages etc. I learned these things when I was in hospital, after I was injured in Afghanistan." (#9)

> „I would make sure he got the treatment prescribed by doctors on time, administer his injections through a subclavian catheter." (#16)

> „This period was terrible for the whole family. My wife and I had to go to work, then cook, tidy up, because my mother's wounds after the operation kept leaking, the area around the wound was decomposing. There was always an awful smell in the house. It was very hard to treat those wounds; it took about 3 hours to take care of my mother's wounds and hygiene. We were very tired, did not

> get enough sleep. We slept on average about 3 hours per night during that period.” (#102)

Care of personal hygiene of the dying person was also a commonly unexpected and physically demanding care task that took its toll on carer’s both emotionally and physically. Often families simply did not have the equipment to meet the challenges of these taken-for-granted nursing tasks. In the absence of professional support services many families had to simply improvise.

> „I used to sleep in the adjoining room, and during the night, he would bang on the wall and shout, „Ion, come, I have wet myself…” It was like this a few times at night.” (#63)

> „I took care of her hygiene. It was very hard because my mother was a big fat woman. I could not lift her. It was hard to turn her to one side and wash her, then turn her to the other side… this is how I made sure she was clean. We made her a toilet out of a bucket; I had to lift her each time and hold her until she relieved herself. There was a period when I told my mother I could not hold her like this every time anymore; physically I was unable. I asked her not to be upset with me. I got several mattresses and told her to relieve herself in bed, and I would immediately swap her mattress with a dry clean one. I would immediately wash the dirty mattress and hang it out to dry. So she was always lying on something clean, I did not even use a plastic sheet; I was afraid she might get cold or traumatized.” (#19)

> „Going to the toilet was a problem. My father and I had to hold her. My Dad made a chair for a toilet so we did not have to take her through the house all the way to the bathroom.” (#18)

> „She always had urinary and fecal incontinence as well. This caused me a lot of trouble: I had more clothes and bed linen to wash. Likewise, I had to wash the patient more often. I made a hole in her chair, put a basin underneath, and that was her toilet. I tied a long towel to the chair so she could stand up on her own while

> holding onto the towel and relieve herself unaided. Even so, she was relieving herself in bed." (#11)

> „First of all, I did not allow others to get involved with her care because I thought it would have been embarrassing. Sometimes, even I was ashamed of „intimately" washing my mother, who was old and powerless. I did not want my daughters or especially my husband to experience such emotions." (#4)

Such heavy tasks often took more than an emotional toll as several respondents observed of their own physical injuries during care.

> „I would look after her, carry her in my arms to the medical centre, to specialists but eventually I broke my back. Luckily we had a car." (#34)

> „If she said she wanted a bath, I had to lift her to the bathtub myself and give her a bath. It was very hard to lift such a weight and eventually my spine collapsed because of the strain." (#41)

The Emotional Impact

The overwhelming majority of respondents in this study reported that the main feelings they encountered during care was anguish. Anguish was often described as an emotional experience of stress and pain directly related to watching a loved one suffer but not feeling able to do anything significant to relieve that suffering. Carer descriptions range from painting a self-portrait of being caught up in a personal tragedy, continual emotional „pain", and a constant cycle of anxiety and upset over the predicament of their dying relative.

> „It was a very tragic period. I could see him dry up, cry because of the pain, and I could not help him. I would ask myself, „why are there such illnesses?" He said that every cell was burning inside him… he was being destroyed…" (#42)

> „It was hard emotionally because I could not help him get rid of the pain. I thought I was going to die with him just from being unable to help him." (#38)

> „Psychologically, it was a very difficult period. I felt very sorry for her. I saw her lying in bed every day… nearer her death I could hear her pray, saying: „God, give me a few more days, I don't want to die." And I could see all this, how she wanted to live, but I knew that death was inevitable. It was terrible. You know, a few years before she died, I had got to such a state that I went to see one of those women who tell your fortune, deal in magic, and she told me that Mum would die after a long period of time but she was going to die on a big religious holiday. And you can imagine how all these years I greeted the holidays. Every time I would get stressed up about it, wondering if that was going to be the day (when she was going to die); it was like that on every holiday." (#48)

> „It was an emotionally difficult period for me. I was very affected by the events. I found it very difficult to see Mum suffer like that. I would cry often. My Dad would calm me down. He would say I had to accept things as they were, to accept my mother's death was inevitable and to go on living, to look after her for as long as necessary." (#18)

> „It was a difficult period. It was very stressful. First of all, this was someone close, and when you know that death is inevitable and she is young, you feel sorry for her. You think about her small child who will be left behind without a mother at an early age. I thought about my son too, that is, her husband. You are dealing with people who are close to you, and therefore, it is psychologically hard." (#62)

> „God forbid! What could I as a mother feel? I knew that my child had this illness and she was going to die." (#25)

Carers almost invariably reported experiencing great stress during their period of care. Depression and anxiety were common reports. Some carers identified with the suffering of their charges, sometimes reporting fear of changes in their own bodies. Pity and weeping were common. Reports of lasting stress, experienced long after the death of their loved one was common too. The day-to-day hardships of care created serious and taxing psychological effects.

> „It was a terrible period, very stressful. There were times when I was ready to crack up and take my own life. I could take it no more. It was a year from Hell, and I am ill and have many problems – the addition of this new problem to my own personal ones completely destroyed me. But I did not have any other solution, there was no way out of this situation. Toward the end of that period I wanted to leave my husband, the house, the old woman, and leave home. I could not take it anymore. Then my husband would intervene, would ask me not to leave, and explained to me that there was no other solution, that nobody would help us and we had to manage on our own. She was our mother…" (#10)

> „For me it was an emotionally very difficult period. I was doing my best to encourage her but I knew I was much afraid of her illness. I had a lump in my breast, and after speaking with her, I started to feel pain round that lump and I was afraid of the illness, of the fact that you could die so young. I felt very sorry for her, her children, and at the same time, I knew there was nothing I could do to help her. I did not give her a lot of time, only a few hours a day, but I would get very emotional, when I was going home, I would need about an hour to recover before I could take care of my own family problems." (#15)

> „It was a difficult period for me, both emotionally and physically. I used to cry often. I was sorry for her. I also sometimes cried for myself. But I was doing the best to make my peace with the situation, to spend as much time as possible at her side. It was very hard, I do not wish it upon anyone else to go through what I went through then." (#19)

> „It was a very difficult period. It is harder to look after an old man than to be in prison. Psychologically, it was terrible. I could see him wither day after day. I felt extremely sorry for him. It was horrible." (#63)

> „I felt very sorry for her. It was painful. I would often cry. It was very hard. I had no help from anywhere. My sense of duty as a daughter helped me overcome all difficulties and I did my best to give her everything she wanted." (#14)

> „A great pain, which I cannot express. I did not think it would be so hard. I can't express this pain right now even. I did not think it would be so hard... I never thought it would be like this. I am sorry because she suffered and she looked like a child. I did not think it would be so hard. You could tell she wanted to live, that's what I saw in her eyes. Not a day goes by without my thinking of her." (#24)

> „Great pain, which I can still feel in my heart to this day. I always think about him. I keep myself busy with work, but I don't know how I have been able to withstand such pain... the only things that keep me going are my faith and praying to God." (#26)

It is commonly thought that grief and loss is an experience that occurs to people AFTER the death of someone they love. However, both loss and the grief that this prompts commonly occurs during the care of a dying loved one. People reflect on what might have been but will not now come to pass because of the illness and impending death. Some carers continue to hope for the best but regularly realize that death is inevitable and grieve at this prospect. Some carers understandably grieve over their own hardship as well as the future loss of a loved one. The grieving that begins during care continues after the death – not simply because of the lost relationship – but also because the routines of care that were integral to that relationship in the last weeks and months are also now gone. The loss of the routines of care continually remind the carer of his or her loss even more than the actual death as the final event might do.

> „You know how it is: you cry for the patient but you cry for yourself… I felt very sorry for him, about the fact that he would not be able to enjoy the children, the grandchildren, our family. I was heartbroken, not because I was having a hard time, but because he had worked, amassed, brought up children, grandchildren, and now, when we were left to enjoy our lives and everything that we

> had accomplished, he was going to die and we could not enjoy this together. Like two old people – to get into a good car and drive to see our children, grandchildren, to give them presents, to take care of them, etc. Emotionally, it was a very difficult period." (#16)
>
> „As a mother I felt very sad and upset for her. I was asking myself, „Why me, why did the Lord set such a trial especially for me?" With time, I made peace with this. I did my best to give her everything she wanted and needed." (#6)
>
> „It was very hard, traumatic. I always felt unwell, cried, worried about my mother. But I cried even more when she died, I missed her so. I had tired of caring for her but at the same time I could not come to terms with the fact that she was not there anymore." (#84)
>
> „I don't think anyone could describe something like this. Psychologically, I cannot describe it. It is as though I still cannot believe she is dead. At first, it was as though I were waiting for her to call me any minute. We were very close, we always knew where we were and it was as though I felt a need to call her, to tell her where I was, that I was going to be late, etc. Situations and feelings like these occurred even half a year after her death. I would say I had to call mother to tell her I was going to be late or that I was taking the bus at a certain time." (#30)

Aside from the obvious stress and grief of care, there were other emotional impacts that were not anticipated but were just as serious and debilitating in their personal consequences. Often this was because they were often totally unexpected. Anger, frustration, and self doubt are common consequences of both the dying experience (Kubler-Ross 2009) and the experience of its care. These emotions strike not only at the heart of home life but also sometimes have an impact on one's self image as a professional.

> „It was a terrible period, very tough emotionally. Especially in the last two weeks. I would like to tell you as a colleague, after my mother died I started to hate my profession as a medical doctor.

> Probably because I can’t do anything to help; I am unable to cure this kind of patient.” (#55)
>
> „It was a difficult period. I felt very sorry for him but I would also get very annoyed because he had become fussy. He was in a lot of pain and he was groaning all the time. While I was at his side he would be quiet for a while, then, when I went to get some rest, he would start groaning, shouting „oh dear, oh dear”, especially at night. I basically did not sleep. I would ask him not to shout so much. I would tell him I was going to die too because he was making me suffer so much! But he would not relent, saying, „If I am not sleeping, you are not sleeping”. That is how it was with us.” (#44)
>
> „It was hard for me. My mother’s illness was something unexpected. I was always unsure about what I should do. I thought she would recover. At the time I went to work as well, performing my duties, and obviously it was hard for me to manage everything. If I am honest, I was not prepared for the difficulties and problems I met with.” (#58)

The Social Impact

There are two equally important but separate social observations to make about the relationships between carers and their networks of family, friends and neighbors. The first observation to note is that the overwhelming majority of carers reported either no change or positive changes in their social relationships during their period of care (75%). This is an important platform of stability and support for most families in the Republic. Typical remarks related to this part of our interviews include:

> „This period of care did not affect our family or relations with friends. And our relations with neighbors remained the same.” (#52)
>
> „Relations with friends, neighbors did not change. Likewise, no problems arose in our family. On the contrary, family members understood (the situation) and helped as much as they could.” (#47)

> „There were no big changes. The friendships stayed the same, as always. I do my best to keep good relations with everyone and my relationships with my friends did not suffer, either then or after my mother’s death. My relationships with my neighbors did not change either. My relationship with my children was good throughout that period. Now the children remember the food cooked by my mother, they say how good it was and compare it to mine!” (#24)

Beyond the usual and normal relations enjoyed with family, friends or neighbors are many stories of increased attention and support from these groups. In fact, one person in three in our study reported positive effects on their relationships during the period of care. Such attentions were always welcome and appreciated by the often beleaguered carer. These attentions were important sources of care and moral support in a time of great stress and isolation.

> „You know what they say, a friend in need is a friend indeed, and we had friends and relatives who came to see us. And when they came to see him I too was glad and moved to tears because they had come to see us. He was very glad too, and I was too. There are still good people out there, even though they say the world is now not what it used to be. We were more united then.” (#38)

> „…those close to me gave their support and helped me a lot. I am very grateful to my husband, who was always beside me, gave me support and helped me with everything throughout this period. Generally speaking, I would say this period made our family very strong just because we all wanted to help my father.” (#91)

> „They all knew, mother came to my workplace. I was lucky with a colleague of mine whose husband took care of my mother’s treatment, that is why she knew about it and got involved. There were no conflicts because of it. I was even offered the company car to bring her whatever she needed to the hospital: food, medication. There were no problems within the family either – my father-in-law had also died of cancer one year before so they all understood me and helped me. My brothers, my wife’s brothers

> and I stuck together; we are not a big family, we help each other. We are close.” (#35)
>
> „In the countryside, it is the female neighbors and female friends in the village and their husbands who are a great help. We have good relations with them. We help each other when in need. We call each other when there is an emergency. We would call our (female) neighbors more often than the medical nurses who, in fact, did not live far away from us. I didn’t want to disturb them because, in our village, a medical nurse has a lot of work to do and are often disturbed by the villagers... In the countryside, people are helpful in times of need and hardship.” (#3)

Common were short comments about the positive nature of family and the support garnered from there. Short comments, but deeply appreciated ones nevertheless. Examples include:

> „My husband always did his best to be beside me; he was not aggressive, he helped me and gave me moral support.” (#41)
>
> „My husband was understanding…” (#12)
>
> „Both my husband and I looked after my father – we supported each other.” (#97)
>
> „Relations with our neighbors strengthened, they were and are good. They all come to me when they have problems.” (#75)
>
> „The family became even more united. We became even closer, both family and friends got involved in looking after her.” (#25)
>
> „I could not say that this period caused our family any problems. On the contrary, our family became united and we all got involved in solving the various problems caused by this situation. We all did our best to help her – it was a fight for life!” (#62)

There were, however, serious social costs for other carers and this is the second important observation to make alongside the earlier, more positive one. Some carers, although often reporting steady and usual support from their social network nevertheless experienced sacrifice due to their commitment to round-the-clock care. Many respondents reported having to forgo paid work – or even marriage – to commit to this kind of care. Others reported increasing social isolation as the tasks became more complex and demanding.

> „I could not go to work because there was always something I had to help her with, to care for her. During this whole period of two years I had no work and no job." (#2)
>
> „Like I said, I had to stop working during this period. I was working abroad at the time and I came back home. Because I had to be at home all the time I could not get a job. I only got a job after my father died." (#101)
>
> „Certainly, this event has left a deep mark on me and will affect me for the rest of my life. That is why I gave up my job – to have time to care for my father. I was on holiday at the time, I called at work, and it was I who suggested that I be released from my duties as I did not know how long I would need to care for my father." (#1)
>
> „I had to give up work. I was living off the pension…" (#6)
>
> „I did not work. I did not have enough time to manage both at work and at home. I had to give up work." (#13)
>
> „When mother became ill I was raising three children, building a house, my husband would not help me to care for her, so I had to give up work." (#14)
>
> „I could not stay away from her. I did not even get married because she would get upset if I talked about that so I thought it would be better if I looked after her rather than a stranger." (#67)

Social isolation was a constant threat or reality for many carers, even with a strong network, the tasks of caring could often become so absorbing that carers frequently had to forgo the usual recreational life they might have previously enjoyed. Although social isolation is a common experience for all carers of dying people in all countries (Soothill & colleagues 2003, Kellehear 2009) it can be more acute and widespread in resource poor countries (Bingley & MacDermott 2007, Hunt 2009).

> „I spent most of the time at home and I could not go anywhere. I could not even go to my daughter's to have a bath, because it is harder in the countryside. I could barely go to see my neighbors for five minutes and then quickly go home because my mother had to be supervised, maybe she needed something, besides, she liked to have a drink and she was not allowed." (#74)
>
> „I did not go to parties, weddings, etc., practically did not go anywhere. I could not leave her alone for a long time. Other worries, thoughts appeared." (#48)
>
> „I could not go somewhere to have fun or rest, and I was giving less time to my children. I did not go anywhere, I looked after Mum for a year and a half." (#18)
>
> „I became secluded because of this problem. I could go nowhere." (#10)
>
> „Obviously, life changes radically when you have a patient like this in your house. I basically did not leave the house for 8 months." (#19)

More serious than isolation was the perception by one person in four of this study of negative social effects. About 25% of the sample of those interviewed complained of deteriorating social relationships, even rejection. Many respondents recalled with sadness, and some with bitterness, the cooling of social relationships with friends or neighbors. Some explained this distancing of relations by attributing this to a fear of the disease, of avoiding unpleasant illness, or of avoiding a sad situation or person (the carer). But others attributed this stigma to existing poor friendships or of poor human nature.

Whatever the reason that was speculated to be behind the distancing or rejection, there can be no doubt that such reactions were hurtful and contributed to undermining a carer’s ability to maintain a healthy and positive morale. Social support is crucial to all people at times of crisis and need and social rejection and distancing is undoubtedly harmful to well being.

> „My friends in the end only gave condolences. The neighbors were indifferent. Even though at the beginning they said they would help me, at one point I understood I had been left on my own, and there would be no help from anywhere.” (#9)

> „I started to see things in a different way. I can see the lies and cowardice of others. My friends disappeared, when I asked them for help they would find many excuses and in the end turned me down. My wife refused to look after her. She eventually went to Italy.” (#8)

> „We basically did not have any support from anywhere else. Even our good acquaintances, some of them friends of ours, did not give us any support. They only had very little time to talk to us and encourage us. It is very sad.” (#100)

> „Relations with neighbors did not change – it was total indifference.” (#77)

> „At first, relations with friends, neighbors, did not seem to change a lot, but you could tell they had somehow cooled. There were fewer visits and conversations. Maybe they thought I was feeling low, they did not want to bother, I don’t know.” (#16)

> „Our friends or neighbors did not come to visit. Who could stay with him if he kept moaning and saying, „Oh dear, oh dear? ” ” (#44)

> „People distanced themselves, as though I had a contagious disease. They do not understand what I have been through, neither at work nor my friends. Such situations make it very clear who your friends are and who aren’t.” (#33)

> „I saw how many friends and relatives behaved towards my father and us during this period and I came to the conclusion that people will remember you (only) when you are well. This period, though, has made me stronger; I have become more careful about the friends I choose." (#54)

Concluding Remarks

There are 3 main observations to summarize about the carer's experience. First, the tasks of caring are both demanding and total. They frequently require the acquisition of new skills. Often these tasks must be undertaken with little or no technical support, that is, without suitable equipment, financial aid, or respite care. Although visits from doctors and nurses are welcome and important, the tasks of day-to-day, and hour-to-hour care involve far more than medical or nursing attention. The management of body washing and toileting, or the lifting demands involved in turning patients in their beds to avoid bedsores, or the juggling of paid work and home care, are often dramatically difficult without the proper equipment or additional social help. The long term consequences of such tasks, with minimum social help, are personal injury and burn-out, and social isolation (Hunt 2009: 84).

Secondly, the emotional costs of care are high. The majority of carers report deep grief, stress and anguish. These are often emotions that – at their very best – last long after the period of care. At worst, they lead to suicidal thoughts, long term emotional disability, and or estrangement from friends and family. Although, there are important needs concerning the practical tasks of care such as equipment and respite care, the widespread reports of emotional stress and difficulty do suggest an equally widespread need for personal support – from friends and neighbors to professional psychological supports (see Harding and Higginson 2009). This highlights the social impact of care for a small but significant group of carers.

Finally, although most people report no change or even positive changes from their family and neighbors, the fact is that one in four respondents report rejection, stigma, or social distancing during their period of care. Clearly 25% of respondents who report these experiences is a significant and culturally unacceptable figure – a figure that should be of concern in any national context where social policies are designed – or should be designed – to encourage compassionate support and care (Kellehear 2005, 2007). The social stories behind this figure of 25% also suggest expressions of fear and ignorance about cancer, dying, or long term care, and such fears seem to focus not only on the caring household more generally but more specifically on the carer as an individual person. There is much a public education campaign might do to illuminate the plight of long term carers as well as in suggesting what positive and constructive roles neighbors and friends might play in such a situation. We will say more about this in our final chapter.

In terms of the international literature on end of life care experiences of family, this chapter repeats and reinforces findings that have been demonstrated in other resource-poor countries in Africa, India and the Middle East (see Bingley and MacDermott 2007, Hunt 2009). Poor public education about life-threatening illness – whether this refers to AIDS, cancer or organ failure – can lead to ignorant or poor social responses from the wider community. Even in wealthy economic circumstances, people from resource rich countries may still fail to step up their care for families laboring under family care of dying people (Soothill and colleagues 2003). Although people in wealthier countries may *choose* to receive care at home, most people in countries such as the Republic of Moldova have little or no choice. Carers have few or no respite care options with serious psychological, physical and social consequences for these carers (Hunt 2009). In this international context, the experiences of carers in the Republic of Moldova are consistent with poor health care infrastructure and co-ordination. The review of carers experiences in this chapter compels us to conclude that dying people and their carers in the Republic of Moldova suffer greatly in circumstances of end of life care.

CHAPTER 3

Customs for Dying and Death

The carer’s experience is not bounded by duties that relate entirely to the health and social care of the dying person. In other words, the care of people who are dying is not exhausted by medical or nursing concerns for the sick person. Some weeks, days and hours before death itself most families engage in some form of traditional custom. Usually these customs relate to the dominant form of religion in the Republic of Moldova, that is, the belief in Orthodox Christianity. This religious tradition of belief is widely regarded as the well spring of the Republic’s traditional customs, sweeping into its core rituals other village customs and superstitions. And although most people believe that the Republic is largely dominated by these beliefs, especially in the rural areas of the Republic yet this is not entirely the case when examining a cross-section of the Republic’s society as we have done in this study.

Although the majority of respondents did claim to initiate or participate in traditional religious or village customs for death and dying (about 56%) a very large majority did NOT engage in these activities (44%). In other words, it can almost be said that nearly half the study’s participants claim not to be a significant part of traditional ways in respect to death and dying in the Republic.

In this chapter, we will summarize our findings, as we have done in the previous chapter, by employing the literal words of the participant wherever possible. We will begin the chapter by describing the large minority of respondents who do not engage in traditional customs of death and dying, taking care to describe the main sources of their reasons for not doing so. We will then describe some typical narratives by respondents describing their religious customs for the dying (but not dead) person. This will then be followed by a description of some customs for death and dying that seem more influenced by folk or village traditions. Often these rituals blend with those of Orthodox Christianity and may seem to many to often be indistinguishable. Finally, we will end the chapter by describing some of the folk beliefs and superstitions around dying that carers have reported as being informative to them in some way. Through these descriptions we hope to highlight the fact that important parts of care for the dying by families in the Republic are not only physical, psychological and social but also spiritual.

Non-participation in Customs

About 44% of respondents reported that they did not perform any traditional rituals or customs for the dying person. There were a variety of reasons for this non-participation. The simplest reason offered was the lack of knowledge of any of these customs.

> „I don't know any customs (for dying); although we did perform customs after her death." (#34)
>
> „Nothing special was done because in our family we have had no special customs passed on to us." (#51)
>
> „Nothing at all, no rituals, none of that, first of all because I don't know them." (#55)

For other respondents, the reason for not performing any rites was the secularization of their family – they were not religious.

> „We did not perform any customs. He was an atheist and did not go to church. He did not have any special requests. After he died, we had a memorial meal. We did not perform any other customs." (#17)

For other families, dying came suddenly, before any customs could be put into place; or dying was unexpected during that time and caught many carers by surprise.

> „We didn't do anything, it came unexpectedly." (#39)

> „Although we are Orthodox Christians, we did not do anything in particular. And you know, until the very last moment, neither my wife or I could believe that she was going to die. We were sure she would recover." (#93)

> „You usually call the priest in to read prayers but we did not expect her to die then, so we did not do anything before her death." (#82)

One respondent blamed the place of death for not performing any rites, reasoning that institutions were, almost by definition, a place where customs would not or could not take place.

> „There were no customs because she was in hospital." (#37)

Another respondent blamed her tiredness for not performing any rites:

> „In the village you keep vigil but we did not do it for father. I had no strength left to stay up and my brother refused so we decided to take him to the morgue until his burial. There was just a (female) neighbor who kept vigil for a while until the car came." (#46)

A number of respondents claimed not to perform any traditional customs because they were not Orthodox Christians but Christians of another sort that did not have rites for the dying or dead.

> „We are Adventists. We too believe in Jesus Christ but we do not go to church. We don't have all these customs, such as memorial meals and alms. That is why we did not perform any customs. After

> he died I invited some brothers in faith, who read from the prayer book.” (#40)

> „I am a Baptist, and with us, when somebody dies, we do not observe any customs. One must take care of the person when they are alive. We had a memorial meal and that’s it.” (#7)

Another respondent explained that the family had abandoned religious practices during the Soviet times and this was a reason why no rites were performed.

> „We did not have any customs, she was not religious. You know what times had been like, you could not get a job if you were religious. A (female) student of mine was not given a „red diploma” because she was religious.” (#84)

And a final respondent attributed their lack of customary compliance to the resistance of the dying person herself.

> „We did not call anyone, did not do any customs because we had not expected it to happen so soon, nor had she asked for it. In fact, she even got upset when my sister bought the candles. She asked: „What, am I dead yet? ” ” (#78)

Customs for Dying (religious)

For the majority of carers, customs were performed (56%). Most of these customs were drawn from the Orthodox Christian tradition with some folk and village influences. These influences can be seen not only in the *kinds* of rites performed but at other times *when* these rites are to be performed. Our data show little consistency in the *extent and sophistication of the customs*. For some families, the customs were brief and performed in a flexible and general manner. For other families, the customs were elaborate and formal, with great attention paid to detail and obligation. Some rites involved small groups of people – a carer and another member of the family, perhaps a neighbor. For others, the rites may involve many members of the village and church communities. It goes beyond the methodology of this small study to provide a more proportional understanding of these patterns. What follows are the basic patterns of compliance and performance. These are the basic „models" of ritual that people in the Republic seem to follow in respect to dying and death.

For many families, the rites for the dying were simple enough – the lighting of a lamp or candle. This kind of lighting was believed to help light the way for dying people as they enter the „next world". In ancient Christian cultures oil in lamps was the usual choice since candles tended to be made from animals (from animal fats). However, according to Bowker (2000) by the Middle Ages candles were in use for most rites, including those for the marking the commencement of dying and commemorating the dead. In the Republic both the use of votive oil lamps and candles are found in common use in these settings, though, candles are most frequently mentioned.

> „We held a candle for her while she was dying." (#28)
>
> „She has a small icon in her house. The only thing her husband did was to put candles and matches under her bed and told me that, should she die in my presence, to light them, which is what I did." (#79)
>
> „We performed Orthodox customs: we lit the candle, the votive oil lamp, said prayers." (#70)
>
> „But I called the priest on the last day and asked what rituals I should perform and he said, if she had been baptized, then a lit candle should be held. I held her candle. I lit some frankincense." (#31)
>
> „I did not do anything in the last 48 hours. Mother was Orthodox Christian. When I realized that she was dying, that is, her breathing was getting deeper and rarer, I lit a candle." (#57)
>
> „In our village it is considered that a person who is dying needs the light from a lit candle, which is why in the last few evenings, almost in the last week, we had to stay up talking and take turns to sleep so that somebody would be present when the patient died and would hold the candle for him." (#13)

> „I decided to act according to the Orthodox Christian faith: the candle was lit in her room all week so she would not die „without light”... and there always had to be one of us staying with her, in case something happened and we had to intervene. So I would stay for five or six hours at a time then my husband would come to replace me... in fact this is a tradition in our village, to stay beside the patient, not to leave them alone...” (#10)

For some families, two candles were lit in recognition that dying people may also act as messengers or helpers to those former loved ones who had died without the „light”.

> „Another custom that we performed was the Passing of Light into the World of the Righteous. It is performed when someone close to the person who is about to die is supposed to have died without light, and the person who is about to pass away will bring light to this relative who has already died. It is performed only with the agreement of the person who is about to die. They give her two candles to hold and the person who is about to die has to find the other relative in the world of the righteous and pass on the light to them. It is said that the person who is about to die could spend centuries looking for the soul of their close relative. My Dad, that is, my mother’s husband, had died without light, and my Mum agreed to pass on the light to him.” (#41)

Other respondents participated or arranged for more elaborate and earlier rites for the dying. Sometimes these rites were additional to the above „rites of the light”. These frequently involved the administering of sacraments such as Confession and/or the Eucharist as well as the *custom of untying*.

> „We performed the custom of confession about a month before she died. A week before she died, when mother could not speak anymore, we performed the custom of untying: you gather flour from nine widows, some money, and you take this to the church, to the priest, who reads the prayer of untying, and if the patient is meant to live, they get well. If they are not meant to live, it will ease their death, or as they say, it will „open up (untie) the road”.

Mother died one day after we had done this. After she died we gave alms, had a memorial meal, etc.” (#14)

„The priest came to our place a day before he died, that is on Sunday. I called him because I saw that Dad was suffering, he was not eating anymore, his pain was getting worse, Tramadol did not help anymore. I went to the priest and told him things were going badly and asked him to come and read from the Holy Book the prayer for forgiving one’s sins (untying). So the priest came and read and then Dad died as soon as the next day.” (#1)

„She was Orthodox Christian. We called the priest one week before she died. He performed the Holy Unction and read the prayer for „Untying the Road”. This custom is performed as follows: Seven widows go to the priest, give him some money as alms, and ask him to read the prayer for the untying at the patient’s bedside. After this custom is performed, the patient stops suffering and gets well, or if they have no more days left, they die. When the priest reads the prayer and opens the book, if the pages turn black, the patient has no more days left, and if they are white, they recover.” (#61)

„The priest, when I called him on the phone, asked me if my husband was spitting or throwing up. These things are very important during the traditional procedure of the Eucharist. During this time, it is very important, from a religious point of view that the recipient of this procedure, called the mystery of the Eucharist („tainele împărtăşaniei”) does not eat or drink, does not spit or throw up, so that he may receive the Eucharist from God. At that point, 48 hours before his death, my husband did not eat and did not throw up anymore, which is why I took the personal decision of calling for the priest to come to our home and thus the Eucharist procedure was completed. This procedure is performed over the whole territory of the Republic of Moldova, in almost all of the villages, and it consists of the priest coming to the sick person’s home. The sick person confesses, which means he tells the priest all his sins, the bad things he did during his life, and the priest in turn forgives

> them so that the dying person may die in peace. The Eucharist can only take place when the sick person is conscious; if the patient is not conscious then the procedure does not take place." (53)

Other Customs for Dying & Death (village)

As the reader can see from a perusal of the above accounts, the details of the rites performed vary in their descriptive details. Some of this may be due to regional variation; others to interpretive difference; and yet others to the more broadly anthropological fact that all customary norms are acted according to their individual performance as mediated by individual knowledge, experience and competence. All rites experience cultural variation because they are all performed more or less by individuals of varied competence and expertise. This is well illustrated by the use of candles both *before* and *after* the dying process by different families. Some families believe that is essential that a candle be lit before death and others are equally comfortable with the fact that a candle may be held *at death or as soon as possible after death*.

> „When she died, a lit candle was held for her. In fact, there were two lit candles because her father had died without one and they say that she should bring the light for him too."(#30)

> „The votive oil lamp was always lit and when she died a lit candle was held for her." (#21)

> „We did not do anything in the last 48 hours although my husband was Orthodox Christian. After he died, we immediately lit a candle." (#59)

> „My husband was a Christian although, as I said, he did not go to church, did not believe in priests. When he died I lit and held a candle." (#89)

In some villages, a more elaborate folk custom may be observed that involves children. One respondent (out of the total of 102 reports) described her efforts at this custom.

> „There is a tradition in our village: when the person is suffering and can’t die, you invite nine or more children who will pray for the dying person’s sins to be forgiven. It is thought that children are sinless; they are like angels who help the dying person to cross over to the other world. The children sit beside the patient, holding lit candles, and pray for the patient’s sins to be forgiven. I did the same. When I realized that my mother-in-law was dying (it was her last day), I called the children in the area to come and pray for the patient’s sins. I did not manage to call nine children, but did manage to collect about six or seven…” (#11)

After the moment of death had come and passed, other customs for the departing soul are recognized and performed by some families. These usually involve a wake or vigil for the dead and this occasionally involves a memorial meal, the giving of alms and occasionally traditional songs. Vigils for the dying often informally continue in the form of vigils for the dead in many cultures as the moment of death moves into pre-funeral rites and preparations (see Crualaoich 1998, and the work of Donnelly 1999a, 1999b).

> „…this also remains true when the patient has died, again, you have to stay beside them for the entire three days; and three nights before they are buried. We call this tradition a wake („priveghi”). People in our village know this and come to see the dead person even late at night, that is why you must always be with the dead person, otherwise they will speak badly of you in the village.” (#10)

> „After she died, we called the (female) neighbor to come and wash her and dress her up, then they took her downstairs to another room. We tied her hands, feet and chin. We gave alms to the woman who washed her – soap, towel, bread, gave her a glass of wine. We threw away the water that she had been washed with in a place that no-one was going to tread and we hid the basin because it should not be used anymore. We went to church in the morning, announcing her death, and the bells tolled.” (#21)

> „A candle was held for her when she died. Then the carer and I washed her, placed a small cross and icon on her body. We

> prepared a bottle of wine with oil to put in her coffin and with which you spray the shape of a cross on the white cover and the grave. We kept vigil until her funeral. On the day of the funeral the priest and two choir women sang prayers at home and in the cemetery. We gave alms: 24 „bridges", bundles to those who carry the coffin, coffin lid and wreaths, special alms for the carer who took part in her washing, alms also for all those who took part in the funeral, the memorial meal. There is a custom whereby, before the meal, after having arrived from the cemetery, everybody has to first wash their hands. Then the priest read a prayer and we all sit at the table. She was Orthodox Christian." (#77)

One respondent in our study was kind enough to supply us with an example of a village song from her local area, customarily – as noted above – sung over the dead between the period of death and burial. Although there must be hundreds of variants and other distinct versions of such songs in the Republic we publish this one here by way of illustration. These songs are sung by family, neighbors and other villages to commemorate the dead, usually during time of vigil.

SONG FOR THE SOUL'S DEPARTURE

O, bitter and heavy sorrow
Death without consolation
O, what merciless death
Rips your soul out of the bones.

And separates us
From our relatives with woe
And I'm going don't know where
And return I will no more.

And I'm going to another world
Into earth and putrefaction
And I'm not going there to live
I am going there to rot.

Yesterday I was standing and talking
But tomorrow I will be in my grave.

Not knowing the day or hour
My voice too has fallen silent
And when the sun sets
I will be gone from this world.
And I will turn to dry clay
And I will be forgotten tomorrow

By my relatives and parents
Like they have forgotten all those long gone
And death has not given me anything
Only great fear

And they've made me no other gift
But a grave, a dark grave
Wherein they lay me
As though I were some kind of great criminal.

I was here yesterday but not tomorrow
Come, brothers and sisters,
Cry for me longingly.

Come you, too, my parents
Friends and loved ones
And look at me with grief
As I lie with a sad face
A yellow face
Hands lying on my chest
Waiting for my funeral.

O, tormented legs of mine
You're leaving everything behind
Come and sprinkle me with wine
As though I were some great stranger.

And wash me with water
And take me to the grave
Where I am going to live
Until judgement day.

They will ask me then
How long did I live in the world?
What did I do?
Did I do many good things?

[If so] I will be happy
But if I've done many bad things
I will go down to Hell with them
And I will toil for my sins with woe
Because you cannot repent after death.

Only the pity you have shown
And shared with the poor ones
Will do you good and join you
When you go into the other world

To a plain full of green fields
Where you have to rest
And meet with your guardian angel!

And think that happily, my soul,
You too have listened

While you were in the world
Where the angels sang on and on:
There is only one true God,
Lord! You are blessed!
Amen.

There are also other customs that relate to the clothing that the dead might were to prepare them to meet their Creator. We came across one respondent who observed this custom. She described her work in the following way:

> „A relative of ours works for the church and she explained to us that the dying person must wear a white shirt with long sleeves and over her knees, and without any imprints on it. According to what she said, the deceased will show up in this shirt before God, and should she wear something else, then on judgement day she will appear naked before God. Only if you show up wearing this shirt will you be dressed before God. When she was dying, we bought material and sewed this special shirt for her. I went to see a sister of my mother's and asked her to sew a shirt like this and to make it a bit larger so it would be easier to dress the deceased in this shirt. My mother's sister sewed it up in a few hours." (#22)

The last custom does not appear to have any relationship to Orthodox Christian teaching but may be part of a collection of folk beliefs and superstitions associated with death and dying held by many, particularly rural dwellers. Folk beliefs and superstitions are a normal and usual part of farming communities in particular and it is common for this to be integrated rather seamlessly into more mainstream religious and moral beliefs of the church.

Folk Beliefs and Superstitions

Berta (2000) and Redfield and Rojas (1934) emphasize in Hungarian and Mexican peasant death cultures respectively the widespread tendency to blend folk beliefs and superstitions into otherwise broadly Christian beliefs and practices. The idea of seeing or seeking omens for impending death, or for confirmation of death from animals, birds, even falling stars, are common. Shaping the journey of the soul from the place of death (the sick bed) towards the outside world and on to the otherworld is also a commonplace custom and all these tendencies are in evidence in carer conduct in the Republic.

> „We are both atheists, that is why we did not observe any customs or traditions. A week before he died, he wanted the priest to come.

> He probably had his confession then (which was rather strange because all his life he had been an ardent atheist!). As he lay dying, our godfather noted that our dog was howling; the Master is about to die. It is a superstition but that is exactly what happened.” (#9)
>
> „With regard to superstitions, I noticed that an owl was singing in the yard – people say that when an owl sings somebody will die. This happened a few days before my mother died.” (#2)
>
> „There weren’t any special customs. We stayed at his side and lit candles. A woman placed a candle on his chest, and when he died, I thought I saw some small vapour, like cigarette smoke, coming out of his mouth. They say that this is how the soul comes out; I have heard it happen with other people too.” (#71)
>
> „They held a candle for him. We put a glass of water and a piece of bread on the window sill because, when the soul leaves the person, it goes to the glass of water and the bread covers the glass – we keep them there for 40 days. An icon was hung on the wall. They also made a funeral candle („toiag”) for him, which is lit for three days in the dead man’s room, then you take it to the cemetery when you bury him, spread its smoke around as incense, then you take it home and keep it for three days, then you give it as alms to the woman who made it and she has to burn it little by little for forty days.” (#36)

There is also a widespread belief that premature grief and wailing can disturb the dying and dead, preventing them from leaving their loved ones and interrupting their forward journey into the afterworld. This is also a common belief worldwide and has been extensively documented by anthropologists and folklorists studying Irish traditions in particular (see Frazer 1913 but also Lysaght 1995). We document here several examples of this concern in our study.

> „The votive oil lamp was lit. They held his candle, it had to be someone from outside the family, and when he dies he must not

> be turned back, you must not cry too loud or shout because it is a sin to turn him back. He was Orthodox Christian.” (#85)
>
> „When I saw she was dying I called an aunt („mătusă”) from the area to hold the candle for her, because I felt I could not do it. I was going to cry and make her „come back” and she was going to suffer.” (#49)

And rather more graphically:

> „She was Orthodox Christian. The priest came to our place about two months before she died, he heard her confession. He read the Holy Unction prayer, which is read for patients so that they might get well or so that their suffering may stop and they can die easily. All the nephews were in the house that day, many relatives, who started to cry, to wail and ask my mother not to go away, not to leave them, and my mother regained consciousness. She lived another two months after this. An old woman then told us we should not have cried for her after the Holy Unction prayer had been read, because she was already going into the other world and we got her back and now she would continue to suffer even more.” (#19)

Summary of typical customary features for dying and death

It appears that most participants who perform customs for dying and death more or less follow a pattern of conduct that is widely understood in cultural terms. Some months or weeks before dying, those of Orthodox persuasion call a priest to administer the sacraments. This might involve hearing confession and receiving the Eucharist. This is particularly the case if the patient is well enough to speak and is able to eat morsels such as Eucharist bread without vomiting. At the same time, or later, a priest may also be petitioned by family or agents of the family (widows, neighbors or other villagers) to perform Extreme Unction, also known as the prayer of untying – to seek a recovery, or alternatively, to ease the passage of dying (see Bowker 2000).

Up to a week, and sometimes as late as the last few minutes of a dying person's life, a candle will be lit to accompany the soul of the dying person into the afterlife. In some exceptional circumstances, two candles may be lit so that the dying person may take an extra light to someone close who had previously died without a lit candle. These candles are most commonly also associated with the lighting of a traditional votive lamp, but may be done in their absence as well, in their own right. At death, it will be commonly important not to grieve too loudly. Wailing is especially to be avoided so as not to „turn back" the dead from their duty to move on to the afterlife.

Sometimes, a vigil of carers, other family, or even some neighbors, may form a vigil that extends into a more formal wake before the funeral. Occasionally, and in some villages, children may be sought to help pray for the dying, and certainly at death the singing of prayers is common. Some respondents report superstitions at the moment of death – dogs howling or owls singing, that they believe signals death, or represent its portents. At death, sometimes relatives, and sometimes others from the village, will wash and dress the deceased (traditionally, not relatives, but strange people). This may entail the making of special garments for the deceased. Alms will be given to those who labor on behalf of the dead – who wash and clothe the deceased, or who carry the coffin, or preside over special rites during the funeral. After the funeral, other observances might include the offering of a memorial meal – called „praznic" or „parastas", and the lighting of the funeral candle for forty days after death.

In all these matters, the local folk beliefs and customs, and those others whose origins are clearly derived from the Orthodox Christian teachings, blend somewhat seamlessly. These customs for dying and death form the core of the carer's final responsibilities and duties toward the dying, but often too, these customs help create an order and finality to a long period of psychological and social care. This can, but not always, bring a certain helpful closure to a very difficult period of carer's lives. Such customs also provide an additional – spiritual – dimension to caring, one that links the physical and psychological ordeals of care to the wider traditions of Church, Village and Society.

Significance of Customs in End of Life Care

The trends we have observed in this national study of end of life care mirror those witnessed in European democracies, Australia, Britain, Canada, and the USA. Secularization is on the rise in all these countries with more and more people no longer attending Churches or Temples, not participating in the rites, customs, or social practices derived from them. And in this study, we do see a significantly large minority of respondents who are no longer „church-goers", no longer „believe in priests", or who declare themselves or the dying person „atheists". Yet, these labels and non-participation do not tell the whole story. The fact is that the majority of respondents in this study DO engage with religious customs, with or without local village variations and additions to them. Many of those who claim not to have connections with formal religion, nevertheless, commonly bring to the dying moments of a relative at least a votive candle or lamp. Others at least engage in a memorial meal or give alms after death. Many hold vigils before or after death, not always consciously articulating the reason.

The debate over the so-called „secularization" of the West continues to demonstrate serious divisions (see Bruce 1992, 2002; Howarth 2007). The decline of the idea of place or „dwelling", and the rise of the idea of seeking or „questing" suggest that although less people satisfy their desire for meaning by going to church this has not necessarily meant they have ceased to seek a greater spiritual meaning in their lives (Rumbold 2002b). People who face death – as carers and as dying people – still search for a meaning to their suffering, particularly a meaning that will help them transcend their current troubles. Hope is a cross-cultural goal for all human beings.

In Western palliative care circles, this recognition that the search for meaning, transcendence, and/or wholeness in the midst of a crisis – such as dying or care for dying – is a major need of all people – religious or not. The real question for health services at the end of life is WHO should provide this care. In the past, this has clearly been the province of religion, even a religion that has recently expanded it's commitment to those not committed to it (see Rumbold 2002a). In the Republic, traditional customs linked to Orthodox beliefs serve just over half the population well. For others, the role of religion and the customs that derive from there are currently undergoing major questioning and revision. For this growing minority, a conversation about the meaning of suffering remains commonly sought – if with some reluctance and hesitation – from health services that have the most experience with mortality.

In the West, this troubling and often ambiguous redirection of spiritual questions has commonly turned towards palliative care professionals – a most trusted and respected group of multidisciplinary health professionals. In the Republic, a place with precious few palliative care services, primary health care personnel may increasingly feel the pressure of these questions and seeking. If this becomes true in the Republic, as it has done so earlier in other secularizing and gentrified societies, doctors, nurses, and social workers may need to re-think their roles in dealing with patients and families living with life-threatening illnesses. Their professional responsibilities may need to broaden beyond clinical work to include a pastoral role. Such challenges may need more complex professional development and education for each of these professions.

Furthermore, most people – in the Republic of Moldova or outside it – view religion as *potentially helpful* in times of crises and, because priests and nuns are often very experienced in social and spiritual problems in the life course, these professionals can be used as important resource people. This is true even of people who do not usually see themselves as „religious”. In this way, health services in the Republic of Moldova may find useful alliances with the church, *as partners in end of life care*. As in Western palliative care services, if the church is not providing direct care of dying patients they may still provide useful support and care for those who do – families AND health professionals (see Speck 2003).

Within the above brief discussion of the changing role of spiritual care for the dying and their families, we can see the beginnings of a major change and challenge in the Republic of Moldova. As families struggle to accomplish their often onerous practical tasks of care, a substantial number of them in isolating and lonely circumstances, the need to also supply spiritual care has also been very important to them. The current study has shown that there remains a strong religious, Orthodox tradition within the Republic that is able to cater to these needs – the needs of both the dying person and their families.

However, two important social observations also emerge from this very same data. First, there is significant evidence of confusion about the customs surrounding dying and death as evidenced by our interviewers witnessing different prescriptions for the same rite during dying and death. Some of this may be attributed to regional diversity but other examples are difficult to rationalize in this way. More research on the changing folk traditions of the Republic, with respect to dying and death is clearly needed. Secondly, increasing numbers of Moldovans now work in uncertainty when it comes to their spiritual care duties toward the dying as well as their own self care. The need to address spiritual care for dying – to help a dying loved one make sense of their lives in the shadow of great suffering and imminent death is a formidable task if performed without any traditions. If the social and spiritual trends of the West are anything to go by, health professions in the Republic will need to ask themselves searching questions about who can or might provide this care – to the dying and their families. These kinds of questions are a vital part of the care given by families and needed by those families for their own care. The current review of customs for dying and death paint a national picture of a seriously traditional country under serious change. This is another challenge for the Republic of Moldova in meeting the needs of its citizens who are providing care at the end of life.

CHAPTER 4

The Dying Person's Experience

The overall picture of the dying person's experience is a complex one. However, it is largely a negative picture characterized by much unrelieved physical pain. The majority of dying people cared for in this study died in these circumstances of unrelieved pain (65%) with at least one other major symptom such as uncontrolled bleeding, vomiting or breathlessness. This clinical picture characterized the last 48 hours of a dying person's life. However, that said, a sizeable minority nonetheless died peacefully in the last 1 or 2 hours of their life (42%).

There is clear evidence that medication at the end of life is inadequate – both in terms of the management of a wide variety of symptoms and in terms of dosage of the usual pharmacotherapies. Often, families need to rely on emergency services, such as paramedics, to administer simple interventions such as pain relieving injections, or indeed, to admit their relatives to inpatient facilities if these are conveniently nearby. Often these facilities are not nearby. In both cases, the interventions are often inadequate, too late, or represent poor dosage or inconsistent management regimes. In the latter case, for example, pain relief is not simply about adequate dose but also managing a regular, often increasing dose of drugs, in a consistent and timely way. Such coverage was rare as documented in this study – the result being that most dying people suffered significantly.

In this chapter, we wish to document the medical and social experience of the dying person. Consistent with the aims of the book as whole, we will use the voices of the carers to illustrate the dying person's predicament where-ever possible. In the first part of this chapter we will describe the significance of the problem of unrelieved pain and how this was experienced by the dying person. We will also describe the diversity of other troublesome symptoms – also frequently unrelieved by current medical or nursing interventions. We will then describe, for purposes of illustration, the last moments of those fortunate few (42%) dying persons who died calmly.

In the second part of the chapter, we will describe some of the important social and psychological issues that arose for dying people during their final hours. This will consistent of detailing some of the key emotional challenges encountered by the dying person in terms of support, withdrawal and desperation. Finally, we will describe and discuss the prevalence of deathbed visions in this sample of dying persons. Deathbed visions are perceptions by dying persons that they are encountering communications from deceased friends and relatives. Often these deceased people are believed to be visiting to take the dying person with them to the land of the dead but at other times they seem to provide comfort and other types of communication. The causes of such visions are not fully understood by modern medicine but neither are such phenomenon confined to the Republic of Moldova. Deathbed visions are a cross-cultural phenomenon and are often a comfort to dying persons and the families who care for them. We will discuss some of these issues at the end of the chapter.

The problem of unrelieved physical distress

(a) PAIN

A key goal, clinical claim and actual achievement of palliative care in nations such as the USA, UK and Western Europe is pain control at the end of life. Most pain CAN be relieved by a planned, well-regulated regime of pharmoco-therapies. The present study reveals that this is not currently the case in the Republic of Moldova. Most dying people clearly experience unacceptable levels of pain that marks their final weeks and days of life. Quality of life is radically reduced for people dying in conditions of poor symptom relief and control. This, in turn, creates trauma and grief in their carers. The following personal accounts illustrate this problem clearly:

> „She died with great difficulty. It was a nightmare. She suffered for two days. She was in great pain." (#65)
>
> „She was bleeding on the last day, she suffered organ prolapse, had lost a lot of weight because she had not been eating a lot beforehand. It was though she could not swallow, *she was in such pain even the injections would not help.* In the last evening, she asked to be given an injection [saying] „maybe I will calm down a bit"; she was then given an injection for pain. Then she fell asleep. At night, she started breathing heavily, her nails turned yellow, she was not answering when I was shaking or calling her. When my sister came – she died – as though she had been waiting for her." (#21)
>
> *„She was in pain all over, terrible pain, she was groaning, biting her tongue*, not swallowing, had to spit out her saliva, she could not taste food, her body was giving out a terrible smell, she had become very thin, she was just a bag of bones, like those people from concentration camps." (#31)
>
> „She was in great pain all over her body. She could not move her arms anymore, she would only raise her legs and cry to God, „Either take me or do something!". *I would administer her injections to alleviate her pain but nothing would help anymore.*" (#25)
>
> „His pain had already been great, but in the last two days he groaned and shouted more." (#44)
>
> „His condition got worse in the last two days. His pain became more acute and he could not eat. I gave him morphine five times during the day and once at night. He slept very badly during the last two nights, he groaned all night, he would ask me to turn him from one side to the other. *Morphine was not helping anymore*. He woke up

> in the morning, he was feeling ill, he was sad, calm, he had tears in his eyes. Around 10.30am he started to groan loudly and breathe quickly, and all of a sudden, he stopped. That is how my husband passed away." (#16)
>
> „She was in great pain *which injections could not alleviate.* She had cachexia, she threw up repeatedly, including blood clots. She wanted to eat but she would immediately throw up everything she ate." (#49)
>
> „Her situation got worse in the last 48 hours. Her pain became more acute, she could not eat, *the morphine injections did not help*, she could not sleep at night, was groaning all the time." (#15)
>
> „I kept asking him where it hurt and he would say that it hurt everywhere. He was very weak. The oncologist came on the last day *but he did not change the treatment or prescribe a new one.*" (#90)
>
> „She was in a lot of pain and she could not stand it. She was bleeding, losing her consciousness, was really sick, constipated, and had wounds on her back." (#37)
>
> „It was hard…she was in a lot of pain…she could only cry; she could not talk." (#69)

(b) OTHER SYMPTOMS

Pain as a severe medical symptom of cancer and organ failure rarely occurs alone. Often pain is accompanied by other symptoms. Common too is the fact that, for some people, pain will not be the main medical trouble but other symptoms such as breathlessness or vomiting. Once again, palliative medicine does have an array of pharmaco-therapeutic interventions for these physical troubles. In our study, these were not in evidence, or their presence seemed inadequate to the tasks and challenges being presented by the different dying people.

We offer below a broad range of examples of the type and severity of some of these, most uncontrolled troubles that dying people experienced (and with which family carers struggled). This is not an exhaustive list of these troubles but they are excellent examples of the clinical challenges in end of life care management that currently exist in Moldova alongside inadequate pain relief.

(i) Breathlessness

> „His general condition was serious in the last 48 hours. He was in a lot of pain; he had obstructive asphyxia. He would have fits of asphyxia more and more often. I called the doctor. He said there was nothing he could do. He prescribed some medication, administered some narcotics, and he was off. In the last morning he had a fit of asphyxia, could not breathe at all; he stood up, he would stretch upwards so he could breathe in, he was restless. I called our son and took him outside for fresh air. We had a small bed in the orchard, we laid him there and he seemed to calm down. I noticed he was giving in, his breathing became very rare. You know, I even had a candle ready, I was holding it. After a while he stretched again, he breathed heavily, and he died." (#43)

(ii) Intestinal obstruction

> „In the last three days there appeared to be total intestinal obstruction, intoxication, nausea, stool vomiting, stupor, no urination. She was semi-conscious, would come to regularly, speak for a while, then lose consciousness again. She was conscious in the last two hours, spoke with her husband, said good-bye, until she had a cardiac and respiratory arrest." (#77)

(iii) Blindness, vomiting and choking

> „The situation got worse six days before he died. He lost his sight, could not talk anymore, could not eat, he could only drink a bit of water and that's it. He threw up repeatedly. He started to choke, to breathe heavily. He did not react to questions. We called the ambulance and the doctor said he was in a coma and could die at any moment. He was like this, in a coma, until he died." (#17)

(iv) Confusion and coma

> „He was stressed towards the end, mentally deranged, he would refuse injections. But in the penultimate week I called a neighbour to give him Apaurin injections so he would calm down. He slept a lot after that. He slept from Saturday evening till Sunday. He woke up on Sunday, could not sit up and he fell back asleep... He slept until Thursday, he woke up on Thursday, opened his eyes, cried, did not eat, did not stay awake and fell back asleep until Sunday. He woke up on Sunday, he cried, then slept till Tuesday, when he died. He did not eat for 11 days, did not drink anything, did not speak. It was though he were already dead. His face was expressionless." (#29)

(v) Other symptoms

> „She was very weak and had the hiccups all the time. Because she was in a coma she did not eat. I don't think she was sleeping, she was just not conscious." (#57)

> „I did not sleep during those nights. She was hot, she wasn't feeling well and I could feel that she was going away. I set the alarm for every ten minutes. I would wake up, give her water. I could see she was going away, she was not moving, I would turn her from one side to the other. I did not know how long this would last… In the last 48 hours my aunt was sweating, could not breathe, *the medication was not helping*." (#23)

(c) BUT A CALM DEATH FOR SOME

As mentioned at the commencement of this chapter, for 42% of the total sample studied, the actual final hours or minutes of dying appeared to bring with it a certain „calmness". Struggle and suffering for a significant minority seemed to give way to a certain quietness and uncomplicated end for some dying people. The following personal observation of these kinds of endings are illustrated below:

„I fed her, she often asked for semolina, and then she asked to hold my hand. I gave it to her, but how long could I stay like this? It was Christmas and I switched the Christmas tree lights on, went to the adjoining room and kept watching what she was doing. She was sleeping peacefully but suddenly I noticed her lips had turned black and her dentures had fallen out. I would put them back in and they would fall out again. And I saw her hand fall and suddenly she became calm. I gathered all my strength, because I was alone at home, and I quickly looked for a candle, lit it, because that is what you have to do, and brought it near her nose: I saw the flame was not moving and I understood…" (#80)

„Things were as usual as the previous days. He was feeling unwell, had a good appetite, wanted to go for a walk. The day he died he went to the lake with my sister, he was cheerful. After they came back from their walk he ate well and said he wanted to have a rest. We took him to bed. Then my sister called me to go quickly into the room. He was breathing heavily and quickly, groaning and sweating. It was hard to see him suffer like this, I did not know what I could do to help him. Then he calmed down. We left the room and, when we came back a few minutes later, he had stopped breathing. I wanted to call the emergency doctor but I realised it was already too late, he had died." (#7)

„…and three days later, slowly and quietly, without our noticing, she passed away. She stopped breathing and that was that." (#84)

„On the last day, she spoke most of the day, nothing unusual happened. She ate as usual: one raw egg, tea, milk. I gave her a Cerucale injection on the last day so she would not throw up. I went to heat up her egg, because it had been in the fridge, and when I came back I was surprised because she had got up by herself– although she had not been able to do it before – and moved to another side of the bed where she was lying all curled up. I asked her what was happening. She said she was very ill and told me to leave her alone, to go look after the child. It was though she were

> chasing me away from the room. I went into the kitchen and about one or two minutes later I came back to ask her what she wanted to drink, tea or milk, but she was already gone… I stood beside her and could not believe she was gone. We had talked till the last moment.” (#78)

> „We did not call anyone in the last 48 hours, did not call a doctor nor a priest. She did not receive any medication, she refused to take it. I could not say that her condition got worse in the last few days. She was calm, did not eat. She died like a little chick.” (#61)

Social and emotional matters at the end

The social and emotional issues faced by dying people in the Republic of Moldova are representative of those faced by dying people everywhere. There is a strong need for close social and emotional support. There is a tendency for some dying to feel depressed and withdrawn with some dying people experiencing impatience and anger, sometimes as a response to unrelieved pain, sometimes as a response to the personal loss felt in such situations. Communication between the dying person and loved ones continues to be important even in situations of coma.

There are instances of requested death and the impact of poor professional care on the emotional and social well-being of dying people and their carers. The following personal accounts illustrate these regular and pressing challenges for dying people and their families in this study. Most dying people require close social and emotional support during their care, especially in the last few hours of their lives. The first example described below is of parental support for their dying 17 year old daughter in her last days. The second comments refer to a niece’s care for her 82 year old aunt.

> „During those nights she would ask us to hold her in our arms. On the last night, I sent my wife to bed because she was exhausted and I stayed with my daughter. She asked me to hold her and then, I don’t know why, I had this thought that, if I didn’t hold her, she

> would die, even though I did not expect her to die. Subconsciously I knew that it would one day happen but at that point I thought: „What if I don't hold her and she dies? I will never in my whole life forgive myself." So I carried her in my arms, walking around the room, until I got tired and called my wife to help me. She would do it for a bit and I would do it for a bit, we barely had any strength left. When I carried her I could feel the water moving inside her. During the day we called the ambulance and took her to the hospital. When we got there, my wife said me to go home with our son but I said: „What will we two do without you two? Let us stay a bit longer." We all stayed with my daughter and she talked; she talked till she stopped. You see, we did not understand what was happening, it came unexpectedly. The boy became pale and then started to cry: who would now help him with his homework? We called the nurse, she looked for a candle and she told us to go outside." (#54)

> „She held my hands in hers to the last moment. I did not dare to withdraw them, even though they got bruised because she held them so tightly." (#27)

Many dying persons experienced depression and felt a need to withdraw from loved ones. Sometimes this withdrawal was from neighbours and friends but at other times this also applied to family and carers. Anger, depression and withdrawal were often respected but we have found no account where professional assistance was sought or offered in all these cases. It appears that the weight of loss and sadness is invariably dealt with solely by the dying person as part of his or her journey towards their final days and hours. No descriptions of pastoral or psychological support are documented in all these accounts.

> „He was upset, depressed. He had absolutely no strength in the last two days. He basically would not move or talk." (#59)

> „He was sad and depressed. The last time we went to see him he had tears in his eyes but when he saw us he began to smile. He refused visits from strangers, female neighbours, he only waited to

> see his children. He spoke very little towards the end; he could not speak, mother gave him a piece of paper to write on.” (#83)
>
> „She was aggressive, would forget who the people around her were, but she also had periods when she was calm, indifferent, did not care if she fell and died.” (#76)

Withdrawal was a common response to illness in the last 48 hours of a dying person. Often the intense pain and suffering experienced by the dying person may account for this but at other times loss, vulnerability, resentment and heightened sensitivity at perceived slights may have played a role. It is difficult to know because the carer’s accounts themselves do not interrogate the dying person about these issues and this is commonly complicated by the fact that carers themselves are sometimes targets of this withdrawal. No counselling or pastoral interventions were offered or involved so these kinds of interventions are not available to shed light on these behaviours.

> „After he came back from his operation in Chisinau my husband was always upset, did not want to see anybody, did not want anyone to visit him. And in the last two days he was particularly weak, he basically could not stand on his feet, did not speak with anyone. He was very upset, indifferent, could not stand anyone. He would not even let me touch him; he would hit me, push my hands away. He complained he was in a lot of pain but I could also see for myself how he suffered because of it. I called the ambulance once. They did not change his treatment.” (#87)
>
> „In the last few days this pain got even worse. He did not complain but I could see how much he suffered. He asked me not to invite anybody, he wanted people to remember him active, full of life, rather than powerless.” (#60)
>
> „He was avoiding people. Relatives would come to visit him but he hated that, especially if someone said: „Please forgive me”, he would say: „What? You want to bury me? I am not going to die, I’m going to live.” ” (#36)

> „She was in a lot of pain in the last few days of her life. I would administer her Omnopon, I don't know if it helped her because she became aggressive in a way, she did not want to see anybody. Even the priest, whom I had called to perform the usual Christian rituals, she did not want to speak with him, she probably did not even confess. Likewise her brother, she refused to speak with him, saying he should have come to visit her when she was well not now when she was about to die. She did not speak at all in the last day. I don't know whether she felt she was dying but her behaviours changed, it was as though she were upset with those around her… the doctor said there was nothing he could help her with, he prescribed some injections and left." (#2)

Clearly, the medical attention to dying people, in the matter of symptom control, is less than optimal. Here again, in the matter of social and emotional matters pertaining to the dying experience, the professional approach to social and emotional care falls short of the ideal. Examples of bedside care of the dying – that involve listening to the cares and worries of the dying patient, perhaps even providing some counsel – are absent from these accounts. Even if medical professionals do not see this style of patient engagement as part of their usual role, there appears to be no attempt to refer these social and emotional problems to other health care colleagues or pastoral colleagues in the church. Nevertheless, however inadequate the communication between professional carers and the dying person might be, this is mostly not the case with family who, even during times of apparent coma in their charges, are still able to exchange information and affections.

> „One week before she died she slipped into a coma. I learned about this from the health professional, whom I had invited for this. He told us this could last a few days but it can also be for the long duration. During this period she could not see, could not talk, but she could hear and feel. I once saw something on television and tried the experiment on my mother-in-law: the last week when she slipped into a coma I would talk into her ear and tell her that, if she could hear me, to squeeze my hand, and she would very

> gently squeeze it. Then I tested her again: I asked her if she could understand me and the same thing happened again, she squeezed my hand again. The same thing happened again when her daughter came back from Italy, again, she asked her if she could hear her and recognize her by her voice, to which her mother reacted the same way, gently squeezing her when asked, thus showing response or agreement. All these memories bring up a host of emotions within me… (cries).” (#10)

> „Even though she was in a coma, she reacted to people talking, especially when we spoke in a loud voice. She would actually recognise us by our voices, I mean she recognised all her four children.” (#45)

> „He had stopped talking. He could only communicate with us by blinking and squeezing. He could understand what we said because he reacted to whatever we asked him or said to him. But he was somehow far away, emotionless, without an active reaction.” (#96)

> „In the afternoon, one day before she died, she was in a coma, she was not reacting anymore. She died the next day, in the afternoon. In the last moment, she tried to open her eyes but she was not able to, she just shed a tear and passed away.” (#30)

There were also occasional instances of an expressed desire to die, a situation which is uncommon but not unusual in these circumstances (Seale and Addington-Hall 1995). Given the poor symptom control characteristic of the situation of dying persons in this study it is remarkable that such requests were not more common. This may in part be explained by the prevalence and adherence of traditional Christian ideas in the Republic.

> „He was in pain. He had wounds on his legs and I would give him injections as he requested. He was eating well, had good appetite, he would even ask for food at night but he was ashamed of that because he was disturbing me. He would say not to look after him so, with washing and everything: „Mother, don’t prolong my

> suffering. Give me some pills to take (Ed: to help him die) and you’d better take some too because you will die of hunger on your own. Somebody will treat you badly.” At first, when I cried for him and held him, he did not want that, but in the last hours he asked to be held – „Come mother, take pity on me”, he would say.” (#26)

Finally, there is one tragic case of mistreatment by a hospital – an incident which consequently marred the remaining life and death of both the dying person and their carer. This final account, once again, illustrates the overall unsatisfactory response by the national health care system in providing sensitive and timely care for people at the end of their lives. Whatever the actual details of the bureaucratic difficulties encountered by the administration of the hospital such ambiguities should not translate into altered approached to patient care.

> „During a repeated bout of pain, which my husband had had before, I appealed as usual to the emergency department and we ended up in hospital. At the time, they were making changes relating to the insurance policy. Even though my husband had the right to insurance, at the time I could not sort it out quickly, bureaucratically speaking, you had to go through several authorities in order to get it. Eventually, I found a solution but he had already left the hospital by himself. We found him at the train station, he was wearing slippers and hospital clothes. I asked him what was happening and he told me about the problem with the insurance policy: as he did not have it, the medical nurses at the hospital asked him constantly, every time they changed shifts, every day, when he was going to bring it. He couldn’t stand these questions any longer and left the hospital. Moreover, at the time, in his opinion, they were not performing major procedures on him, and with tears in his eyes, he asked me, his wife, to take him home, so he can die at home. He was upset with the situation. So I took him back home. From that moment on he never wanted to go to the hospital again, indeed, when I would ask him to call for a doctor at home, he would categorically refuse and asked me not to fetch a doctor for him.” (#3)

The Occurrence of Deathbed Visions

Deathbed visions by dying people are a cross-cultural phenomenon commonly witnessed by health care staff and families (Jaffe 1979). There has been a steady stream of US, UK and Australian-based medical and psychological research into these occurrences (see Barrett 1926, Osis 1961, Osis and Haraldsson 1977, Barbato et al 1999, Fountain 2001, and Fenwick & Fenwick 2008). There is significant academic debate and theorizing about the underlying causes (see Betty 2006, Greyson 2009). Prevalence estimates vary for deathbed visions specifically, but it is thought by most observers that the prevalence is around 25-30% (Barbato 2002, Muthumana et al 2010).

In this present study the prevalence of all deathbed visions and other hallucinations is about 40% of the total sample. This is slightly lower than the British estimate by Fountain (2001) of 47%. However, most of the visions and hallucinations in this study are largely deathbed visions. These are true to type, in the sense that the pattern and subjects of the visions reported by the dying person to their carers are both cross-culturally and psychiatrically consistent. Dying people sight dead relatives and friends and report that they receive important communications about their illness and its prospects, or alternatively they are beckoned by the dead to join them in a more pleasant and beautiful environment beyond our physical eyes.

In this study, classic forms of the deathbed vision number 33%; obvious hallucinations related to organic deterioration number 5%, and 3% of the sample display both common hallucinations and deathbed visions. With the mixed sample, this brings the estimate for the prevalence of specifically deathbed visions in this study to 36%. This is slightly higher than the recent estimate of prevalence for deathbed visions in India reported by Muthumana and colleagues (2010) of 30%.

Examples of common hallucinations include the following cases:

> „She had visions. I called the psychiatrist when she could still talk, she said she could see a plane coming and other things. My mother had been a very lucid and well organised woman, both her family

> and mine used to listen to her, and when she started to tell me all sorts of things which were not real I was horrified, that is how bad it was. But she had „good visions", for example, „Look, a helicopter full of ice-cream has come, it has brought so much ice-cream... give me some. Why are you not giving me some ice-cream?" And I would give her ice-cream and she would calm down. The psychiatrist said it was because of the stroke, something sclerotic, he prescribed her medication but it had absolutely no effect, the visions continued. He gave her some sedatives so she could sleep." (#84)

> „Nothing unusual happened in her last few moments. Just that about a month before she died she started to have visions, especially when she was in hospital she first told me that she had seen three angels dressed in white who came close to her. These dreams then recurred often." (#55)

> „The day before he died he was calm, even indifferent, and he did not talk on his last day. He had visions the day before he died, he thought he saw doves perched on his hands, could see God. He held his arm raised in the last two hours, he kept it tense till the end." (#89)

Deathbed visions are characterized by their consistent imagery and messages. Diversity of imagery is NOT a feature of deathbed visions. On the contrary, the ordinariness of the family and friend contact is unremarkable save for the exceptional fact that the dying person claims these are DEAD friends and relatives.

> „I noticed something strange one day. We were sitting together in the room, chatting, and at one point mother reproached me that a man from our village, she said who he was and his name (I knew he had died a long time before; he had been friendly with our family and used to sing in the church choir), she said he had come wearing a hat and a short-sleeved shirt and was standing at the door but could not get in because of me. I replied to my mother that I did not see anybody around and then she asked me to go outside. I did not leave but continued to stay with her. And then again she said that

her mother had this time come to her (I never knew her, she had died before I was born), who, likewise, had been long dead. I again told her I could not see anybody around and mother replied that I could not see them but they had come to get her… and she asked me to leave the door wide open.” (#4)

„She had visions very often; she would be sitting at the table and at one point she would say, „Can you not see that I have guests, lay the table to welcome the guests… here is my mother, right beside me.” Then she would talk to someone who was not there. This sort of thing happened very often with her but they did not become more pronounced in the last month.” (#10)

„She told me she was dreaming about dead people who were calling her to go to them. She had visions too. She would lie in bed, look into a corner where the icon was hung, and talk to those who had died. If I asked her who she was talking to, she would say, „What, can’t you see them sitting there, calling me?” ” (#61)

„He had visions. He said there was a man who stayed with him and talked to him all the time.” (#81)

„Before he died, we were all in the house, together. I was at his feet; at this time he turned his head towards the wall and it was as though he was talking to someone and he said, „No worries, everything will be alright, everything will be enough, it will be good and beautiful…” We don’t know who he spoke to and we don’t know what he meant either. But he told our daughter Svetlana, she is our second daughter, „Be aware that everything will be left on your shoulders.” ” (#3)

„He dreamed that his dead mother had come through the door. It happened in the last few days, he spoke often about this and would say that his mother was coming to get him. He would ask me if I could see her too, he was saying this with his eyes open, he would say a few times a day that his mother had come.” (#36)

> „He had dreams. He said, „The Lord has told me I am going to stand up in a week's time and walk." (This happened one week before he died). He also dreamed before the operation, about dead relatives now in Heaven, who were calling to him, asking him to cross over a fence, but he said he was not leaving without me, so he lived another three years. He said it had been a bad dream but he had been given another chance to live." (#42)
>
> „About a month before he died, he told me he was dreaming about people who had died. And I noticed during the day that he was talking with the dead people, he had visions. When he recovered from these states, he would tell me his relatives who had already died had come to see him, they would grab him and take him somewhere but he would resist. He told me he held on to the pole outside the house, with difficulty, but he did not leave with them. He also had dreams during this period. He told me he was visiting his dead relatives." (#40)
>
> „She saw everybody who was dead! – her grandmother and other people, my father, her mother, brothers, sisters. She had visions, she would say they had died and she had to go to them, she would cry for them even though they had been dead for over twenty years. She would cry and ask why they had left her. She would ask us to make sarmale, to bring the pots from the attic for that, to prepare the alms, she would ask to be bathed, etc. She would say she could not go to see them. This happened about two months before she died." (#73)

The following example is a typical case of mixed imagery, one characterized by a confusional state but also one that, on a separate occasion, displayed a typical deathbed type vision.

> „In the last two months, after she recovered from her coma, she could be in a strange state, as though she did not know where she was, she did not know me. She thought she was in a hospital and I was a nurse looking after her; she would ask me if I had children, how many did I have, etc. She would thank me for looking after her

> and she was feeling better because I was there. Then she would come out of that state, she would realise she was at home and I was her daughter. She also had dreams during this period. She would dream about those who had died. She would tell me mostly that she dreamed about her mother, but she also dreamed about other relatives who had died.” (#19)

Although, many accounts employ the term „dreams”, these in fact represent descriptions of only 19 cases. 13 cases are described as experiences during full wakefulness, while there are 4 cases of both dreams and waking visions. This brings the number of dreams vs wakeful experiences to approximately half and half. In the case of the descriptor „dreams”, it is not always clear that the carers are accepting the dying person’s view of what is happening and are instead ascribing or attributing this descriptor to the waking experiences of the dying person. Obviously, in cases where the dying person describes their experience as a dream this is not the case.

The range of time when these experiences seem to occur is anywhere between 1 day (the day of death) to several months. The range of deceased „visitors” appears to be between one and more than four people, with a median number of 2 visitors per dying person. This finding is identical to the recent Indian study (Muthumana et al 2010). The most common deceased visitor appears to be a mother (13/36 cases) and this too is an identical finding to one described in the recent Indian study (Muthumana et al 2010). Other important visitors appear to be deceased „other relatives” (commonly grandmothers, aunts or unspecified relatives) (10/36 cases); deceased fathers (8/36 cases); and deceased spouses (8/36 cases). Neighbours, friends and even strangers were reported by 8 dying people, while only one dying person reported a communication from God.

It is interesting to note one cultural observation about the report of deathbed visions by family carers of the dying person and this is the common remark by carers that these occurrences did not seem to them „unusual”. This was a recurring theme in reports of at least 11 carers – nearly a third of those who report these occurrences. This is a comment on the traditional nature of Moldovian society because such experiences tend to be more widely held in suspicion, or viewed as a possible source of psychiatric concern in more affluent national contexts such as the USA, Britain or Australia. The common „medicalized" view of such events seem more tempered in the Republic though even in the more secular USA and Europe such events are greeted with a respectful mixture of concern but also awe and wonder by families who report them.

Concluding remarks

In summary, the situation and experiences of dying in the Republic is one of chronic and unrelieved suffering. Pain is widely experienced as uncontrolled. Toward the latter period of dying, reports of worsening pain are common. Other symptoms, such as vomiting, breathlessness, or uncontrolled bleeding are also common. Carers widely report that they receive little or inadequate support for the management of these severe and distressing symptoms. Furthermore, there are few reports of pastoral or psychological interventions for the dying person. Despite the common reports of depression, social withdrawal, and anger, reports of professional help for these emotional and spiritual experiences are absent.

Symptom management, especially pain relief, is a key priority in end of life care in all major industrial economies now (see Clark 1999; Doyle, Hanks, Cherny et al 2005). The near absence of such services in the Republic is clearly noticeable in the experiences of dying people in this study. Although attempts at pain control are commonly in evidence in the treatment of dying people it is also true that the inadequacy of these treatments is equally evident.

Deathbed visions are also widely reported in this study – both the prevalence and character of these visions are consistent with those reported in Europe, America and Asia. While there is some debate about how or even whether these visions are linked to the medical effects of opiates, their occurrence continues to offer dying people comfort at the same time as these promote curiosity and concern in societies where secularisation is spreading. Some health professionals tend to be dismissive of these experiences while other families are quick to view these as new „symptoms" in need of control by psychiatry or oncology. Both academic and clinical knowledge of these experiences, and the pastoral and psychological implications for the dying and their families are rarely explored or acknowledged.

The experiences of dying people in this study are a serious concern in terms of their implications for professional practice and health services design in the Republic of Moldova. The difficulties and distress so widely reported in this study ably demonstrates not only the challenges in providing adequate care at the end of life for the dying person but also the challenges that families face in providing that care in partnership with health services – such as they are in the Republic. The distress and trauma of the dying readily translates into the distress and trauma for their families and other carers. In the next chapter, we will describe the needs of the dying and their carers as these are formulated and articulated by them.

CHAPTER 5

Needs of Carers and Dying People

In the previous three chapters we have reviewed the personal experiences of carers and people under their care. We have described the main social and psychological experiences of care, the customs for dying and death, and the personal and medical experiences of dying people. The burden of care is significant. Families often labour under extremely difficult circumstances with minimal health service support, limited financial means, and commonly in circumstances of social or personal isolation. Many people are unaware of religious or village customs that might support them or the dying person in their care. The moment of death is commonly marked by the lighting of a candle or votive lamp but little more. Customs that are performed enjoy high variation though most of these seem linked to Orthodox traditions and can sometimes also be expensive for families.

Dying people suffer significantly, and we have described their physical and psychological plight in great detail. Pain is often uncontrolled, as is bleeding, bowel problems, vomiting and breathlessness. Anger, isolation, depression, grief and fear are often unaddressed by health services and it is, once again, to families that dying people look for any comfort and solace. There are significant communication challenges for health services and dying people with poor support or communication reported by families. After death, families are left entirely to themselves or their close friends or relatives for support. Again, the presence of health services is difficult to discern in the bereavement period for these families.

In this chapter, we examine what family carers actually say they need and want and what they believe other families undergoing these experiences of care will need in the future. In the second half of the chapter we will also describe what these families believe the needs of dying people were and are. Necessarily these observations and reflections about need are based on their own recent complex and diificult experiences of living with a critically ill and dying person.

Families have a deep and complex understanding about their own needs in relation to care. Their recent experience of care has mostly made a deep and lasting impression on them and they are articulate about what needs to be done. The consensus appears to be a need for greater state support and involvement, the need for a specialist service to support dying and its care, and greater health service support for carers. What „support" actually means in the context of these needs is described below. In the first section carers identify their needs. The vast majority of respondents ask for psychosocial support. Only a minority (33%) requested doctors or nurses for their own support. The majority requested greater psychological support, greater social support – especially equipment, financial aid or respite care.

On the other hand, the dying, according to their family carers, do require greater medical and nursing support, preferably a specialist palliative care system familiar to the rest of the European world, and especially pain relief. There is significant criticism, by respondents in this study, of the poor national support for living with and caring for dying people in the Republic of Moldova. There is significant criticism about hospital and medical attitudes towards the dying and their carers, especially in matters to do with a lack of perceived empathy and communication. We describe all these views, needs and criticism below.

Carers Needs

The single most important need articulated by family carers is the need for psychological support. This support was believed to be needed during the course of care but especially afterwards, during the long period of bereavement after death. Mostly people expressed a desire to see or to be supported by a professional psychologist. Sometimes this need for psychological support was more informal, expressed as a need to „talk to someone" on a regular basis for support. At least 1 in 4 people we interviewed desired some form of psychological support during and after their experiences of care.

1. *<u>The need for psychological support</u>*

> „Maybe I could have done with someone talking to me, supporting me because, look, two years have passed and I am still suffering… Maybe a psychologist could have helped me after his death; there were times when I could not sleep at all at night, I could not fall asleep because I could see him in my mind's eye. I have now recovered a bit but when I go to the village and see that the house is falling apart I get really sad again and cry till shake." (#75)
>
> „Even I needed to see a psychologist after father died, I had psychological and emotional problems for about two months." (#17)
>
> „I don't really know what to say…You could tell she had no chance of surviving. Maybe it would have been good if a psychologist had spoken to her – to us – but we don't have this [kind of service] in the village." (#65)
>
> „You need time after someone has died, support from the family so you can recover. Maybe a doctor or a psychologist would help but we don't have something like this; something happens inside your body and it needs to get back to normal." (#21)
>
> „Generally speaking, I think I needed help from a psychologist. I was depressed towards the end. I did not see any psychologist, I held myself together, kept myself busy with work and that is how I got out of those [depressive] states." (#15)
>
> „Maybe, if there had been a good psychologist after my mother died, I would have gone to them because I find it very hard to

recover, I am very agitated, used to cry at any moment, I have lost weight, my hair was falling out. I only calmed down a bit after two years…” (#78)

„I don’t know. I think if somebody had come to help me it would have been easier. But the main thing for me was the fact that I had no-one to talk to about how I felt. I think I could have done with a psychologist, both during the illness and after my husband died.” (#40)

„Generally speaking, I felt I needed help from a psychologist. I think the other family members too needed to talk to a psychologist; my daughter took the last few days of the patient’s life very badly, when she was losing weight, was feeling worse, etc.” (#6)

„After she died, we would have all needed psychological assistance, father too – he was lost, he saw no point in living without her, he died less than a year after she did.” (#35)

„After her death I would have needed treatment, peace and quiet; I could not get to calm myself down, I would remember her words; a psychologist or a person who had been through a similar experience would have been helpful.” (#28)

„We could have also done with psychological help because both patient and carer need it. To this day I have been left thinking that maybe there was something else I should have done and I did not know; I have these kinds of thoughts. I also often dream about her at home... maybe I would have needed help, let others take on some of my work... I don’t know why I have this impression. I can’t forget her. I can’t stop dreaming about her, I dream that I am in her house. This situation is hard to get over on your own, it is hard psychologically. My sister has got over it but not me... there should be a psychologist for this kind of situation.” (#82)

„It is good to have doctors treating different organs but it would be good if there were doctors who treat the pain in someone’s heart.

> There are psychologists but very few of them really know what they are doing. To this day, I have great pain in my heart.” (#67)

2. The need for financial support

A substantial number of the carers interviewed also expressed a great need for financial support in one way or another. About 10% of everyone interviewed described how care taxed their financial situation and not all of these people were poor or without means. Medication and hired help place great burdens on family carers and most families experience care for a dying family member as both a personal and material stress.

> „I could have done with help from parents or someone else; I had great need of financial help. It would have been good if a doctor had helped me too. After he died, I missed him a lot, they all went back to their homes and I was left alone, helpless. I would have also needed someone regarding health, would have needed money too – everything.” (#29)

> „You need financial and moral support in such situations.” (#39)

> „I would have needed coal, wood to make a fire, but the mayor’s office did not give me any for my aunt. Nobody helped us with one penny. It would have been helpful, in the last hours, if I had had some people around me, a few women to help me.” (#27)

> „Financial aid is necessary because nobody helped me.” (#26)

> „Maybe it would be good if we had professional carers. The state should pay a salary to the carer so they don’t end up with a gap in their employment record, so that, for example, a daughter or son don’t have to go to work and let a stranger look after their parent for fear that they may end up with a small pension or without a salary because their employment period is shorter and has gaps in it.” (#79)

> „We did not have any nappies, bed sheets, nurses who could stay with him, medication even, because we had no money – we still don’t have any money.” (#71)
>
> „The state should give social, financial help, because it is very hard, our pensions are small, everything is very expensive, what with all these crises, I barely ate anything and I was physically and emotionally exhausted.” (#42)
>
> „There is no-one to help you. We should have had more money, we spent 15,000 Lei on medications and our pension is only 1000 Lei.” (#34)
>
> „Sometimes I did not even have money for food.” (#46)

3. *<u>The need for information, advice & support</u>*

Carers sometimes mentioned the importance of having a health care team or professional person on hand – not for the patient’s needs specifically – but for themselves. These carers felt the need for advice and support.

> „I think I could have done with consultation from a doctor and help from a nurse. I felt I needed psychological assistance.” (#18)
>
> „Generally speaking, you need a nurse for the specialised medical work. You can manage the other things to do with [the patient’s] care but, for example, I could not clean the urinary catheter, and so on.” (#16)
>
> „I think regular consultations with a doctor would be useful. It would be good to get help from a medical nurse. While the nurse is with the patient, I can do other things – it would have been a lot easier.” (#19)

4. *<u>The need for equipment and inclusive facilities</u>*

Some carers stressed the need for better equipment – not only in their own homes but sometimes in public areas where they and the patient they cared for needed to go. Even hospitals were places sometimes seen to be inadequate, particularly for carers needs. Some institutions seem not to be able to acknowledge that patients are not lone entities without families and that both their needs and ongoing care involve other carers and supports – supports not catered for by institutional places of care.

> „I don’t think these patients should be in hospital, they should be with their families. What is a hospital? You send the patient like you would an animal and leave them there. Who will take care of them? We don’t have hospitals where families can stay as well.” (#69)

> „We had a transportation problem – we did not have a wheelchair for paralysed patients (when we managed to get the chair she cheered up, she was feeling better). I think it would be good if there was an organization which could offer such chairs (not everyone can get them).” (#2)

> „You need special plasters for palliative care; suitable, comfortable, light wheelchairs; proper stretchers; logically made nappies for men so they can be easily put on patients lying in bed; the legislation regarding medication should be improved so I should not have problems with tax exemption on the medication I bring from abroad, if this country does not import the required medication and preparations.” (#33)

5. <u>The need for respite care</u>

Many families argued for the need for respite care. Often the 24/7 round-the-clock care by families had taken their toll on carers both physically and emotionally. The inability to get even a small break away from the daily grind of care for another was wearing at best, traumatic at its worst. Respite care was and remains a crucial need for many families.

> „Maybe a carer would’ve been of help. If she could have stayed in hospital for a period of time, that would’ve been good, but she did not want to stay in hospitals, not even during the whole period of care.” (#23)

> „We suffered because we don’t have the same means as in civilised countries where, if a person is tired, the patient can be taken to the hospital and looked after there so the family may rest.” (#73)

> „It would have helped if I had had the possibility to leave him in someone else’s care during the day, so I would not worry about him tripping or that something might happen to him while I was away, and would know that he had someone to talk to. Or if I could have at least left him in someone else’s care for a week, so I could go somewhere to get treatment or rest; there is no such thing in this country.” (#46)

The key theme that emerges from these above accounts is *the crucial need for support*. Social and psychological support is crucial in providing better quality of care for dying people, especially as this applies to greater financial support for medical aids and equipment. It is also a key part of supporting the supporter. Family care in end of life care is currently THE basic form of care in the Republic but it is struggling to perform this function efficiently and effectively without some broad but minimal input from the state. Clearly, greater psychosocial support from psychologists, social workers or even organized pastoral support from the church will increase the effectiveness of family care.

Furthermore, respite care and a re-examination of the public message and mission of hospitals is clearly needed. Hospitals are commonly seen as narrowly focussed on patients only (rather than the family as the unit of care) and of cure (as opposed to care). Hospitals are not generally viewed in Western countries as solely places of technical expertise but rather as places where the technical needs of patients are *combined* with their more holistic care – a place where their ongoing carers (families) are also both welcomed and accommodated. Hospices are the most recent development of that example.

Not surprisingly, the identification of these needs – and the needs of the dying loved one in their care – has exposed more than anything before, the gaps in health service and state care in general. Such gaps and omissions have been the subject of serious criticism by families who, in these circumstances, have often felt abandoned by government services and health professionals. We begin our next section of care needs of the dying with these criticisms before moving on to what families believe their dying need from others, including the medical professionals and the state.

Needs of Dying People

When asked about what they felt they needed to better care for their dying relative about 10% of interviewees began or ended their remarks with criticism. Most of the criticism was aimed at the medical profession or hospitals. And although some of this criticism was directed at the poor quality of hospital facilities, most of the discontent was directed at poor, unsympathetic or unkind behaviour and attitudes of health care staff. Institutions are generally poor at accommodating the individual and health care institutions such as hospitals are no different. But when it comes to end of life care – the care of dying and grieving families – poor communication, a lack of obvious empathy, or bluntness by hospital or medical staff heavily compounds the burden and anxiety of patients and their families.

These are also current troubles noted by the National Health Service in the UK. Over half the complaints that national hospitals received about from the general public about hospitals concerned family experiences of end of life care. (Healthcare Commission 2007). Accommodating the special needs of dying people and their families is emerging as a great challenge for all medical and hospital staff and this points to the need for greater professional education programs for medical, nursing and allied health staff working in hospitals everywhere today.

1. <u>Criticism – and the need for greater care and sensitivity</u>

Some of the criticism was quite specific but other respondents traced their dissatisfaction to government neglect of health care infrastructure and quality control. Some compared their experiences of treatment with their own international experiences in Europe or Russia. Some respondents were reluctant to say too much while others were close to vitriol. All expected more from doctors and the health care system as a whole. And to be fair to these families, much of these criticisms can be addressed by simply stressing to doctors and hospital staff the need for extra social or interpersonal sensitivity when dealing with people at the end of life. A regular in-house, short course made widely available to hospital staff or professional development programs for all medical practitioners would address these concerns very quickly.

> „...they don't take good care of you there [hospital]. They either don't give her water to drink, or they didn't bring her the chamber pot on time, when she asked for it. Besides, *they had no hot water*; I would bring hot water in a thermos to wash her. I fed her, gave her water to drink. Seeing this situation, I asked that she be allowed to come home." (#84)
>
> „You know what the quality of medical care is like [here]? If you pay, they care for you, if you don't, they don't. That is why I took care of everything. Even when she was in hospital..." (#80)
>
> „In my opinion, the first thing that needs to be improved is the doctor's attitude toward the patient, which is sometimes incompetent... unfortunately. People in the countryside are very disappointed, they do not believe in the rural medical service but it is very complicated to get to town for consultation." (#3)
>
> „First of all, this kind of patient needs encouragement and adequate medical care; medical workers should show more pity, be more kind hearted and attentive with these patients." (#89)
>
> „You need to give them support with kind, soft words, and this applies to all stages, to doctors and to nurses. In our case, it was the oncologist, who first suspected my mother had cancer, who was extremely insensitive." (#53)
>
> „In our country, they don't take care of ill people. For example, if someone has bedsores and is taken to hospital, nobody cares for him. It is different abroad; these people are cared for in a special way. I saw that in Austria, where I used to help nurses look after this kind of patient. They are not refused anything there. I think it is

> mainly because of a lack of money, small salaries. Everything is paid for in Austria, not like here. If the medical staff were paid better, they would take better care of patients, be more attentive. And then you add in one's humanity and professional calling. I think it will take a long time before any changes occur; how can you live on 1600 Lei. I tell my daughter: „Go, do what you want. What will you become here? A beggar?" " (#68)
>
> „I did not get any help from the hospital doctors and very little attention... I did not get any help, whoever came – health practitioner, doctor, whatever they are called – they did not even stay a minute, just a few seconds, came in, waved, did not even lift the sheet to look at his leg. There were others who did not even come into the ward... I don't know why in hospitals they don't give patients injections to alleviate their pain." (#38)
>
> „I think the medical assistance in villages should be improved. Can you imagine, I had to walk three, four kilometres to the neighbouring village to call the doctor to come to our house." (#44)

Many of those interviewed felt that more state involvement would help address these criticisms, the greater state control would improve quality and accountability if not infrastructure. Help with medications, financial aid, or simply better health and social care might be expected if the state were to take greater interest in the plight of these families.

> „The best thing would be if the state got involved." (#99)
>
> „Support from the state would also be good, especially in terms of getting medication for these patients. Medication is very expensive, every time I went to buy some more the price would be higher and higher. Maybe some support organizations would be welcome in this kind of situation." (#97)
>
> „I think the main thing is that the state should get more involved in these patients' problems. In fact, in our country there is practically no help from the state. You see, I was able to care for her at home, to give her the right conditions, but I have seen a lot of families

> who are not able to care for such patients as appropriate. That is why I think they would feel much better if there were social help, with some home visits from specialists, specialised consultations to care for these patients.” (#48)

One young 36 year old wife who cared for her dying husband alone was unsparing in her criticism of the predicament she found herself in during her long and difficult period of care. Her husband died of cancer and the cost of treatment and support for this young widow was crippling.

> „What is being done in Moldova with regard to such patients could be equated to genocide against one’s own people. There is not enough information, neither at the level of doctors, nor at the level of patients and their families (for example, in Russia they have manuals containing detailed descriptions of the cancer treatment plan). There is no medication and what there is, it is not the most effective and anyway the price is astronomical. The authorities do not check how much pharmacies charge on top of the original price. At a basic level, there are no nappies for men – the price does not even matter anymore, they simply don’t exist. There is no law which allows you to bring in powerful analgesics into the country, which would work for seriously ill patients. And in chemotherapy rooms there is a particular smell that is hard to bear and it is terribly cold. It is also hard to get over the humiliation we are put through in medical clinics.” (#33)

The „humiliation we are put through in medical clinics” is a continuing theme in our interviews and this criticism of doctors continues more broadly in the interpersonal experience of families. Some of this criticism is direct while others take the form of a plea for greater consideration during this difficult time.

> „They need to be nice to the patients, not to be harsh with them, physically or verbally; they must understand and help them. If you are rough with them, turn them roughly, push them, they get upset because they are ill they should do everything earnestly, wholeheartedly.” (#36)

> „There should be doctors and nurses, doctors who put soul into it, who understand the specific situation, special doctors who would also be appreciated for everything they do." (#31)

> „What can I say? The doctors should be more attentive. You know, after he was sent home from the hospital, they gave him no indications what to do, how to do it, they simply saw there was nothing they could do and they sent him home without a care. They should have somehow clarified things, given him some hope, do something to make his last moments bearable…" (#43)

> „I want to begin with the observation that we people, all of us, need to communicate, need some assistance, all the more so those who are dying." (#41)

2. *<u>The need for pain relief</u>*

One of the key gifts of good palliative care is sound symptom management in general but strong and adequate pain relief in particular. A patient in chronic pain is not only a patient unnecessarily struggling in their inevitable descent towards death but also a family in anguish watching this unrelieved plight. Both circumstances are a tragedy and for many families it is to this problem that they address any questions about needs that should be addressed for the dying person.

> „First of all they need encouragement. Also, these patients need medication that would calm them down, so that their last days will not turn into physical as well as emotional torment." (#57)

> „To have her pain alleviated." (#25)

> „First of all, these patients need medication for pain." (#90)

> „We know that cancer can't be cured but patients should receive medical help to feel less pain." (#93)

> „The health care in the countryside should provide adequate medication to these patients because that is a problem in a village." (#4)

For 1 in 5 people interviewed, this desire to control the distressing symptoms of dying translated into an explicit desire for palliative care – the specialised medical, nursing and allied health care for people who are dying. This is a remarkably high figure given that palliative care is largely unknown in the Republic, certainly outside Chisinau. Some of those interviewed also identified a hospice as a „need” for dying people – an in-patient facility that addresses the needs of dying people. Some respondents did not know what to call such a specialised health service but thought that there should be such a service – if there isn't one, one should be created. The desire for a co-ordinated, multidisciplinary team of people who specialised in care for the dying was a common expressed desire in this study.

3. <u>The need for hospice and palliative care</u>

One young carer in her 30s – a medical practitioner – was able to access the fledgling hospice in Chisinau (at present, offers only house-care services) for some help but largely cared for her 84 year old godmother at home. Being a doctor, however, did not help her escape from the day-to-day problems of inadequate care or equipment that seems to dog every step of someone who cares for the dying in the Republic of Moldova. The list of problems this doctor encountered is long with only one small bright spot – some help from the hospice.

> „It is very hard to find people who can take care of patients who are bedridden, it is basically impossible, there are no trained specialists. Those who work in this field to a certain extent or who have some experience are extremely expensive, it costs between 200-400 Lei per day. This is unsustainable, which is why you hire women from the countryside. For example, why did the bedsores appear? Because that woman [I hired] treated the patient with surgical spirit while I was away, even though I told her not to do that. She replied that she knew better, this was not the first patient that she was looking after, and she was stubborn, she kept doing it, even though I was a doctor and had told her not to do it, until I hid all the spirit away and stopped buying anything containing alcohol so she would be cared for adequately…

> Another problem was the price of nappies, they are very expensive. I could not find a wheelchair that could go through the door posts…
>
> I also had problems with the chamber pots, they are too high and uncomfortable and [matter] gets spilled on the side, she could not lift her pelvis and we were not able to lift her so high either, that is why we used plates…
>
> Treating bedsores was a real nightmare until we got help from the hospice, there was no gel in the pharmacies, only oil and marigold ointment, but nothing we tried helped. I struggled for one month trying various ointments (Ruxola, Levomicol, etc). It was only when I used the gel plaster that the hospice gave me that I saw an improvement after 3 days.” (#77)

Other patients had no access to hospice or to palliative care services but families understood the advantages of such a specialised service after they had undergone the personal and medical trials of caring for a dying family member. There recommendations were expressed in the following ways:

> „…maybe they could have taken better care of her in a specialised centre, administer her the exact medication she needed, when she needed it; I don’t know…” (#37)
>
> „Personally, I could have done with a medical nurse, even at night. Patients draw courage when they speak with a doctor. I think society should get involved and set up special institutions for looking after terminally ill patients. Many of the old patients do not want to be looked after in hospital but will gladly receive medical help and specialised care at home.” (#14)
>
> „Maybe there should be a care centre for these kinds of patients, but I could not have sent my husband away from home. It would be good if there were trained staff who could come home and help relatives at times like these.” (#59)
>
> „Maybe there should be a hospital for this kind of patient, with competent doctors specialised in this age group and there should

be psychologists who can get them out of their depression and communicate with their patients.” (#76)

„…the doctor’s presence is very important, they should visit the patient as often as possible. However, there should also be some kind of specialised home or hospital where we could leave the old woman for a period of time and then take her back home, so we can have time to recover mentally and, at the same time, the patient can receive medical assistance. But the reality of life is, unfortunately, very cruel. Society leaves you alone with your problem and does not offer you any solutions. Socially you are not at all protected, you are stuck with the problem and nobody cares. The whole family gets destroyed because of the patients’ problem, we too become ill and edgy.” (#10)

„Generally speaking, you need a special service or organization able to support the family looking after a terminally ill patient. Because, in this kind of situation, most of them would need moral and material support. For example, both my wife and I worked and we still struggled to cope financially with this situation. Professionals should spend more time looking after these patients, they could perhaps teach us, train us, the people who care for the patient, because we do not know how we should treat a wound and many other things.” (#102)

„I think it would be wonderful if there were support from special institutions because our state health institutions, as they are now, do very little to help incurable patients in their last few days. At the same time, I believe that people should die at home, with their family at their side.” (55)

„The family, while caring for a family member who suffers from a serious incurable disease, also needs care and support from specialists who have experience in working with these kinds of people. It would be good if this were organised in special centres, where both doctors and other specialists would work, and priests could be involved too.” (#86)

> „This kind of patient should have specialised medical assistance, in special institutions for this kind of patient. Not all old people are willing to go to this kind of medical institution but I think doctors should explain to them that it is better to be cared for correctly and on time." (#63)

And for the last word on the need for hospice and palliative care, as a partnership with families:

> „It would be good if in our country, like in other countries, there were hospice type of institutions, where incurable patients could be cared for professionally. The family would obviously have to be there and give support to the patient as well as to the organization, but it is very hard and complicated for the family to bear the burden of caring for the patient on their own." (#54)

Concluding remarks

In summary, carers identified five main needs from their experiences of caring for their dying relative. These were: (1) The need for greater psychosocial support, especially for their emotional well-being and mental health both during care and afterwards during bereavement; (2) The need for greater financial support especially to cope with the significant additional costs of care – medication, travel costs or home care costs; (3) The need for greater information and advice. The information needs of carers varied from cleaning and administering medical equipment such as catheters, to caring for bedsores, or knowing what to expect psychologically from the patient or self during care; (4) The need for equipment. This ranged from chamber pots and wheelchairs to lifting assistance and nappies; (5) The need for respite care, especially for lone carers who had total or near total responsibility for the dying person.

From their experience of care, families identified three important needs of dying people. These were: (1) The need for a more sensitive and empathic approach by health professionals – from the initial telling of „bad news" (prognosis) to the day-to-day visits and bedside care by nurses and doctors;

(2) The need for pain relief. Many complained of inadequate pain relief because of the possible ineffectiveness of drug type, or its inadequate administration, or its untimely or irregular administration; (3) The need for specialist or specialised organization to care for dying people. There was great support for hospice or palliative care type care for these kinds of patients. Families also saw personal benefits to themselves as carers.

The above review of carers and dying person's needs reveal important continuities and differences with end of life care practices in the communities of more affluent countries. Clearly, women take the brunt of care in the Republic of Moldova as indeed they do in the more affluent national examples of the UK, USA or Australia. This has to do with two major factors, the first one refers to a demographic reality and the other to a more sociological factor. First, women tend to outlive men and are therefore more likely then men to look after dying male relatives including their spouses (Kellehear 1994). Secondly, traditional gender roles persist in most countries of the world. Although it is true that greater equity and equality has increased – in economic, political and broader cultural terms, in most countries, domestic issues around care – of children, the sick or vulnerable – often continues to fall to women.

The need for financial aid is also a persistent problem in most countries, including those who have an advanced national palliative care system in operation. Nations such as the USA, for example, have a largely privatised health system where citizens depend on their level of private insurance to protect them. However, if the disease is chronic or long term – such as cancer – they can easily outlive their health coverage. Costs of pharmaceuticals can be high even in affluent industrial contexts and many carers give up work or take part-time work to devote themselves to caring for their dying relative. These situations lower the capacity to cope with the extra costs associated with long-term care (see Neale 1991; Emmanuel et al 2000; Hudson 2004; Stajduhar 2003). Add in the further fact that a large minority of carers, also the case in this study, are retired and therefore poorly prepared for the additional travel, medication, equipment and home care costs associated with end of life care. End of life care in the context of retirement creates a situation where long-term care creates severe social and financial hardship at a time when people are least able to cope with this.

In the Republic, many villages are also depleted of working age men and this creates further problems of social and financial support for women who are caring for the dying. The problem of financial aid and gender imbalance is compounded by two other major problems that dog carers and the dying person at the centre of that care. First, there is no national palliative care system and this means that there is a major omission in the health service coverage for these kinds of patients. Oncology for example, is the treatment of cancer and is not a specialisation for the symptom management of dying people. The same can also be said of cardiology. However, this does not mean that oncology or cardiology might not usefully integrate end of life care training to make these medical specialisms valuable colleagues alongside palliative care physicians in the provision of a broad-based professional approach to end of life care. As things stand, however, most medical specialities are designed for cure and not end of life care provision and support. Secondly, there is a lack of national recognition of the actual set of medical, psychological and social problems associated with end of life care, well documented in this study, and this makes mobilizing existing resources for a basic level of care for these patients and families extremely difficult. There can be no action plan, no policy development, without a broad professional consensus about the state of end of life care in communities throughout Moldova.

In the first case, a national approach to end of life care involving medical, nursing and allied health training is essential for the Republic if our health system is to meet even basic international standards of care for the elderly, those with incurable diseases, those families living with their care, and those living with bereavement after that care. However, in the second case, even before or alongside such health service developments there needs to be national recognition that aging, dying, death and bereavement are significant targets of care worthy of national attention and resources. Existing resources can and should be re-organised in an effort to address at least the worst problems identified by this study's respondents.

The primary needs of carers identified here – psychosocial care, equipment needs, information and advice, and respite care – are all needs that can be adequately addressed with existing resources. Greater involvement and partnership with Church authorities in pastoral care of families is possible. Equipment „libraries” that lend equipment to families on a temporary basis are possible. Information and advice centres can be important functions of existing community health centres across the Republic and these too are quite feasible under presently existing service organisations. Respite care needs can and should be built into the existing services, both health and family care services, of villages and urban areas. In Japan, for example, whole villages and some suburbs have been organised to share the tasks of respite care – shops, schools, or small businesses – can offer several hours each week to those who care for those living with dementia (see 100 Member Committee 2006)

Although there has been a significant and expressed demand for a specialised palliative care service in the Republic by those in this study this demand is often qualified by a desire to see this as a *mainly home care service*. Few respondents in this study seem to want to see Hospice become another form of institutional care – like the hospital. The Hospice, according to those in this study, can be used for those without adequate family supports, those with special or complex medical needs, or as a place for respite care, and a source of continuing advice, information and psychosocial support. Most families wish to see palliative care provided in the home with family being in the front line of that care.

Furthermore, in the absence of an available hospice or palliative care service, carers in this study wish to see a major improvement in the attitude and conduct of health care professionals – doctors and nurses – in relation to their behaviour towards dying people. People who took part in this study demand greater sensitivity, empathy, communication, and more explicit signs of care for dying people. Such needs are not complex or costly to address in the Republic but they do require prioritising „end of life care” as an important and regular component of in-service training. A professional education campaign can address these community needs as indeed they are in places such as the UK, USA and Western Europe.

Finally, there is clearly a need to review the adequacy of both the common medications prescribed for dying people, especially those with cancer and organ failure AND the legislation covering the importation of stronger medication for use with these kinds of patients. The one recurring picture of dying that one receives from reviewing the dying person's experience and the recurring concern of carers is the problem of pain relief. Pain relief for the end of life in the Republic of Moldova is clearly inadequate. The specific types of medication and the usual regimes and timings of these medication for these patients requires review. Opportunistic use of pain relief is poor practice but seems widespread according to carers. Unless strong medication is employed and employed with due attention to dose and timing, dying people will suffer needlessly. This has clearly been the case for most of these 102 families.

CHAPTER 6

Professional and Policy Recommendations

In this final chapter we summarize the key findings of the study and make a series of professional and policy recommendations. This book has described the first major study of end of life care in the Republic of Moldova. Many of its descriptions and insights are difficult to read, sometimes they have been shocking. Such findings cannot fail to move both professionals and other citizens and therefore compel the authors of this study to make recommendations that might address or provide some relief to this ongoing set of sad family circumstances at the end of life in our country. We first provide our brief summary before making our final recommendations.

Summary

This was a study of 102 families in the Republic and a description of their experiences in caring for a dying relative. Some may argue that it is ONLY 102 families but the fact is that this figure is 102 times larger than any previous examination of this problem in our country. Furthermore, these families were drawn representatively from all major regions within Moldova. The experiences of these families now act as benchmarks against which we can compare and test mere social opinion about what happens; to compare and test the many public myths and professional but individual experiences of clinicians and policy makers in health care. From the voices carefully collected by this study we are able to gain real insight into an intimate part of Moldovan social life that has largely gone unrecorded and hidden till now.

Our study has revealed that caring for a close relative who is dying at home is a difficult and testing time. Family support has been crucial. Neighbors and local villagers can do more to help. Public awareness of the loneliness, stress, financial and personal trials of care is low. There is a need for greater awareness of just how difficult end of life care is for families so that more ordinary people can be involved. Furthermore, this awareness needs also to be part of the education and curriculum of all major health care providers. This book should be required reading for everyone in Moldova because without a public discussion and debate about its main findings things will not change for the better for future families and those dying inside them.

For carers (chapter 2) we have found that the tasks of care are extremely demanding and total. Many family members have reduced their work hours or left their jobs for full-time care. Those that work are frequently exhausted by the demands of daily care. Respite care is almost non-existent, financial assistance is rare, and suitable equipment – from commodes to wheelchairs – difficult to obtain or too expensive. There is a great need for lay-education about body washing, toileting, bedsore management, and understandings about drug regimes and their use. Professional carers – even to help with domestic tasks – are highly needed.

The emotional costs of care are high. These include the emotional costs of high demand, physical and emotional work of care to the problem of anticipatory grief and the problem of the aftermath of death itself – of bereavement. Suicidal thoughts, long term emotional disability, and estrangement from friends and family are reported all too commonly. Professional psychological support from psychology, social work or pastoral care is almost non-existent in the accounts we heard in this study. 1 in 4 respondents reported experiences of rejection, stigma or social distancing from family, friends or neighbors. This suggests that fear and ignorance about cancer, dying and death needs greater combating with education, information and professional support.

Customs for dying and death are in evidence in this study but two findings are central (chapter 3). First, these customs enjoy high variability by region as well as by individuals who perform them. People offer varied rationalizations and explanations for the same behaviors and rituals. Religious customs are mixed with local village customs as well as local superstitions. But secondly, whatever variability is enjoyed by these traditions, the fact is that these customs appear to be receding. Secularization is clearly in evidence as some 44% of those in this study confessed to not performing any major customs aside from simple candle lighting during dying or death. Nevertheless, customs remain important for the majority, and for this group, closer relations with the church and their clerics is desired at times of dying, death and bereavement.

Carer's invariably revealed that the dying process for their loved one was difficult (chapter 4). Two-thirds of dying people reported in this study died in unrelieved pain. There was clear evidence that medication for pain relief is inadequate at the end of life. Unrelieved pain was often accompanied by breathlessness, vomiting and choking, confusion and intestinal obstruction, and even coma. Depression, anger and withdrawal are commonly observed of the dying. There were occasional requests by patients to assist the patient to die earlier. Deathbed visions – reports by dying persons that deceased relatives and friends were visiting them regularly – were common. These do not seem to be linked with medication. Such observations are internationally reported of dying people everywhere though their prevalence seems significantly less in countries with superior pain control interventions in place. The overwhelming majority of patients appear to find these visions comforting and represent one of the few positive psychological, social or spiritual features of their dying.

When asked about the needs of carers and their dying (chapter 5) most people articulated a desire for better medical support for dying people and better psychological support for carers. There was a strong desire for more financial aid, respite care, adequate equipment and material supports such as nappies or bandaging. There was an expressed need to be better prepared with information about the disease, about dying and its care, and especially about the medications. There were significant criticisms of the medical profession especially for its sometimes insensitive way of communicating with patients and their families. There was criticism of national policies and laws concerning limitations to strong pain relieving drugs, non-inclusive policies of hospitals, a lack of state involvement and interest in end of life care, and a wish, expressed by many, for a national palliative care system commonly in place in the rest of Europe and older democracies.

Dying has evolved over the last few hundred years. Most people now grow old but that demography has brought with it a changing epidemiology. Cancer and organ failure are serious illnesses for which there is no cure but at the same time bring great pain and other suffering with them. Such „new" and spreading diseases of aging require specialized support – special medication, specialized and expert training in how to use them, and significant non-medical support before, during and after the dying process. People need people. Communities can and should be mobilized to help one another during times of death and dying but this can be difficult when fear and ignorance play too deeply on people's natural desire to help. Without a public education and awareness campaign about living with a life-threatening illness or bereavement or caring for both, fear and ignorance compromise a community's ability to help and assist at a time of great need.

In the following recommendations we urge governments, professionals, churches, teaching and health care organizations, as well as media, to recognize the importance of quality end of life care in the Republic of Moldova. This task is not simply a medical task but equally a political, cultural and community challenge. Health care is not simply the government's responsibility – it is everyone's responsibility. In the same spirit of public health vision, the care of dying is not simply a government matter it is also a community concern. Good palliative care is a partnership between medicine and the allied health professions AND a partnership between the State and all community organizations.

As previously mentioned, in this final chapter we shall try to make a few recommendations aimed at changing the fate of carers and incurable patients in the Republic of Moldova.

The Recommendations

1. Suggestions for professional training

The results of the study published in this book reflect several aspects of the life and suffering of dying persons and their carers, which is why they can be of interest to several organisations which, by virtue of their activities, contribute or can contribute to solving the problems identified. In this respect, changing management strategies in professional training and specialist education in general would have a tremendous impact. Training has to be a priority area and a continuous process since there can be no palliative care services, nor their subsequent development, without well-trained professionals. In this regard, we have outlined below some important activities.

1.1. Individuals who already have palliative care skills should be allowed to undergo training for students and practitioners in this field. It would be an advantage if this training were to take place in health centres which offer palliative care or home care services for cancer patients, patients with debilitating neurological conditions, infectious, heart, liver diseases, etc.

1.2. Since Moldova already has several Palliative Care National Trainers who are accredited by the Ministry of Health, using these professional resources could produce rapid and qualitative benefits, to quickly begin the process of training Palliative Care professionals.

1.3. It is recommended that those individuals who wish to undertake these sorts of activities (i.e. looking after people debilitated by their illnesses) be able to undergo a trial period, perhaps a psychological test, which would reinforce their intention to work in this field and prove that they are psychologically prepared and sufficiently sensitive to the needs of others to undertake this kind of activity. It would be preferable if those enrolled in this field already had health care training.

1.4. It would be an advantage if the professional organisations involved in this kind of medical activity made the best of the support offered by specialists, consultants and experts from abroad, so as to increase the efficiency of implementing the changes needed to create a care service for terminally ill patients.

1.5. Attracting to the profession of carers those individuals who already have experience of this kind and who are unemployed would provide an available source of professional carers needed in Moldova. The retraining of these individuals would also represent an important social benefit.

1.6. Running courses for relatives and close ones, for those who need specialist care knowledge, would enable better patient care, a better understanding of the nature of their problems and meet the needs of the patients in their care. These courses can run alongside existing health centres.

1.7. Bereavement can change people's lives, which is why it is very useful to inform society at large about death, bereavement and death-related problems.

2. *Suggestions for changing further and higher education curricula*

Medical colleges and universities in the Republic of Moldova can explore the most efficient ways for the country to deal with problems concerning education in the fields of palliative care and looking after terminally ill patients.

2.1. In order to increase society's levels of understanding, tolerance and compassion towards terminally ill patients, courses need to be run concerning the educational, social, medical, psychological, religious, etc. aspects for teachers. The courses can vary in form and can be run at universities and educational institutions, whilst current educational curricula can be modernised accordingly.

2.2. The devising and approval of a palliative care curriculum for health and social care students and doctors is a necessity which could provide a strong impetus for the development of this service in this country.

2.3. It is recommended that a Palliative Care curriculum be devised for psychology students.

3. *Suggestions for opening up access to family assistance services*

3.1. Setting up specialist palliative care services at home and developing respite-type services (a form of care which temporarily releases family members from looking after their patient) for families.

3.2. Opening up opportunities for informing society, if needed, through internet networks and access to national and international sites which share information about the problems experienced by incurable patients, their needs and the possibilities for meeting these needs. Likewise, access to links which enable sharing information and experiences related to looking after patients with multiple problems, advertising offers and available services in the country would be welcomed.

3.3. Creating relatives and carers information centres regarding patient care, correct use of painkillers, looking after colostomies, lesions, etc. These centres can operate alongside hospitals and palliative care centres, and their curricula should be adapted to actual needs.

3.4. Devising and distributing small guides about care and death for families and carers is a useful information method which can be made available in clinics and hospitals.

3.5. Local governments can offer and provide financial resources from their budgets, in the form of allowances for family members who look after a relative or dying partner. Families can also be supported by providing them with medical equipment or materials (nappies, underwear, personal hygiene items, wheelchairs, commodes, etc.), which can be given to patients and carers at hospitals and health centres. Equipment may be made available for borrowing. An equipment „library" would be invaluable if located strategically in regional health centres or local hospitals. Family members also need to receive different kinds of support from civil society (schools, organisations, companies, local activists, etc.).

4. *Suggestions for optimising the current medical system with regard to incurable patients*

Currently, the Republic of Moldova is facing many challenges and is in the process of shaping an evolution course in almost all areas of life. If certain measures are not urgently taken, this situation can last to the detriment of those who are currently facing these challenges or will very soon face problems related to looking after close ones. It is recommended that a plan of action be devised, which would develop Palliative Care in this country. Several interventions can be made in this respect:

4.1. Ensuring continuous palliative care, from primary care all the way to tertiary care, is a fundamental necessity.

4.2. At present, it is not customary practice to check in patients for treating pain or those who are at advanced stages of their illness. Extending hospitalisation guidelines by including these categories of patients on the list of free services and having these costs covered by the National Medical Insurance Company (CNAM) would be of obvious benefit to patients and carers first of all. Moldova would thus join many democratic countries who have adopted this practice for many years.

4.3. Creating palliative care educational and practical centres for doctors, nurses, social workers and psychologists, alongside specialist hospitals, should be a priority.

4.4. The fact that family doctors and their nurses, doctors and nurses who work in neurology, internal medicine, oncology, cardiology and infectious diseases departments most often help patients in the terminal stages of illness needs to be taken into account and palliative care should be part of their specialist training.

4.5. Protocols and guides for looking after patients during stages of illness should be devised first of all for the departments listed above.

4.6. Involving experienced carers in the market through carer employment contracts, with the help of the Ministry of Health and Ministry of Social Protection, would enable several problems faced by society to be solved: on the one hand, it would make up for the lack of carers and, on the other hand, it would solve the problem of unemployment. Training carers for these services can also take place in palliative care centres.

5. *Suggestions for setting up partnerships with the church and public health organisations.*

5.1. The church remains an important support for a large part of this country's population and its involvement in the fate of the patients and their families needs to be encouraged. Setting up partnerships between the church and the medical environment is welcome.

5.2. Adapting hospital administration policies so as to increase the opportunities for church workers to get involved in caring for patients during advanced stages of their disease, at the request of family members and carers, is a practice which has long been in use in countries with older democracies.

5.3. Giving educational support to church workers, at their request, in order to understand certain aspects related to a disease, would benefit both patients and relatives, as well as the whole multidisciplinary team involved in a patient's treatment.

5.4. The wider inclusion of palliative care in the activity strategies of non-governmental and medical organisations is also needed.

6. Suggestions for changing national policies

The active involvement of Government and Ministry of Health in promoting Palliative Care in the Republic of Moldova would become a decisive element in bringing about changes at a national level and would induce a change in society's and decision makers' attitude toward this problem.

6.1. Since Palliative Care is by definition a multidisciplinary field and has social implications, it would greatly benefit from the support of the population willing to get involved in sponsoring palliative care activities. Granting tax incentives to these people and organisations would help attract investment in this health care field.

6.2. Taking into account the fact that Palliative Care is a relatively new health care field in Moldova, appropriate guidelines are needed. Thus, devising and approving clinical guides and protocols, as well as updating legislation regarding prescribing, using, and importing of painkillers and other strictly regulated medication, as well as its actual implementation, would represent an essential contribution to the proper working of this service.

6.3. Regrettably, insufficient pain alleviation causes and increases the general suffering of patients and, consequently, makes them, their relatives and carers significantly unhappy. Removing the barriers to prescribing painkillers – the restrictions applied to those who prescribe opioids and the way paperwork is completed, the availability of oral morphine, the diversification of opioids on offer, putting an end to the legal limits on morphine doses, etc. – are among the most current pressing needs, which represent an obstacle to patients' access to painkillers and adequate symptomatic control. This is a particularly urgent recommendation to government.

7. *Suggestions for the development of a National Palliative Care Service*

At present, Palliative Care is not a recognised specialty in the Republic of Moldova. This restricts the activity of those who are active in and promote this health care field. In this context:

7.1. It is extremely necessary that the specialty of Palliative Care be recognised in its own right. This would clearly facilitate the rapid development of the whole service.

7.2. Elaborating a strategic and financial development plan for implementing the palliative care service, which would include the necessary financial resources and infrastructure, would become an event of major importance.

7.3. The Republic of Moldova needs to set up and develop all basic forms of palliative care, at all levels of medical assistance, and to integrate them into the existing health care system.

7.4. Certifying those who already offer palliative care services and who have undergone relevant training, confirmed by international certificates, would be an immediate advantage.

7.5. Creating palliative care medical units in university clinics, with support from the state, would provide an excellent basis for training the young generation of specialists.

7.6. The collaboration between Moldovan specialists in the field of palliative care and looking after terminally ill patients and specialists from other countries, for the purpose of devising educational curricula on the basis of common projects, would facilitate the task of approving documents relevant to the developing service.

7.7. Setting up partnerships with specialised international bodies, getting involved in scientific collaboration and Masters programmes in the fields of terminal and palliative care represent a source which has not been fully explored in the Republic of Moldova.

7.8. The involvement of mass media, medical staff and the wider public must be consolidated in creating an adequate image of palliative care in society.

7.9. Consultations and discussions with specialised international institutions, supporting organisations and key individuals in the field through the Telemedia network can become a useful method for informing and assisting those involved in this activity in the Republic of Moldova.

We do not claim to have exhaustively covered the recommendations and suggestions needed so that the system of palliative care and looking after terminally ill patients may work properly in the Republic of Moldova. However, given that this system is virtually non-existent at a professional medical level legislated by state structures, and given the importance of this problem, setting up such a system becomes an immediate imperative. We have, therefore, outlined in this chapter suggestions recommended for taking the first steps in setting up a new medical and health care field, a new multidisciplinary specialty – Palliative Care. We also recommend setting guidelines for this field (some of which already exist in countries with better developed democracies) that are useful for the incipient activity in this field of Palliative Care and specifically for looking after terminally ill patients. We are certain that, once activity is initiated in this field, new challenges will arise and new recommendations for improvement will be needed.

We hope that this book will not be found only on the shelves of public and personal libraries, but will also come to the attention of decision makers: state authorities, medical specialists and civil society in general, thus creating a national conversation that will bring beneficial changes to the lives of patients and their families coping with the terminal stages of illness, death and bereavement.

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