Impacts of Rationing and Missed Nursing Care: Challenges and Solutions

RANCARE Action

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ISBN 978-3-030-71072-9 ISBN 978-3-030-71073-6 (eBook)
https://doi.org/10.1007/978-3-030-71073-6

This Springer imprint is published by the registered company Springer Nature Switzerland AG
The registered company address is: Gewerbestrasse 11, 6330 Cham, Switzerland

Preface

This book is an introduction to the theory and research of rationing and missed nursing care. It includes information, discussed from different perceptions (i.e., conceptual, ethical, methodological, managerial), useful for researchers, health care workers and health care consumers, students, managers, and policy makers.

Rationing of nursing care is both a sensitive and challenging aspect of care that cause a great deal of controversy and debate at different levels, for example, research, education, clinical practice, and politics. Although the issue is discussed for some years now as a problem of under-staffing limited to nursing, it was realized that this phenomenon is much more complicated, having multiple dimensions given the complexity of contemporary health care organizations. This was more obvious during the COVID-19 pandemic, a health crisis that has shaken the entire global economy challenging the ability of health care systems to deal with and brought the problem to the surface.

The motivation for writing this book was also the fact that no systematic work that tackled the phenomenon from multiple perspectives of missed nursing care has been published before. On the contrary, the fragmented work and gaps related to issues such as ethics, patient safety, the availability of resources, and research inconsistencies created confusion and misunderstandings. The organized theoretical, empirical, and practical work done during the almost 5 years of life of the RANCARE COST Action gave the idea as well as the opportunity to gather all the conceptual, spiritual, philosophical, ethical, educational, and methodological pursuits together in a single book that aspires to fill in some gaps of knowledge in the science of care. Through this Action, we have advanced the understanding of the topic, added reading, and other material for scholars, students, and nurses in clinical practice. Much literature is produced, scientific, philosophical, and empirical that triggered the interest in the phenomenon internationally as it is shown by the vast increase of scientific publications on the topic during this last 5 years, from people participating the Action and globally.

Hopefully, this book will raise the level of awareness among practicing nurses, policy makers, and the general public and initiate discussion that in turn may entail major changes in care in which the beneficiaries will be both the health care systems and their consumers as well as the health care professionals.

Since the RANCARE Action was programmed to end by the year 2020, the International Year of the Nurse and Midwife, this book is devoted to all nurses, and to the memory of those nurses who lost their lives when struggling to offer care to people to the best they could.

Limassol, Cyprus — Evridiki Papastavrou
Turku, Finland — Riitta Suhonen

Acknowledgments

This book would not have been possible without the contribution of chapter authors as well as the input of many people who worked together during the almost 5 years of life of the RANCARE Action, discussing and bringing new ideas and conceptual challenges in the exploration of rationing and missed care phenomenon. The book is designed around the objectives of the Action, that is discussion, exploration, and understanding of (a) the concepts, the organizational factors, and the research methodology; (b) the interventions and strategies that may give some solutions to the problem; (c) the ethical perspective of rationing and missed care; and (d) the educational aspect of care rationing as related to patient safety. The above objectives were achieved through the endless efforts and commitment of the Working Group (WG) leaders and vice leaders whom we deeply thank and appreciate both for their devotion to the Action as well as their contribution for writing this book. Especially the leader of WG1 Professor Walter Sermeus from the KU Leuven Institute for Healthcare Policy (Belgium), the leader of WG2 Professor Maria Schubert from ZHAW Zurich University of Applied Sciences School of Health Professions Institute of Nursing (Switzerland), the leader of WG3 Professor Riitta Suhonen from the University of Turku, Department of Nursing Science (Finland), and the leader of WG4 Professor Olga Riklikiene from the Lithuanian University of Health Sciences, Faculty of Nursing, Nursing and Care Department (Lithuania).

The work of the WGs was facilitated by the WG Vice leaders to whom we would also like to express our gratitude for writing chapters and contributing to knowledge, namely Professor Anat Drah-Zahavy (Israel) and Dr. Renata Zelenikova (Czech Republic) of WG1, Dr. Dietmar Ausserhofer (Switzerland) of WG2, Professor Anne Scott (UK) of WG3, and Dr. Marcia Kirwan (Ireland) of WG4. Many thanks are expressed to those who contributed to the achievement of the capacity building objectives, namely the Short-Term Scientific Missions coordinator Dr. Georgios Efstathiou (Cyprus) and the Science Communication Manager Dr. Mario Amorim Lopes (Portugal). In addition, we thank all horizontal groups who organized conferences and supported training schools, headed by Dr. Raul Cordeiro (Portugal) and Dr. Izabella Uchmanowicz (Poland). The Vice Chair of the Action, Professor Chrysoula Lemonidou, Chair of the Department of Nursing of the National and Kapodistrian University of Athens, is also acknowledged for her support and encouragement throughout the duration of the Action.

Special thanks are ought to Professors Anne Scott, Riitta Suhonen, Marcia Kirwan, and Maria Schubert who took the lead in the publication of special issues in two prestigious international scientific journals, the Journal of Nursing Management and Nursing Philosophy, increasing the visibility and scientific impact of our work.

We also wish to thank those who, although they were not directly involved in the writing this book, through their support facilitated this endeavor. That is the funding organization, COST—European Cooperation in Science and Technology, for giving us this opportunity to share ideas and knowledge and create collaborations and synergies to go further and deeper into this intellectual and fascinating journey. COST is a funding agency for research and innovation networks. COST Actions help connect research initiatives across Europe and enable scientists to grow their ideas by sharing them with their peers. This boosts their research, career and innovation (www.cost.eu). The Grant Holder Manager, Dr. Elena Rousou, and our associates Dr. Areti Efthymiou, Dr. Panayiota Andreou, and George Mitseas of the Cyprus University of Technology are also acknowledged for their support. Finally, we would like to acknowledge the contribution of the COST Science Officer Dr. Karina Marcus and the administrative officer Ms. Katchamon Nimprang for their help and their patience during these years.

Contents

Introduction

1

Evridiki Papastavrou and Riitta Suhonen

1.1 Introduction

The interest in the problem of care rationing and missed care came out after many years of scientific inquiry and studying the general area of "care" and its multiple dimensions, the elements, magnitudes as well as the challenges embedded in this elusive concept. Many professions claim that "care" lies within their own scope of practice although health-care professionals have historically supported having the exclusiveness of the term, the concept, and the notion. In his classic article for the history of the notion of care published in 1995, Warren Thomas Reich [1] describes the meaning of care in a variety of settings such as mythological, religious, philosophical, psychological, theological, moral, and practical and how the notion of care has developed throughout history, influencing moral orientation and behaviors. Although the author focuses on the ethics of care, he recognizes that there are constraints and restrictions in the delivery of care and interestingly in his conclusive statements he points out the "limits of caring of others" introducing to the idea of care rationing. The term rationing is used to demonstrate the allocation of scarce resources between competing health-care demands at a macrolevel, that is, both an economical challenge and a political problem (see Chap. 2). It is therefore argued that care rationing entails withholding potentially beneficial treatments from some

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E. Papastavrou, R. Suhonen (eds.), *Impacts of Rationing and Missed Nursing Care: Challenges and Solutions*, https://doi.org/10.1007/978-3-030-71073-6_1

individuals, but it is unavoidable because need is limitless, and resources are not [2]. Given these restrictions, at a microlevel, health-care professional usually focus on assessed needs and prioritize according to the severity or the urgency of patient needs according to their own judgment and ethical principles of justice, autonomy, fidelity, beneficence, and non-maleficence. However, there are strong voices and arguments against the use of the term "care rationing" in nursing, therefore several terms and concepts are developed to describe the phenomenon, such as missed care, care left undone, compromised care, and so on, increasing the confusion and misunderstandings.

In a resource allocation in nursing care discussion paper, Scott et al. [3] are making an important distinction in the terms "allocation of resources" and "rationing of care" raising interesting conceptual and ethical considerations. The difference lies on the fact that at the organizational level, allocation of resources is applied mainly by policy makers and is based on explicit principles and policies, whereas rationing of care at the bedside is based on an individual level, and it depends on the discretion of the clinician to use his or her own judgment on how to set priorities, always for the benefit and the best interest of the patient. Although in the medical profession, there is some form of generally accepted explicit rationing criteria based mainly on outcomes, in the case of nursing decisions on how nurses allocate their time to care for patients, these are left mainly to the professionals, although there are countries in which these criteria refer to nursing as well [4]. It is also interesting to note that in the medical literature that has a long tradition in discussing health-care rationing, the concept of omission is not treated as synonymous, and omissions are terms used only in cases of liability and legal responsibility. The argument here is the assumption that rationing of care is synonymous to other terms such as missed care, care omissions, care left undone, and so on, and it is creating a lot of misconceptions and misunderstandings. Instead, rationing of care is the focal point at which nurses make critical decisions using their own judgment on how to prioritize care which will inevitably lead to care omissions or delays, especially in situations of severe shortages of staff. Therefore, if rationing of nursing care is accepted as a part of the decision-making process, it is argued that there is a strong ethical element involved including decisions on whom to care, what the appropriate nursing care is, how much time and effort should each patient receive, how urgent the need for care is and how urgency is defined as well as by whom [5]. This means that at the bedside, that is, the microeconomic level of care, nurses' decisions may be more influenced by their knowledge and competence, their assessment, and decision-making skills, as well as their personal feelings, values, and beliefs. This situation also causes a moral burden on nurses who are left to use their discretion unaided and not supported by guidelines or explicit principles on how to act in the cases of time scarcity and raises emotions of guilt and ethical challenges on nurses. Missed nursing care, care omissions, or care left undone are the outcomes of this process which in turn may contribute to developing negative outcomes to patients such as severe complications or in simple words the patient will not receive the full care needed to promote health and recovery.

In nursing, the scientific inquiry has started in the USA in 2001 with the work of Linda Aiken et al. [6] using the term "care left undone", the conceptual definition used by B. Kalisch [7] with the term "care omissions" and in Europe M. Schubert

[8] made use of "implicit rationing of care" following the Donabedian theoretical framework of resource—process—outcome concentrating mainly on the process. Since then, a plethora of terms have emerged mainly focusing on the outcome, but all trying to understand the multidimensional nature and explain the phenomenon within the patient safety context.

The idea of looking on this phenomenon from a more broad, global and systematic perspective began in 2016 with the submission of a proposal to the COST ASSOCIATION (European Cooperation in Science and Technology) [9], a funding organization for research and innovation networks in Europe. The decision to apply to this organization is that it provided the opportunity to scholars and practitioners around the world to jointly discuss, develop their own ideas and explore new initiatives across all fields in the science of nursing, through pan-European networking of nationally funded research activities. The main aim and objective of the Action was to facilitate discussion about rationing of nursing care and missed care based on a cross-national approach with implications for practice and professional development [10]. This could be achieved by advancing collaboration and networking by integrating different disciplines including nursing, ethics, moral philosophy, psychology, and other health-care studies.

The specific objectives of RANCARE [10] were twofold, the research coordination and the capacity building. Research coordination included aspects such as (a) developing the theoretical conceptualization and creating a common understanding of the phenomenon and the associated factors as well as the directions of research, (b) encouraging discussion on the ethical perspective, exploring the available interventions, and examining the implications on nursing education.

The capacity building objectives included the creation of a network to foster knowledge exchange and dissemination of good practices at a European and International level, the development of Early Career researchers and bringing together academics, clinicians, policy makers, and care consumers to develop innovative approaches to minimize the problem [11].

The whole idea, the aim, and objectives of the RANCARE Action [10] were materialized through the work of four working groups working on the following pillars:

1. The mapping and evaluation of the existing knowledge on nursing care rationing and missed care and the examination of the evidence regarding organizational and system factors related to the phenomenon, as well as the concept and methodological considerations and challenges in investigating and monitoring the phenomenon and related aspects.
2. The investigation of theoretically and empirically based interventions and strategies that reduce or minimize missed care and the negative consequences on both patients and nurses and the exchange ideas for other possible solutions including the use of technology.
3. The exploration and understanding of the ethical perspective of care rationing and missed care, and the analysis of the issue from a patients' rights perspective (including possible discriminations), the value principles underlying clinical judgment, and the impact on nurses and patients.

4. The educational aspect and training nurses on the importance of looking on missed care from the patient safety perspective, as well as the examination of nursing curricula and exchange of practices regarding patient safety as related to missed care.

The working groups (WG) had several tools for the achievement of their specific goals, such as meetings, training schools, short-term scientific missions, conferences, and international workshops. Among the major deliverables that the WGs were engaged to provide were the scientific papers in national and international journals. RANCARE members were extremely productive in this aspect as they succeeded to publish internationally more than 50 articles in scientific journals before the end of the Action and with no budget supporting research since the COST Association supports mainly networking activities, not research. Added to this are two special issues published by the scientific journals "Nursing Philosophy" and "Journal of Nursing Management", devoted to the work of the Action. It is also very interesting to note that after the beginning of RANCARE, a huge interest on the phenomenon of rationing and missed care was observed as it is evident from the related published literature in scientific journals. Even research projects that were performed prior to RANCARE and looked on the issue as secondary and less important, they started analyzing and publishing parts of their work related to missed care. This means that the awareness of the academic community was increased and expanded to a problem that was hidden and not recognized nor accepted for many years by the academics as well as health-care practitioners.

In designing the book, the idea was to collect some of the work done by the RANCARE Action and present the main ideas, the notions, the concepts, and the challenges as well as the consensus that has been achieved after long discussions within the groups.

The aim is to inform both the academic community as well as the clinicians working in any health-care facility, about the knowledge obtained and the developments achieved during the 5 year's work. At a policy level, the aim is to increase acknowledgment on the phenomenon of missed care as an important dimension of the patient safety framework and provide the tools for assessing and recording missed care and hopefully reducing it to a standard that it is not harmful for patients.

The book consists of ten chapters, plus the conclusions, the preface, and the acknowledgments.

After Chap. 1 (that is, the introduction), Chap. 2 opens the discussion by examining the concept of missed care in the context of theoretical paradigms and reviewing the empirical evidence associated with the translation, interpretation, understanding, and popularity of the related terminology. The authors have attempted to draw a common conceptual picture that might be useful to the reader, given the challenges in translating missed care terminology across languages. They have also looked on the use of the term in other disciplines focusing on the health-care quality and placing the issue under the broader classification of errors as depicted in the patient safety literature. Chapter 2 continues with the prevalence of missed care in several health-care settings such as the acute care, the long care facilities for the

aged population, and in the community. Some useful theoretical perspectives are also explained within the microsystem, the macrosystem, and the integrated system, and it continues with the outcomes of missed care and the impact on the various health-care facilities both from a patients' and nurses' perspective.

In Chap. 3 the concept of nursing care rationing and missed care are discussed from the philosophical, the legal as well as the practical aspect. The authors refer to the concept of omission and how it is understood from the philosophical perspective raising interesting ethical and moral arguments. It continues with the legal point of view, making clear distinctions from the philosophical aspect explaining the liability in the case of actions and omissions, and giving examples from specific court cases. Similarly, the authors continue to explain the concepts of allocation of resources, rationing of nursing care, and missed nursing care from a different angle of laws and regulations. After describing the concept of rationing on the medical and nursing contexts, the authors discuss the notion and the possibility of harm associated with missed nursing tasks, and if missed nursing care can be counted as nursing error, concluding that nursing has always been striving for the best interest of patients by gathering evidence that will guide structural changes in the provision of health care.

Chapter 4 examines the research methodology used to date in the field of missed nursing care, the designs, the instruments, and the reporting guidelines developed inside the RANCARE network aiming in supporting the evaluation and comparison of studies in this area of research. Although the authors admit that most studies are in the level of finding associations, they observed some progress on the level of causation using an excellent description of the Hill's criteria for causation. Following, the existing instruments measuring missed care are described, including published studies that have validated the instruments as well as several critical issues regarding missed care instruments and their use both in research and in practice. The chapter continues with the work done by a steering group consisting by experienced researchers, members of the WG2 who developed the RANCARE guidelines. The group used the consensus approach consisting of a Delphi survey and an international workshop to identify, refine and agree on relevant items for the guidelines. The resulted "Strengthening tRansparent reporting of reseArch on uNfinished nursing CARE—the RANCARE guideline" is described in detail hoping to contribute to the better understanding of research methodology around the issue. The guidelines can also be used complementary with more general research guidelines that will facilitate meaningful comparisons across studies and improve the quality and replicability of research.

Chapter 5 analyzes the phenomenon from three different perspectives, that is, the organizational and societal level, the professional nursing staff, and the patient or care consumer's point of view, raising essential ethical and moral considerations and challenges, aiming to increase nurses' awareness of the ethical issues in missed care. Basic concepts such as equity, justice, autonomy, and liberty are explained in their relationship with the delivery of nursing care and the differences of care rationing at the different organizational levels as regards the ethical consideration are explained. The authors also discuss the need for clear guidelines in prioritization of

nursing care especially during periods of scarcity of resources (e.g., low staffing levels) together with the professional roles, responsibilities, and role conflicts. Most importantly, this chapter is the only one that looks missed care from the patient perspective and discusses the evidence about unmet care needs from studies and reports for violations of fundamental human rights, pointing out that the patients' perspective is largely neglected in the literature.

Chapter 6 reflects the ethical perspective and challenges in the research of missed care. The authors start with a brief introduction of research ethics and the ethical principles guiding research involving human subjects and health care providing a short historical overview. They continue with the most common ethical principles, for example, beneficence, non-maleficence, respect for autonomy, and justice, and they discuss those ethical principles at risk in the missed care research. The authors raise important issues and challenges, such as the risk of the participants to feel pressured, the moral obligations toward the participants and not viewing them as "means for an end," and the responsibility of the researchers to promote changes in nursing practice. Following they discuss the notion of justice supporting that research discovers that missed care often affects the most vulnerable, the elderly, the least outspoken, the ones with little family support, challenging in this way the researchers' responsibility when uncovering findings proves patients suffer from injustice. The chapter closes with research ethical responsibilities and implications and developing future research tacking on these aspects.

Chapter 7 explores interventions to reduce and limit rationing and missed nursing care, and the authors provide a synthesis of studies reporting on interventions to reduce or limit missed nursing care. They also try to outline in depth the current and future directions for promising interventions by taking a clinical-practical as well as research-methodological perspective. The authors divided the chapter into four major categories of interventions, describing and analyzing in depth the content and the evidence available for each intervention. The first category includes the state of the literature providing studies that investigated the effectiveness of certain approaches that can prevent missed care. These approaches include interventions focusing on the proper ward staffing and effective teamwork, care reminders, and interventions improving the quality of the nursing care process. Based on the Missed care model developed by Kalisch et al., the second category focuses specifically on teamwork and staffing as the two major issues in nursing related to missed care. The third category is concentrating on the technological solutions such as telehealth, telemonitoring, wearable devices for patient monitoring, unobtrusive sensing for patient monitoring, and the use of robots related to the promising possibility to reduce missed care due to scarce resources. The last category is about tackling methodological challenges underlining the lack of intervention studies with a strong experimental design and insufficient evidence regarding the sustainability of the effects of interventions, as the major gap in research. Each category in the Chap. 7 ends with a conclusion that summarizes the intervention and the discussion on the subject.

Chapter 8 gives a different perspective of the phenomenon, under the patient safety framework, and how it is included in nursing education. The authors start with a detailed historical and conceptual description of the evolution of the patient safety movement as an important discipline in health care, and they explain the role

of nurses in promoting and safeguarding patient safety. They continue by focusing on the status of patient safety in nursing education and reporting on the findings of a survey conducted by the RANCARE COST Action which examined patient safety teaching in nurse education across 27 countries. The chapter ends with suggestions for nursing education, based on recognized frameworks for teaching patient safety that have been developed in the USA or by the WHO that both offer a roadmap for patient safety education for nursing students as well as other healthcare workers.

In Chap. 9, the authors highlight the importance of nurse leaders in managing situations resulting from missed care, and they explain the process of building a good practice guide for nurse managers, regarding the promotion of patient safety through minimizing missed nursing care. It starts with some concepts of leadership, clinical governance, and accountability as well as caring for the nursing workforce. Managing the circumstances resulting from nursing care rationing is the focal point on which the authors based the good practice guide for managers, and they describe the objectives, the foundations of the guide, the process of development of the guide as well as the structure.

Chapter 10, that is, the last chapter of the book prior to the conclusions, is about the synergies formed during the RANCARE Action and the opportunities provided for networking and establishment of collaborations. Most of the work during the 4 years life was succeeded because of the collaborations between researchers, early career investigators, policy makers, academics, clinicians, and others, and the opportunities they had to study, to discuss, and to work on the several dimensions of the phenomenon under study. The chapter gives an overview of the work done through the Short-Term Scientific Missions, such as the examination of research methodologies and the conceptual basis of missed care, the managerial approaches and leadership interventions, education, the ethics of missed care as well as the collaborations on missed care developed through the STSM.

This book comes after almost 5 years' work and networking of 104 people coming from 34 counties from Europe as well as other parts of the World such as Neighboring countries (e.g., Lebanon), the USA, Canada, Australia, and New Zealand, underlining the significant work achieved by the RANCARE Action. Apart from multicultural, the RANCARE group is multidisciplinary, including professionals and academics from the health-care section, economics, philosophy, policy making, psychology, and others who all gave their own perspective in understanding the phenomenon under study.

In conclusion, this book is structured around the four main areas of the phenomenon explored through the RANCARE COST Action, and the basic assumption is that understanding rationing and missed care will facilitate to promote patient safety and quality of care. Although this is an international problem, there are still important differences between the EU and other participating countries, in terms of health-care systems, national legislations, experiences, tradition, and nursing educational systems. However, this COST Action gave the opportunity to understand and realize the commonalities and the unities within the group, to make synergies and collaborations working together to a common goal creating the basis for further research and development.

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Understanding Missed Care: Definitions, Measures, Conceptualizations, Evidence, Prevalence, and Challenges

2

Terry Jones, Anat Drach-Zahavy, Walter Sermeus, Eileen Willis, and Renata Zelenikova

2.1 Introduction

There is substantial empirical evidence that patients worldwide do not always receive the full complement of nursing care needed to promote health, alleviate suffering, and prevent illness and injury. Moreover, it is an issue that arguably fits the category of wicked problems resistant to singular disciplinary solutions and in need of transdisciplinary problem-solving [1–3]. Multiple teams of international scientists collaborate to inform our understanding of this phenomenon to include its causal mechanisms, the effectiveness of interventions, and the associated outcomes. Not surprisingly, the combination of rapid growth and broad interest has created critical challenges for those engaged in advancing this young science. One fundamental critical challenge is this—what shall we call this phenomenon? After almost two decades of inquiry, the science still suffers from a lack of conceptual clarity as

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E. Papastavrou, R. Suhonen (eds.), *Impacts of Rationing and Missed Nursing Care: Challenges and Solutions*, https://doi.org/10.1007/978-3-030-71073-6_2

key stakeholders have yet to reach consensus on conceptual terminologies and definitions. This lack of conceptual clarity impedes the kind of cross-disciplinary knowledge exchange needed to support transdisciplinary problem-solving.

The phenomenon was first introduced in 2001 under the label *tasks left undone* [4]. By 2007, additional terms for the phenomenon began to appear in the literature with regularity to include *missed nursing care* [5] and *implicitly rationed nursing care* [6]. The findings of an early state of the science review suggested that these terms were being used to reflect a common underlying phenomenon, and the term *unfinished nursing care* was introduced to serve as a unifying umbrella term [7]. The common phenomenon was defined as, "a problem of time scarcity that prompts nurses to engage in implicit rationing of care through the process of clinical prioritization that results in care left undone" [7] (p. 1134). However, the umbrella term and associated definition were not widely adopted. The debate about whether the original terms (care left undone, missed care, and implicitly rationed care) really reflect a common phenomenon continues as does the diversity of terms appearing in the literature. Clearly, the underlying concept is not fully developed, and more theoretical scholarship is needed to attain conceptual clarity and shared meaning. For the sake of brevity, we will use the term *missed care* when referring to the general phenomenon of patients not receiving necessary nursing care.

The concept of missed care is a difficult concept to grasp because, in fact, it does not exist as it is *missed*. It is like a missed phone call, a missed opportunity, a job you did not get. The missed experience mainly exists in the mind of the beholder. Missed care is studied mainly because of the impact on patient safety and quality. When care is missed, we surmise that patient safety might be compromised. Missed care often acts as a *canary test*. Canaries were once used in coal mining to alert miners when carbon monoxide and other toxic gases reached dangerous levels. When canaries stopped singing (i.e., when they died and were *missed*), it was an early warning of danger and a signal to leave the tunnels immediately. Missed care seems to be the most sensitive "canary test" for health-care organizations and systems. Therefore, scholars in this field are challenged to develop robust theories to help explain why patients do not get the nursing care they need, what outcomes result, and what solutions are effective and sustainable. In this chapter we will address the use of multiple terms related to this phenomenon and the difficulties in translation of these terms to different languages, contexts, and cultures. Through this process we will consider whether common terms have the same or rather different meanings and potential interpretations. Finally, we will consider the prevalence and impact of missed care across selected practice settings.

2.2 Methods

We will provide a comprehensive discussion of the current science around missed care to achieve the aims of this chapter. Our discussion is based on a critical review of the relevant theoretical and empirical literature. The emerging body of science