

This is a self-archived – parallel published version of an original article. This version may differ from the original in pagination and typographic details. When using please cite the original.

This is a post-peer-review, pre-copyedit version of an article published in

Book Impacts of Rationing and Missed Nursing Care: Challenges and Solutions

The final authenticated version is available online at

DOI 10.1007/978-3-030-71073-6_5

CITATION Suhonen R., Scott P.A., Igoumenidis M. (2021) An Ethical Perspective of Nursing Care Rationing and Missed Care. In: Papastavrou E., Suhonen R. (eds) Impacts of Rationing and Missed Nursing Care: Challenges and Solutions. Springer, Cham. <u>https://doi.org/10.1007/978-3-030-71073-6_5</u>

Chapter 5 An ethical perspective of nursing care rationing and missed care R. Suhonen, P.A. Scott, M. Igoumenidis

Book: Impacts of Rationing and Missed Nursing Care: Challenges and Solutions - RANCARE Action

Author information: Riitta Suhonen, RN, PhD, FEANS, Professor and Director of Nursing (part time) University of Turku, Department of Nursing Science and Turku University Hospital and City of Turku, Welfare Division 20014 University of Turku, Finland Tel: +358-50-4350662, Email: riisuh@utu.fi ORCID: 0000-0002-4315-5550

P Anne Scott, PhD, MSc, BA (Mod), RGN, Professor Office of the Vice President for Equality and Diversity, National University of Ireland Galway, Galway, Ireland Tel: +353 (0)91 492639, Email: anne.scott@nuigalway.ie ORCID: 0000-0002-5790-8066

Michael Igoumenidis, PhD, MA, BSc, RN, Assistant Professor Department of Nursing, University of Patras, Patras Greece Tel: +306944365635; Email: igoum@upatras.gr ORCID: 0000-0002-9458-3424

Abstract

This chapter discusses ethical issues in the area of rationing and missed nursing care from two different perspectives: 1) philosophical/conceptual and 2) empirical descriptive ethics. In addition, ethical issues can be approached from 1) the societal and organizational levels, i.e. organisational ethics; 2) the professional nursing staff, i.e professional ethics; and 3) the service user's and patient's point of views, from the perspective of rights. These approaches may look at different sides of the same issue, and deserves closer investigation and discussion. The use of the concepts missed care, care left undone, unfinished care and covert rationing of care, varies in the literature, potentially giving rise to some conceptual confusion, inconsistencies and potential misunderstandings. This can lead to unidentified, flawed assumptions and difficulties in clarity of thought regarding the phenomenon /phenomena under question. Finally, the empirical evidence on the missed care/ rationing and similar concepts deserves some conclusive statements from the ethics point of view.

Keywords: Ethics, priority, resource allocation, covert rationing, missed care, nursing care left undone, unfinished care, nurse, patient, organisation

Introduction

Over the past five year or so there is evidence, in the nursing literature, of increased interest and discussion of issues which are on occasion called 'missed nursing care', 'nursing care left undone', 'covert rationing of nursing care', and less commonly, 'unfinished care'. Currently in the nursing literature these terms tend to be used interchangeably [1]. Ultimately these terms may indeed refer to the same thing or they may in fact refer to slightly different things. At present we simply do not know, as the required empirical and analytical work has not been done as yet. However, we do know that missed care/care left undone/covert rationing of care are salient issues in nursing care contexts internationally [2]. There is also an increasing recognition in the patients safety literature that incidents of care missed/left undone/rationed is associated with poorer patient outcomes [3,4], i.e. we do know that less than optimal care provision is not good, therefore, is at best neutral and at worst bad, even dangerous, for patients.

This reality (i.e. that less than optional levels of nursing care can be damaging or dangerous for patients, in other words can do patients harm) provides some insight as to why it may be both useful and important to consider missed care/ care left undone/ covert rationing of nursing care from an ethical perspective. Many authors have argued that the provision of nursing care is inextricably linked with the ethical dimension of practice [4-6]. It seems likely this is the case also in situations of missed care/care left undone/covert rationing of care.

Considering issues of missed care/care left undone/covert rationing of care from an ethics perspective enables, indeed requires, us to engage in a number of different activities including the following:

- A focus on core concepts in use and what they mean for example, what do we mean by missed care/care left undone/covert rationing of care. What is resource allocation or rationing in nursing? Do these two concepts refer to or mean the same thing? Does this matter?
- An identification and elucidation of some of our underlying assumptions regarding matters of missed care/care left undone/covert rationing of care – such as what assumptions (overt or covert) we make regarding the causes or underlying factors which lead to missed care/care left undone/covert rationing of care.
- 3. Is there relevant evidence or empirical work, perhaps from a descriptive ethics perspective, that can be brought to bear as we try to work though and consider these matters?

In this chapter we will introduce the reader to some of the philosophical and descriptive ethics work relevant to missed care/care left undone/covert rationing of care that may be relevant and important to consider in the context of the provision of nursing care in the health service of the 21st Century. Hence forth the term missed care will be used to refer to all three terms – i.e. missed care, care left undone and covert rationing of care.

5.1 The nursing workforce and access to the resource of nursing care

Discussions regarding the nursing workforce, the largest group of health professionals [7] tend to focus on one of two key issues. At the same time as the cost of nursing personnel is identified as a very significant cost to the healthcare budget and for society [8,9], it is increasingly being recognised that this same nursing workforce has the most relevant competence in providing comprehensive care, services and health promotion, and in responding to individuals' and populations' health needs. Therefore, it is important to ensure that nursing care and nursing time are treated as significant and important health care resources [1]. Access to such resources should be governed by explicit discussion, principles and guidance on prioritization, including an overt recognition that allocation of nursing care and nursing time is **an ethical issue**, in addition to being a matter of financial, professional and patient safety concern [10–16].

In many countries health, and health care services (including nursing services) to support health, have been considered as a citizen's right; with explicit quality standards [17] driven by the country's Gross Domestic Product [18] and health expenditure per capita giving the frame for services. Thus, in health care one is faced with trying to balance the resources available on the one hand with the need to provide high quality, ethically sensitive care to diverse populations and groups on the other. At some level all resources, economic and others in society are scarce and limited, while at the same time expectations regarding health (for both individuals and groups) are continuing to increase. The demands for access to new, more effective treatments, better, more comprehensive care, health promotion and activities to maintain health are limitless [19]. Given the current development trends in care technology, treatment modalities, new digital services, and existing knowledge and information, the possibilities for care and treatment are increasing exponentially. However, the limits on available resources make it impossible to offer all possibilities to everyone in need [20]. This imbalance makes it important that a shared understanding be reached regarding how to deal with scarce resources, at both the societal and organizational levels, but also at the individual level in the clinical practice setting.

In many countries, national principles may exist for sharing resources ethically [e.g. 21,22]. Basic principles for sharing resources include equality, need, effectiveness and many others. In resource allocation the decision-maker faces questions related to principles for distribution/allocation of resources - such as principles of justice, fairness, equity and equality. Such questions speak to the ethical dimension of resource allocation decision making. Resource allocation principles, such as those listed above, should be applied to access nursing time and nursing care, as to other treatment and care provision. It is also the case that ever increasing expectation of the population in most western countries continues to put very significant pressure on the health budget in those countries. This inevitably leads to questions about how to best use the available resources and the identified need to ration elements of access to and provision of health care. This is either a very new discussion in some countries in terms of allocating the nursing resource nationally, or had not yet begun. This type of discussion is also quite new in the nursing literature.

To assist clarity of thinking on these matters it is helpful to distinguish between the concept of resource allocation and that of rationing [see 10]. These two concepts are related but distinct terms. Resource allocation refers to the distribution of resources to a service, unit or project. Rationing indicates that the resources to be allocated are so limited that they are not sufficient to meet the need in the particular context, thus forcing the decision-maker to decide who should get the resources available, or how much of the particular resource each person in need should receive (and on the basis of what criteria). Both resource allocation and rationing imply the use of specific criteria to distribute the available resources – usually with the goal of optimizing utility or meeting the demands of procedural fairness. Resource allocation is a morally neutral term. Rationing, including decisions not to provide the particular resource, or decisions prioritising access to the particular resource, is a morally loaded term.

With regards to rationing in the context of nursing care, three important distinctions have to be made [see 10]. Firstly, the originator of rationing needs to be identified: Rationing implemented by an institution (for example via policies/ operational practices) or rationing implemented at the level of the individual practitioner (through their actions in practice context). Secondly, the existence, or not, of an identifiable framework available in the particular context, which is guiding explicit or implicit rationing decisions. In other words is rationing based on explicit (shared and open) principles or policies, or is rationing based on implicit (covert) practices; in this case the individual nurse(s) at the bedside. Finally there is the important "distinction between rationing of the nursing resource per se (i.e. rationing the number of nurses available to provide the required care – this may be at societal and/or organizational level) and the rationing of actual nursing care at the bedside" [10].

5.2 Nursing care rationing and missed care from a societal and organizational perspective

Crudely put, health care is about the provision of health services to the public. Despite its different meanings and definitions, health is a priceless commodity in all human societies. Therefore, the ways in which health care is organised and provided are of fundamental interest, reflecting some of the most basic values at both a societal and an institutional level. Nursing care is a vital aspect of health care provision. Through exploring its allocation and rationing decisions, we can expect to understand several values and priorities set by society and its institutions. We shall first discuss these issues from a more general, societal perspective, and we shall then focus on the institutional level from an organizational perspective.

5.2.1 Nursing care as a reflection of society's values

Modern societies are founded on ethical concepts, such as autonomy, liberty, equality and justice. At a theoretical level, these concepts are eminent in every aspect of health care provision and, as a profession, nursing has always embraced these ideals within its holistic approach. However, real world challenges often necessitate the compromising of guiding principles and values. If we have a principle or a value that we consider to be good, then evil is to be defined as the lack of this principle or value, the failure to meet it. In his influential work *Against Ethics*, John Caputo states that, as a society we are not "beyond" Good and Evil, but stuck between them, being unable to get as far as either one [23, p. 33]. We have too many competing ethical concepts – autonomy vs. justice; public morality vs. freedom of expression; individual freedom vs. the good of all – so many candidates for guiding ethical principles, that no one can agree on their relative importance. Therefore, when it comes to society's goals in the real world, a lowering of expectations seems as the natural state of affairs. Practical ethics is not about the pursuit of unattainable ideals, but the achieving of a satisfactory balance between them. This is evident in nursing care, within the context of limited resources.

Nursing ethics can be seen as a reflection of society's ideal principles. Theoretically, nurses should always act in the best interests of their individual patients. They should respect their autonomous choices, benefit them without inducing any harm, and provide just care, according to each one's needs. In the real world, many different and competing considerations come into play. Neither autonomy nor beneficence or justice are overarching principles. Idealistic nursing ethics is potentially necessarily reduced to situationism. The context of nursing care is different every time; there are different patients with different needs, different nursing professionals with different abilities, and different kinds and amounts of resources. Rationing of these resources is a matter of individual choices, which aim to the best possible and reasonable care. But this cannot be objectively defined. For instance, adequate patient surveillance is a core nursing action to prevent complications – but what does "adequate" mean for each individual patient, given that the nurse's time is limited and that other patients need surveillance too? This is a matter of scientific evidence and professional opinion, but no certainty as to the fairest allocation or even rationing currently exists. Thus, justice and injustice become situational. The problem of missed care constitutes a manifestation of situational injustice.

The same can be said about any kind of social injustices, and this pursuit lies in the core of the concept of *equity*. Equity is different than the similar term of *equality*. Equality is typically defined as treating everyone the same and giving everyone access to the same opportunities. In contrast, equity involves trying to understand and give people what they need, which is not the same for all. Equality aims to promote fairness and justice, but it can only work if everyone starts from the same place and needs the same things; equity refers to the issue of different starting points and different needs, and aims to compensate for these differences [16]. Therefore, to achieve equity, policies and procedures may result in an unequal distribution of resources. In his seminal *Theory of Justice*, John Rawls advocates

this view with his *difference principle* of justice, which holds that inequalities in the distribution of goods are permissible only if they benefit the least well-off members of society [24, p.266]. There are injustices in health by social class, due to different educational levels and subsequent health literacy, as well as different access to health care resources, from both a geographical and an economical point of view. Therefore, people with greater clinical needs, regardless of background or even ability to pay, should have more access to care and treatment than those with lesser needs – that is, unequal access for unequal need [25].

Health care systems, institutions and professions are societal structures. Among other things, they should strive to achieve greater justice and equity, as expected by societies and manifested in their scopes of practice, however imperfect the outcome may be. Systems' organisational structure constitutes an important aspect of this effort. As noted above, there is a clear distinction between rationing of the nursing care at the bedside level and rationing of the nursing resource per se at the organizational level [10]. However, this distinction does not mean that these two levels of rationing are not intertwined. It is natural to expect that health systems' organizational structure should have important implications, both for the nursing profession as a societal organization, and for the daily individual decisions that nurses make regarding resources distribution, as discussed below.

5.2.2 The organisational basis for nursing care resource allocation and rationing

As noted above, *rationing* should be differentiated from resource *allocation*. Rationing has a negative meaning, in the sense that it results in exclusion from resources, or less than optimal benefits for some potential resource recipients [10]. Also, rationing at the organizational level, such as rationing performed by policymakers, should be differentiated from rationing at an individual level, such as rationing performed by nurses. In order to fulfil the daily demands of nursing work, nurses are frequently obliged to ration the care they give. This rationing of care is for a variety of reasons – some completely legitimate and supportable, some less so [1]. In any case, patients' needs can be irregular and unpredictable [26] and thus rationing can be necessary even within the most adequate and carefully designed health care systems.

Having this in mind, it needs to be noted that, in many cases, resource allocation and rationing of nursing care, at the organisational level and below, is largely a covert activity [1,10]. There is a definite and constant need to discuss these issues in greater detail and achieve better organisational insight, understanding and coordination, by establishing more direct contacts between policymakers, nurses, other health professionals, as well as nurse educators and researchers. Levels at which healthcare services are rationed and clarity of the rationing criteria/process are important structural considerations in the development of an equitable, appropriate, and ethical healthcare system; notwithstanding the fact that individual nurses' values, attitudes and beliefs determine their behaviours and practices, such as complete care provision or delaying and even eliminating some care duties [27]. In

all its aspects, the procedure and criteria used in rationing decisions are critical as they not only influence people's lives, but also reflect the values that dominate in the society [28]. There are instances where rationing may be an inevitable process, but its negative consequences can be minimized with proper interventions at the structural level of health care systems. Better organisational and institutional rationing can create the framework for better rationing decisions on an individual basis.

As an example, we can briefly refer to the notion of *ethical climate*. Ethical climate is a part of any work environment. It can be described as a sub-climate of the whole organisational climate that refers to the employees' collective perception of what is ethically acceptable within the context of an organisation [29]. It is largely shaped by the organisational structure of any institution, and it exercises influence of varying degrees to all individuals coexisting within the institution. Nurses may work in various institutions, in the community or in hospitals, but they all share the same ethical foundations, as evidenced by common elements in nursing codes of ethics and codes of professional conduct worldwide. For instance, the International Council of Nursing (ICN) code of ethics is frequently revised to be better fitted for the current needs of nurses all around the globe [30]. However, the prevailing ethical climate within their working environment may either facilitate or constrain nurses' work. In the latter case, it may limit the ability for nurses to sustain their moral identity [31,32]. This in turn will reduce their ability to allocate their time and skills in a manner that is consistent with values such as equity and justice, and, consequently, it will result in augmenting the problem of missed care/covert rationing of care, and may lead to discrimination and infringement of patient rights. Various studies confirm this remark, as nurses who perceive a caring ethical climate, or one that is guided by respect of rules, laws, standards and codes of conduct, also report less care omissions (i.e. less covert rationing of care) occurring in their units [33-35]. Therefore, when nurses need to prioritize certain elements of care or certain patients, and leave other elements of care undone or particular patients' needs unmet, they should conform to a highly regulated environment and the necessity to adhere to certain rules and procedures [32,33].

Structure plays an important role, but the essence of any professional organisation or institution lies in its professionals and the way they interact with service users. In the following section, our attention is drawn mainly to the professionals' and the patients' viewpoints on missed care.

5.3 Empirical descriptive ethics perspective

Empirical descriptive ethics literature has increased during the last ten years. Such literature includes many reviews to collect ideas, approaches, topics, concepts, methods used and existing evidence, and it has illustrated the need for empirical investigation of this topic, the circumstances under which this missed nursing care appears, and its preconditions and consequences. This empirical evidence on ethical issues in the area of covert rationing and missed nursing care is gathered from three different perspectives: 1) societal and

organizational levels, 2) professional nursing staff and 3) the patient or service users. In empirical literature, the term prioritisation and priority setting are much used in addition to resource allocation and rationing.

As highlighted below, not all prioritisation is a resource issue but rather the result of deciding that work duties and nursing activities are done in a certain order. However, in terms of prioritisation that is linked to less than optimum care, clear evidence exists that some examples of missed care is not linked to scarce resources or any need for rationing, but is due to poor professional practice leading to poor care or negligence, especially based on age, representing also a form of discrimination, violating human rights.

5.3.1 Priorities in society meet nursing

Priority setting and ethical guidelines for health care provision exists in many countries [21,22,36] and are of ongoing political concern worldwide [37]. In many countries, such guidelines exist overarching the health care services and all professional care providers. In nursing, the question arises whether such visible principles and guidelines exist, and if so, what are they, and is nursing visible in such guidelines or policy papers [22]. Although prioritization in health care has been on the political agenda for many years, prioritization in nursing seems to be obscure in policy documents [22]. For example, the Nordic countries share similar approaches for ensuring equality and justice in access to health care. In Norway, work has also been done to produce nursing sensitive guidelines for priority setting to help nurses in allocation of resources in practice, bedside. According to Tonnessen et al. [22, p. 1397] "the lack of explicit principles in nursing practice is particularly problematic as it may result in, firstly, nurses rationing care without recognizing that they are doing so (implying lack of careful analysis and consideration of the "bigger picture") and actual impacts on patients. Secondly, the situation is problematic, as the burden of morally difficult rationing decisions falls directly on individual nurses without any responsibility or accountability resting at the door of the managers and decision makers who allocate the nursing resource to the particular clinical ward/unit.

The need for standards is clear, and the role of nurse leaders and managers in developing, setting and making the standards visible is evident. Prioritization takes place every day, and research shows how difficult it is to ensure a minimum standard of nursing care and provide for fundamental needs if prioritization remains implicit [22]. Therefore, priority setting, not least from the explicit guiding point of view is very important. The articulation of nursing priorities can start with nursing management explicitly describing nursing needs and consequences of provision of care according to setting, needs and context. It is especially important for health care policymakers to consider making explicit their reasoning behind the prioritization of nursing and care in response to patients' fundamental care needs.

Prioritization of nursing interventions/ nursing care in a particular context may be an example of effective organisation of clinical practice, or it may be an example of care rationing – overt or covert rationing, and/or required rationing due to limited resources, or rationing by default due to poor clinical competence, leadership or commitment. It is necessary that both realities (effective organisation of clinical practice or care rationing) and their fundamental distinctions, are recognised, identified, described and understood. If these kinds of distinctions are not recognised and explicitly addressed we are in grave danger of confused thinking and ultimately confused practice, policy, education and guidance.

Nurses at all levels in health care organisations set priorities on a daily basis [11] when nursing patients. However, as suggested above we need to clarify the difference between prioritising in terms of a list of duties the nurses plan to complete in sequence (one after another because nurses cannot do all at the one time) and prioritising of scarce resources – i.e. some patients will not get the nursing care they need. Nurses do both types of prioritisations. With the former, nurses plan the flow of their daily work. However, with the latter that is not necessarily the case. Prioritisation in terms of effective organisation of clinical practice means the nurse chooses to do something (A) instead of something else (B), at a particular time. When a nurse chooses one (A or B), prioritising the need for either A or B, the choice may or may not cause any problem for the patient. For example, if all the work is done eventually (i.e. both A and B get done), there may be no problems at all, or any problems that arise from slight delays to care may not be significant. More significant problems arise in situations where the nursing work force does not have the capacity to provide effective and safe care appropriate to patient need, based on a skilled clinical (as different from a financial) assessment [4].

Missed care can be considered as an outcome of 'prioritization-as-rationing' (either covert or overt rationing, necessary or unnecessary rationing). 'Prioritisation – as – rationing' can be the consequence of inadequate staffing, skill mix, competence and unclear care processes [38]. However, there is a need to distinguish missed care resulting from rationing, i.e. due to the limited resources (let's call this necessary rationing), from other type of missed nursing care resulting from unnecessary rationing/ poor practice/poor clinical leadership. An example of the latter type of missed care may be negligence that can happen both in higher level decision-making and/or at the bedside. Missed care-as-negligence, occurring at the society level was illustrated in recent literature. Hopkins Walsh and Dillard-Wright [39] introduced the concept of structural missingness, where a group of people or an entire section of a population do not have access, or will not be able to access the services, although the need has been recognised. Structural missingness can also be connected to fundamental human rights.

At the bedside level some nursing contexts are very well resourced and there is little need to prioritise in terms of deciding to exclude some patients from receiving nursing care or time. However in some care contexts that are relatively well resourced, but perhaps not well led, it has been found that if nurses have any spare time they do not use that time for patient care [40]. Nursing interventions such as responding to patients' needs for counselling, education and emotional and psychological support to patient or family have frequently been left undone or missed [e.g. 41].

5.3.2 Priorities in the delivery of nursing care

Research shows how nurses at the bedside, due to an inadequate nursing resource to meet patient needs, are frequently forced to prioritize, deciding which nursing services and interventions to provide and which to leave out [e.g. 2, 42]. Furthermore, the evidence also indicates that nurses experience such prioritization (i.e. the prioritization of scarce resources) as difficult choices, and some priorities seem to infringe on fundamental values of nursing [43,44]. Suhonen et al. [11] describe prioritization in nursing as complex decisions made by different professionals, in diverse positions, on several different levels, in all parts of a health care organisation. Nurses set priorities at the bedside, on the ward and at the organisational and society levels. These decisions concern which patients should receive nursing care, what resources are allocated to care services and how care is delivered [11].

Prioritization of scarce resources such as nursing time or skills has existed historically in nursing care. A review by Suhonen and colleagues [11] revealed that nurses set these priorities in nursing care based on a number of different, both the explicit and implicit criteria. These criteria originates from care guidelines, professional code of conduct and similar. However, such criteria seem not to be consistently used by nurse professionals. Firstly, nurses have been found to prioritise based on patient groups. For example patients with acute conditions were prioritised compared to those with chronic health problems and conditions, patients who underwent on surgical operations were prioritised compared to patients with chronic wounds [e.g. 45,46]. Secondly, nurses prioritised according to individual patients' ill-health situation. Individuals with acute issues were prioritised over individuals with long-term care needs. Thirdly, the severity of a patient's condition including vital signs and patients who were deemed to be at high risk were prioritised over others [e.g. 29,47]. Fourthly, the literature also revealed prioritising younger individuals over older individuals. Examples of prioritisation based on age have also been found, and may be appropriate when benefits and quality of life are considered to large extent [46] and a shared, mutual understanding exists about objectives of care and quality of life in the end of life. However, ideas of ageism have also been found to be present and would mean discrimination by age without expressed reasons and justifications [e.g. 46]. Finally, priorities were set based on expected benefits for the patients.

5.3.3 Professional ethics - Professional roles, responsibilities, and role conflicts

Nurses are aware of professional standards, such as ethical codes (such as ICN 2012) [48] and human rights and patients' rights [17] and the aim for provision of care accordingly. According to Tonnessen and colleagues [4, citing WHO [17]], "human rights entail the right to a universal minimum standard of health and healthcare, including a minimum standard of nursing care". Common understanding and large awareness of such ethical guidelines have a central role in nursing education and nursing practice. Thus, being taught to make decisions to leave some necessary nursing activities undone challenges nurses' ethical decision-making, skills, ethical knowledge and their roles and responsibilities.

Nurses' roles and responsibilities should be considered within the discussion of prioritisation, rationing and missed care in clinical nursing care. A wealth of empirical studies has provided an opportunity to begin the discussion about minimum standards in nursing care [4], safe staffing [49] and similar issues. This discussion together with discussion of missed care is necessary, whether or not such standards need to be defined, on what basis such standards can be defined and what is the responsibility of nurses at bedside. This leads us to think about the quality of nursing care, the fundamental needs, and nursing care needs of individual patients, comprehensive care and professionals' competence. Efforts to find the appropriate standard for staffing in various clinical practice contexts have been the focus in different European countries [1], especially during the RANCARE COST Action. However, it is difficult to determine such standards in units and organisations as patients' needs vary. Nursing care, within the missed care context, has been measured with nursing/ nurses' tasks [e.g. 50], which may also be different from the actual understanding and definitions of comprehensive nursing care. This may raise further questions of professional ethics.

Rationing (due to limited nursing resource) and resulting missed care have caused concerns for nurses. In empirical studies, it has been found that nurses face moral challenges and their decisions may jeopardize professional values [51], leading to role conflict, feelings of guilt, distress and difficulty in fulfilling a morally acceptable role [28,32,45]. Especially, decisions to omit or delay care can cause significant moral distress to the nurses involved [50,52]. As moral distress and other consequences have been found to be reasons for nurses leaving the profession this is a serious concern for the profession, organisation, and especially those in leadership roles.

Can professional nurses be considered as responsible for the consequences of missed nursing care, covertly rationed care and omissions? Kearns [53] argues that 'ought' implies 'can'. He notes that "ethically speaking, it is generally accepted that if a person has a moral obligation to do something, s/he needs to have the capacity to do it. If a person does not have the capacity to fulfil a moral obligation, then s/he cannot be held responsible for failing to do so", (p1). Therefore, it is necessary to differentiate the situation where scarce resources lead to missed care or rationing, and when other causes of missed care are relevant.

5.3 Missed nursing care from the patient perspective

Missed nursing care has largely been considered as professional nursing issues, not being able to meet the assessed care needs of patients and consequences from such situations within the context of scarce resources. However, as important as nurse professionals' views is the approach and analysis from the patients' point of views - whether the care is comprehensive based on assessment and corresponds to the needs of individual patients [54,55]. More serious concern has been raised about missed care as patient outcome, from the patient's point of view. For example, patient safety and quality of care have been found to be significantly affected by the incidence of missed care [56].

The concepts of missed care, unfinished care and care left undone are relevant to patients, clients or users of health care as well. However, difficulties in defining what nursing care should include exist. Missed care has been regarded as an error of omission, meaning failure to do the right thing, which potentially leads to adverse outcomes to patients, impacting the quality of care negatively [54,57,58]. The question appears, do patients witness missed care through negative outcomes or can they have a role in determining the care based on needs assessment or other ways. There is also a growing evidence that incidents of care left undone or missed care is associated with poorer quality of care, patient safety issues and increased patient morbidity and 30 day mortality [3,8,59,60] raising strong ethical issues from both the patients' and nurses' point of views, and violation of patients' or human rights [17]. Whilst it is difficult to capture what is missing, plenty of literature exists, for example, about reported unmet care needs [55], (dis)satisfaction [58,61,62], and complaints, to approach and frame the possibly missed care. However, literature is very limited, especially scientific empirical evidence on missed care from the patients' point of views [54], ethical issues within the priority setting [11] or unmet care needs [55].

Raising the perspective of the patients, discussion about missed care is necessary for many reasons. Today, patients are recognized as partners in health care and as experts on their situation, working alongside professionals, with their own rights as well as responsibilities [63]. This view is associated with the empowerment philosophy to health, which aims to increase patient autonomy and freedom of choice, encouraging patients to oversee their own health values, needs and goals [64,65]. Furthermore, as pointed out earlier in this chapter, evidence exists on the rationing and priority setting in health care [10,11,38] leading to possible situation where patient outcomes are not necessarily all positive. Concerns of missed care have been pointed out especially in the care settings for older people [55]. Several official reports have shown many shortcomings in nursing care of older people including poor quality of care [66,67], poor communication and leadership [67], lack of dignity [66,68] and responding to the fundamental care needs [11,55]. However, there is a lack of interventions to intervene such circumstances. For example, nurse to patient ratios

have been legislated (in Finland), but such legislation does not prevent negligence. Missed fundamental care was actualized in reports of unmet care needs of older people by themselves, their family members, close ones and also professionals [55,66–68]. Finally, some evidence also suggests that elder abuse in the form of neglect or negligence in care settings [11,55] exists.

Studies on different types of negligence focus on several concepts, such as maltreatment, mistreatment, abuse and neglect reflecting age discrimination [69] violating equality, justice and fundamental human rights [17]. Such actions are due and present based on both the omissions and commissions of nursing care [70]. Yon and colleagues [71]-in their systematic review and meta-analysis of recent studies on elder abuse, based on self-report by older adults, suggest that the rates of abuse are much higher in institutions than in community settings [71]. According to Clarke and Pierson [72, p. 632], in general, "neglect is thought of as including the refusal or failure of a caregiver to fulfil one's obligations or duties to an older person, including providing any food, clothing, medicine, shelter, supervision, and medical care and services that a prudent person would deem essential for the well-being of another." This type of missed care is not due to rationing and available resources. As missed care may be unintentional, due to some circumstances or in some situations, the most serious type, negligence usually is not.

Conclusions

Discussion of missed care/care left undone/covert rationing of care begins at the societal level, continuing at the organizational and professional levels, encompassing patients' points of view, and culminating once again in the societal level. The emerging issues and questions are all intertwined, but it is important to lay emphasis on the link between patients and society in particular, as it is largely overlooked. As health care service users, patients represent society. Health care systems, nurses and other health care professionals represent society's commitment to safe and effective care for all, according to their needs. If patients are not satisfied with the care they receive they can blame individual professionals or health organizations, express their concerns or make negligence claims, but, in essence, their claims go against society at large – and the imbalance between societal expectations and the resources allocated to meet these expectations. It is true that not every aspect of missed care can be linked to limited resources, and that individual professionals may ration their time and expertise in an inconsistent, unfair, or negligent manner. However, this should not blind us to the fact that these professionals are also part of the wider system, and that bedside decision making, despite individual differences, also reflects society's values and the ways in which these values are applied within ever changing health care services. In our effort to provide the best possible care, the ethical dimensions of missed care should constantly be explored at every level, and especially from the patients' perspective. Throughout this exploration, which this entire book is all about, it is expected that clear messages can emerge, aiming to improve the quality of nursing care,

ameliorate health care services, ease nursing professionals' moral distress, and renew patients' and society's confidence in health care systems in terms of justice, equity and respect.

References:

- Scott PA, Suhonen R, Leino-Kilpi H, Schwanda M, Halvorsen K, Tonnessen S, Christiansen K, Harvey C, Habermann M, Hjaltadóttir I, Papastavrou E. Missed care, care left undone, covert rationing of care and allocation of the nursing resource through an ethics lens. 2020b. RANCARE Consortium COST- CA15208: <u>https://cyna.org/wp-content/uploads/2020/06/Briefing-paper-Missed-care.ASCOTT.pdf</u> (accessed 4 Jan 2021)
- Jones T, Hamilton P, Murry N. Unfinished nursing care, missed care, and implicitly rationed care: State of the science review. Int J Nurs Stud. 2015; 52 (6):1121–1137. doi: 10.1016/j.ijnurstu.2015.02.012
- Ball JE, Bruyneel L, Aiken LH, Sermeus W, Sloane DM, Rafferty AM, ... Griffiths P. (2018). Post-operative mortality, missed care and nurse staffing in nine countries: A cross-sectional study. Int J Nurs Stud. 2018; 78:10–15. doi: 10.1016/j.ijnurstu.2017.08.004
- 4. Tønnessen S, Scott A, Nortvedt P. Safe and competent nursing care: An argument for a minimum standard? Nurs Ethics. 2020;27(6):1396–1407.
- 5. Nortvedt P. Clinical sensitivity: the inseparability of ethical perceptiveness and clinical knowledge. Sch Inq Nurs Pract. 2001 Spring; 15(1):25–43; discussion 45-8.
- 6. Scott PA. Nursing and the ethical dimension of practice In: Scott PA. (ed) Key concepts and issues in nursing ethics. Cham: Springer; 2017, pp. 1–13.
- Eurostat 2020. Healthcare personnel statistics nursing and caring professionals. <u>https://ec.europa.eu/eurostat/statistics-explained/index.php/</u> <u>Healthcare personnel statistics - nursing and caring professionals (accessed 4 Jan</u> 2021)
- Aiken LH, Sloane DM, Bruyneel L, Van den Heede K, Griffiths P, Busse R, Diomidous M, Kinnunen J, Kózka M, Lesaffre E, McHugh MD, Moreno-Casbas MT, Rafferty AM, Schwendimann R, Scott PA, Tishelman C, van Achterberg T, Sermeus W; RN4CAST consortium. Nurse staffing and education and hospital mortality in nine European countries: a retrospective observational study. Lancet. 2014;383(9931):1824–30. doi: 10.1016/S0140-6736(13)62631-8
- 9. Lee IC, Chang CS, Du PL. Do healthier lifestyles lead to less utilization of healthcare resources? BMC Health Serv Res. 2017;17(1):243. doi: 10.1186/s12913-017-2185-4
- Scott PA, Harvey C, Felzmann H, Suhonen R, Habermann M, Halvorsen K, Christiansen K, Toffoli L, Papastavrou E. Resource allocation and rationing in nursing care: A discussion paper. Nurs Ethics. 2019;26(5):1528–1539. doi: 10.1177/0969733018759831
- 11. Suhonen R, Stolt M, Habermann M, Hjaltadottir I, Vryonides S, Tonnesen S, Halvorsen K, Harvey C, Toffoli L, Scott A. Ethical elements in priority setting in nursing care A scoping review. Int J Nurs Stud. 2018;88:25–42. doi: 0.1016/j.ijnurstu.2018.08.006
- 12. Suhonen R, Scott PA. Missed care A need for careful ethical discussion. Editorial. Nurs Ethics. 2018;25(5):549–51. doi:10.1177/0969733018790837

- Evripidou M, Charalambous A, Merkouris A, Papastavrou E. Implementation of a training program to increase knowledge, improve attitudes and reduce nursing care omissions towards patients with dementia in hospital settings: a mixed-method study protocol. BMJ Open. 2019;9(7):e030459. doi: 10.1136/bmjopen-2019-030459
- 14. Scott PA, Suhonen R, Kirwan M. Editorial: Missed care, care left undone: Organisation ethics and the appropriate use of the nursing resource. Nurs Philos. 2020a;21(1):e12288. doi: 10.1111/nup.12288.
- Igoumenidis M, Kiekkas P, Papastavrou E. The gap between macroeconomic and microeconomic health resources allocation decisions: The case of nurses. Nurs Philos. 2020;21(1):e12283. doi: 10.1111/nup.12283.
- Papastavrou E, Igoumenidis M, Lemonidou C. Equality as an ethical concept within the context of nursing care rationing. Nurs Philos. 2020;21(1):e12284. doi: 10.1111/nup.12284.
- 17. WHO 2017. Human rights and health. <u>https://www.who.int/news-room/fact-sheets/detail/human-rights-and-health</u> (accessed 4 Jan 2021)
- 18. OECD. "Health expenditure in relation to GDP", in Health at a Glance 2019: OECD Indicators. Paris: OECD Publishing; 2019. DOI: https://doi.org/10.1787/592ed0e4-en
- 19. Daniels N. Just Health Care. Studies in Philosophy and Health Policy. Cambridge University Press; 1985.
- 20. Phelan A, McCarthy S, Adams E. (2018). Examining the context of community nursing in Ireland and the impact of missed care. Br J Community Nurs. 2018;23(1):34–41. doi: 10.12968/bjcn.2018.23.1.34.
- Hofmann B. Priority setting in health care: trends and models from Scandinavian experiences. Med Health Care and Philos. 2013;16(3):349–56. doi: 10.1007/s11019-012-9414-8
- Tønnessen S, Christiansen K, Hjaltadóttir I, Leino-Kilpi H, Scott A, Suhonen R, Öhlen J, Halvorsen K. Visibility of nursing in policy documents related to health care priorities. J Nurs Manag. 2020;28(8):2081–90. doi: 10.1111/jonm.12977
- 23. Caputo J. Against Ethics. Bloomington and Indianapolis: Indiana University Press; 1993.
- 24. Rawls J. A Theory of Justice. Cambridge, MA: Belknap Press of Harvard University Press; 1971.
- 25. Raine R, Or Z, Prady S, Bevan G. Evaluating health-care equity. In Raine, R., Fitzpatrick, R., Barratt, H., Bevan, G., Black, N., Boaden, R., et al. Challenges, solutions and future directions in the evaluation of service innovations in health care and public health. Health Services and Delivery Research 2016;4(16):69-84. doi:10.3310/hsdr04160-69
- 26. Arrow K. Uncertainty and the Welfare Economics of Medical Care. Am Econ Rev. 1963;53(5):941–73.
- 27. Kalisch BJ, Landstrom GL, Hinshaw AS. Missed nursing care: a concept analysis. J Adv Nurs. 2009;65:1509–17. doi: 10.1111/j.1365-2648.2009.05027.x
- 28. Rooddehghan Z, Yekta ZP, Nasrabadi AN. Ethics of rationing of nursing care. Nurs Ethics. 2018;25(5):591–600. doi: 10.1177/0969733016664973.
- 29. Malloy DC, Hadjistavropoulos T, McCarthy EF, Evans RJ, Zakus DH, Park I, Lee Y, Williams J. Culture and organizational climate: nurses' insights into their relationship with physicians. Nurs Ethics. 2009;16(6):719–33. doi:10.1177/0969733009342636
- 30. Stievano A, Tschudin V. The ICN code of ethics for nurses: a time for revision. Int Nurs Rev. 2019;66(2):154–6. doi: 10.1111/inr.12525

- Vryonides S, Papastavrou E, Charalambous A, Andreou P, Eleftheriou C, Merkouris A. Ethical climate and missed nursing care in cancer care units. Nurs Ethics. 2018;25(6):707–23. doi: 10.1177/0969733016664979
- 32. Vryonides S, Papastavrou E, Charalambous A, Andreou P, Merkouris A. The ethical dimension of nursing care rationing: A thematic synthesis of qualitative studies. Nurs Ethics. 2015;22(8):881–900. doi: 10.1177/0969733014551377.
- Papastavrou E, Acaroglu R, Sendir M, et al. The relationship between individualized care and the practice environment: an international study. Int J Nurs Stud. 2015;52(1):121– 33. doi:10.1016/j.ijnurstu.2014.05.008
- Papastavrou E, Andreou P, Tsangari H, Schubert M, De Geest S. Rationing of Nursing Care Within Professional Environmental Constraints: A Correlational Study. Clin Nurs Res. 2014;23(3):314–35. doi:10.1177/1054773812469543
- 35. Suhonen R, Stolt M, Gustafsson ML, Katajisto J, Charalambous A. The associations among the ethical climate, the professional practice environment and individualized care in care settings for older people. J Adv Nurs. 2014;70(6):1356–68. doi:10.1111/jan.12297
- 36. Norwegian Ministry of health and Care services (2015). Principles for priority setting in health care Summary of a white paper on priority setting in the Norwegian health care sector. Meld. St. 34 (2015-2016).
- 37. World Health Organization. Making fair choices on the path to universal health coverage. Final report of the WHO Consultative Group on Equity and Universal Health Coverage ISBN: 978 92 4 150715 8. / 07.09.2020; 2014. <u>https://www.who.int/choice/documents/making_fair_choices/en/</u> (accessed 4 Jan 2021)
- 38. Schubert M, Glass TR, Clarke SP, et al. Rationing of nursing care and its relationship to patient outcomes: the Swiss extension of the International Hospital Outcomes Study. Int J Qual Health Care. 2008; 20(4):227–37. doi: 10.1093/intqhc/mzn017
- 39. Hopkins Walsh J, Dillard-Wright J. The case for "structural missigness"; A critical discourse of missed care. Nurs Philos. 2020;21(1):e12279. doi: 10.1111/nup.12279.
- Milton-Wildey K, O'Brien L, 2010. Care of acutely ill older patients in hospital: clinical decision-making. J Clin Nurs. 2010;19(9–10):1252–60. doil: 10.1111/j.1365-2702.2009.03141.x
- Zeleníková R, Gurková E, Friganovic A, Uchmanowicz I, Jarošová D, Žiaková K, Plevová I, Papastavrou E. Unfinished nursing care in four central European countries. J Nurs Manag. 2020;28(8):1888–1900. doi: 10.1111/jonm.12896
- Ausserhofer D, Zander B, Busse R, Schubert M, De Geest S, Rafferty AM, ... Schwendimann R. Prevalence, patterns and predictors of nursing care left undone in European hospitals: Results from the multicountry cross-sectional RN4CAST study. BMJ Qual Saf. 2014; 23(2):126–35.
- 43. Halvorsen K. The ethics of bedside priorities in intensive care: Value choices and considerations. A qualitative study. Doctoral thesis. Oslo, Norway: Unipub; 2009.
- 44. Tønnessen S. The Challenge To Provide Sound Services and Diligent Care a qualitative study of nurses prioritization and patients experiences of the home nursing service. Doctoral thesis. Oslo, Norway: Unipub; 2011.
- 45. Bentzen G, Harsvik A, Brinchmann BS, "Values that vanish into thin air": nurses' experience of ethical values in their daily work. Nurs. Res. Pract. 2013: 939153. doi: 10.1155/2013/939153.

- 46. Skirbekk H, Nortvedt P. Inadequate treatment for elderly patients: professional norms and tight budgets could cause "ageism" in hospitals. Health Care Anal. 2014;22(2):192–201. doi: 10.1007/s10728-012-0207-2.
- Barra M, Broqvist M, Gustavsson E, Henriksson M, Juth N, Sandman L, Solberg CT. Severity as a Priority Setting Criterion: Setting a Challenging Research Agenda. Health Care Anal. 2020;28(1):25–44. doi: 10.1007/s10728-019-00371-z
- 48. International Council of Nurses. Codes of ethics for nurses. Geneva: ICN, 2012, <u>https://www.icn.ch/sites/default/files/inline-</u> <u>files/2012_ICN_Codeofethicsfornurses_%20eng.pdf</u> (accessed 4 Jan 2021)
- 49. Van den Heede K, Cornelis J, Bouckaert N, Bruyneel L, Van de Voorde C, Sermeus W. Safe nurse staffing policies for hospitals in England, Ireland, California, Victoria and Queensland: A discussion paper. Health Policy. 2020;124(10):1064–73. doi: 10.1016/j.healthpol.2020.08.003.
- 50. Kalisch BJ. Missed nursing care: a qualitative study. J Nurs Care Qual. 2006; 21(4): 306–15.
- 51. Harvey C, Thompson S, Otis E, Willis E. Nurses' views on workload, care rationing and work environments. J Nurs Manag. 2020;28(4):912–8. doi: 10.1111/jonm.13019.
- 52. Choe K, Kang Y, Park Y. Moral distress in critical care nurses: a phenomenological study. J. Adv. Nurs. 2015;71(7):1684–93. doi: 10.1111/jan.12638
- 53. Kearns AJ. "Ought implies can" & missed care. Nurs Philos. 2020;21(1):e12272. doi: 10.1111/nup.12272
- 54. Gustafsson N, Leino-Kilpi H, Prga I, Suhonen R, Stolt M. Missed care from the patient's perspective- a scoping review. Patient Prefer Adherence. 2020;14:383–400. doi: https://doi.org/10.2147/PPA.S238024
- 55. Kalánková, Stolt M, Scott A, Papastavrou E, Suhonen R. Unmet care needs of older people: A scoping review. Nurs. Ethics. 2020; doi: 10.1177/0969733020948112
- 56. Kalánková D, Kirwan M, Bartoníčková D, Cubelo F, Žiaková K, Kurucová R. Missed, rationed or unfinished nursing care: A scoping review of patient outcomes. J Nurs Manag. 2020;28(8):1783–97. doi: 10.1111/jonm.12978
- 57. Papastavrou E, Andreou P, Vryonides S. The hidden ethical element of nursing care rationing. Nurs Ethics. 2014;21(5):583–93. doi: 10.1177/0969733013513210.
- 58. Papastavrou E, Andreou P, Tsangari H, et al. Linking patient satisfaction with nursing care: the case of care rationing a correlational study. *BMC Nurs*. 2014;13:26. doi:10.1186/1472-6955-13-26
- 59. Griffiths P, Recio-Saucedo A, Dall'Ora C, Briggs J, Maruotti A, Meredith P, Smith GB, Ball J, Missed Care Study Group. The association between nurse staffing and omissions in nursing care: A systematic review. J Adv Nurs. 2018;74(7):1474-1487. doi: 10.1111/jan.13564
- 60. DoH. Framework for safe nurse staffing and skills mix in general and specialist medical and surgical care settings in adult hospitals in Ireland. Dublin: Department of Health; 2018. <u>https://www.gov.ie/en/publication/2d1198-framework-for-safe-nurse-staffingand-skill-mix-in-general-and-speci/</u> (accessed 14 Jun 2020).
- Schubert M, Clarke S, Glass T, et al. Identifying thresholds for relationships between impacts of rationing of nursing care and nurse- and patients-reported outcomes on Swiss hospitals: A correlational study. Int J Nurs Stud. 2009;46(7):884–893. doi:10.1016/j.inurstu.2008.10.008

- 62. Lake E, Germack H, Viscardi K. (2016). Missed nursing care is linked to patient satisfaction: a cross-sectional study of US hospitals. *BMJ Qual Saf*. 2016;25(7):535–43. doi: 10.1136/bmjqs-2015-003961
- 63. Coulter A. Paternalism or partnership? Patients have grown up- and there's no going back. *Br Med J.* 1999;319:719–20. doi:10.1136/bmj.319.7212.719
- 64. Feste C, Anderson RM. Empowerment: from philosophy to practice. *Patient Educ Counsel*. 1995;26:139–44. doi:10.1016/0738-3991(95)00730-N
- 65. Orique S, Patty C, Sandidge A, et al. Quantifying missed nursing care using the hospital consumer assessment of healthcare providers and systems (HCAHPS) survey. *J Nurs Admin*. 2017;47(12):616–62. doi:10.1097/NNA.00000000000556
- 66. Care Quality Commission 2011. Dignity and nutrition inspection programme: National overview. <u>https://www.cqc.org.uk/files/dignity-nutrition-inspection-programme-national-overview</u>. (accessed 4 Jan 2021)
- 67. Francis report. 2013. <u>https://www.gov.uk/government/publications/report-of-the-mid-staffordshire-nhs-foundation-trust-public-inquiry (accessed 4 Jan 2021)</u>
- 68. Parliamentary and Health Service Ombudsman 2017. Dying without dignity. Investigations by the Parliamentary and Health Service Ombudsman into complaints about end of life care. <u>https://www.ombudsman.org.uk/sites/default/files/Dying_without_dignity.pdf</u>

(accessed 4 Jan 2021)

- 69. Slettebø A, Kirkevold M, Andersen B, et al., 'Clinical prioritizations and contextual constraints in nursing homes-a qualitative study. Scand J Caring Sci. 2010;24(3):533–40. doi: 10.1111/j.1471-6712.2009.00745.x.
- 70. Hirst SP. Defining resident abuse within the culture of long-term care institutions. Clin Nurs Res. 2002;11(3):267–84. doi: 10.1177/10573802011003004
- 71. Yon Y, Mikton CR, Gassoumis ZD, Wilber KH. Elder abuse prevalence in community settings: a systematic review and meta-analysis. Lancet Glob Health. 2017;5(2):e147-e156. https://www.ncbi.nlm.nih.gov/pubmed/28104184
- 72. Clarke ME, Pierson W. Management of elder abuse in the emergency department. Emerg Med Clin North Am. 1999;17(3):631–644. doi: 10.1016/s0733-8627(05)70087-0.