The ethical dimension of nursing care rationing as it is revealed from existing qualitative research studies

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Nursing as a science is based on solid ethical foundations regarding, humanity, society, life, sickness and health.

The nursing activities are guided by:

- Humanitarian values,
- The commitment to provide a compassionate, comprehensive, individualized and humanitarian care to patients with respect and justice and without any discrimination or restrictions (ICN 2012; ANA 2012),
- And the effort to maintain the safety and quality of care (European Commission, 2007)

HOWEVER....
When nursing resources are not sufficient, as for nurses to be able provide all the necessary care to all patients (e.g. inadequate time, poor staffing levels, poor working environment, inappropriate skill mix, etc.), nurses may be forced to

- Delay or omit some nursing activities and give priority to some other nursing activities....
- or even,
- Give priority to some patients and not to some others.

THUS they are forced to ration their attention across patients or across care activities by using their clinical judgment to prioritise assessments and interventions – increasing as such the risk of negative patient outcomes (Schubert et al., 2008).

This phenomenon is called nursing care rationing.
✓ Several definitions of the phenomenon have been given such as:
✓ the withholding of, or failure to carry out necessary nursing tasks, (Schubert et al 2008),

✓ nursing care that has been omitted (either partially or totally) or delayed, (Kalisch et al 2009),

✓ care needs not being met, or not performed (Lucero et al, 2009)

✓ priority setting, (Arvidsson et al, 2010),

✓ care prioritization, (Nortvedt et al 2011, Tønnessen et 2009)

✓ that are due to inadequate nursing resources.
In all these cases care is rationed or missed, or left undone, or remain unfinished and uncompleted or it is given with delay.

- minimize standards
- reduce quality,
- Move care elements to the next shift,
- assign to relatives
- give less priority to some patient categories

Minimise the standards of care OR reduce the level of care Quality

Insufficient resources
(E.g. insufficient time, low level of staffing, poor team work, wrong skill mix, insufficient material resources, low level or incompetent assistive personnel, poor communication and co-ordination, poor working environment)

Some care elements are moved to the next shift

some care elements assigned to relatives

Patient discrimination (e.g. on the grounds of age, perceived severity of situation, etc)

care left undone or missed care, unfinished care or uncompleted, rationed care
care given with delay
However, it is not clear how nurses are experiencing these options (the allocation of care in scarcity) in relation with the ethical dimension of nursing

- at the level of nurses' decision making
- or as a resulting outcome on nurses as health professionals.

In any case it raises ethical concerns and questions

- Is it Influenced by the moral reasoning of nurses?
- Does it cause moral conflicts with their personal and professional values?
- Does it leads to moral discomfort and moral distress?
The aim of this presentation is to present the results of a systematic review and a thematic synthesis of qualitative research studies that have revealed an ethical dimension of nursing care rationing.

The Objectives of this thematic synthesis were to find out the deeper moral meaning of nursing care rationing (if any) by synthesizing studies that relate this phenomenon with the ethical perspectives of nursing.
Methodology – literature search

The literature search, study selection and extraction process were based on the guidelines suggested by the Joanna Briggs Institute Reviewer’s manual.

✓ In 9 Databases (PubMed, Embase, Cinahl, Academic Search Complete, Web of Science, PsycInfo, PsycArticles, ScienceDirect and ProQuest Platform Databases),

✓ Without considering publishing dates
• Intended to find published studies AND ALSO non-published studies (Grey literature from Open Archives gr, NDLTD - network digital library of theses and dissertations)
  • dealing with any ethical aspects of nursing care rationing, as this was apparent from their title, abstract, or stated research aims

• Additionally, all articles obtained as full text, were screened for citations of relevant studies.

• Key words:
  • ethical dilemma/ ethical climate/ ethical environment/ moral conflict/ moral distress/ethical decision making/ ethical reasoning
  • AND nursing/nursing care/nurses
  • AND rationing/ missed care/ omitted care/ priorities/ priority setting/ delayed care/ resource allocation

• In various Combinations
Studies were included if they met the following criteria:

(i) Qualitative studies relevant with the research questions,

(ii) Aim explicitly addressing rationing,

(iii) They used rationing as the main variable and related it by any means with ethical aspects of nursing care

(iv) sample included nurses at any level of duty and experience,

(v) any acute-care or chronic-care clinical setting or community setting,

(vi) Articles in English and/or Greek language only - due to the proficiency of the researchers in those languages only.
Studies were excluded if

- They **did not clearly examine rationing of** nursing care,

- They were not related in any way **with the ethical** aspects of the phenomenon

- They **focused on health care rationing in general**, including managerial and workforce perspectives
Primary studies were assessed for explicitness and comprehensiveness of reporting in order to avoid drawing unreliable conclusions. BUT we used all studies regardless of their quality.

For this assessing we used the framework of consolidated criteria for comprehensive reporting qualitative research (COREQ)

These are 32 criteria, grouped in three main categories: (i) research team and reflexivity, (ii) study design and (iii) data analysis and reporting
Methodology - synthesis of data

- **Synthesis** of the data from primary studies have been carried out by a method described by (Thomas and Harden, 2008) and called **thematic synthesis**.

- This method has **three stages** that overlapped to some degree and facilitated in part using **an electronic software reviewing system**, 'EPPI-Reviewer 4.
  - **First stage** — **free line-by-line coding**
  - **Second stage** — **construction of descriptive themes**
  - **Third stage** — **Development of analytical themes**
Results - selecting the Studies

2053 Titles
- 1962 excluded
  - 1303 articles with titles irrelevant to the research subject AND
    - 659 article (from titles) as duplicates

91 abstracts
- 72 excluded
  - 33 articles with abstracts irrelevant to the research AND
    - 39 with full text in a language other than English or Greek

19 full text articles
- 11 excluded
  - 6 not meeting the set of inclusion criteria AND
    - 4 articles with text irrelevant to research

8 articles for review

9 articles for review
+ 1 added
  + 1 study with a title relevant to the research subject was found and added after new searches

Figure 1: Flow diagram for identifying and selection of the studies of the review
We decided to use all of them in the synthesis.

The comprehensiveness of reporting varied across studies.

Most of them fulfilled most of the criteria.

### Table 3: Quality assessment of included studies using the COREQ framework of reporting criteria

<table>
<thead>
<tr>
<th>Reporting criteria</th>
<th>No. (%)</th>
<th>Studies reporting each criterion</th>
</tr>
</thead>
<tbody>
<tr>
<td>Characteristics of research team</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Interviewer or facilitator identified</td>
<td>6/9(66.6)</td>
<td>29,46,47,50,79,80</td>
</tr>
<tr>
<td>Credentials</td>
<td>9/9(100.0)</td>
<td>27,29,46,47,50,53,78,79,80</td>
</tr>
<tr>
<td>Occupation</td>
<td>7/9(77.7)</td>
<td>27,29,47,50,53,79,80</td>
</tr>
<tr>
<td>Sex</td>
<td>0/9(00.0)</td>
<td></td>
</tr>
<tr>
<td>Experience and training</td>
<td>5/9(55.5)</td>
<td>27,29,50,53,79</td>
</tr>
<tr>
<td>Relationship with participants</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Relationship established</td>
<td>1/9(11.1)</td>
<td>79,</td>
</tr>
<tr>
<td>Participant knowledge of the interviewer</td>
<td>2/9(22.2)</td>
<td>29,79</td>
</tr>
<tr>
<td>Interviewer characteristics</td>
<td>2/9(22.2)</td>
<td>29,79</td>
</tr>
<tr>
<td>Theoretical framework</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Methodological orientation and theory</td>
<td>9/9(100.0)</td>
<td>27,29,46,47,50,53,78,79,80</td>
</tr>
<tr>
<td>Participant selection</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Sampling</td>
<td>8/9(88.8)</td>
<td>29,46,47,50,53,78,79,80</td>
</tr>
<tr>
<td>Method of approach</td>
<td>4/9(44.4)</td>
<td>29,47,79,80</td>
</tr>
<tr>
<td>Sample size</td>
<td>9/9(100.0)</td>
<td>27,29,46,47,50,53,78,79,80</td>
</tr>
<tr>
<td>Non-participation</td>
<td>3/9(33.3)</td>
<td>29,47,78,</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Reporting criteria</th>
<th>No. (%)</th>
<th>Studies reporting each criterion</th>
</tr>
</thead>
<tbody>
<tr>
<td>Data analysis</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Number of data coders</td>
<td>3/9(33.3)</td>
<td>29,46,78</td>
</tr>
<tr>
<td>Description of the coding tree</td>
<td>0/9(0.0)</td>
<td></td>
</tr>
<tr>
<td>Derivation of themes</td>
<td>6/9(66.6)</td>
<td>29,46,47,78,79,80</td>
</tr>
<tr>
<td>Software</td>
<td>0/9(0.0)</td>
<td></td>
</tr>
<tr>
<td>Participant checking</td>
<td>0/9(0.0)</td>
<td></td>
</tr>
<tr>
<td>Reporting</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Quotations presented</td>
<td>9/9(100.0)</td>
<td>27,29,46,47,50,53,78,79,80</td>
</tr>
<tr>
<td>Data and findings consistent</td>
<td>9/9(100.0)</td>
<td>27,29,46,47,50,53,78,79,80</td>
</tr>
<tr>
<td>Clarity of major themes</td>
<td>9/9(100.0)</td>
<td>27,29,46,47,50,53,78,79,80</td>
</tr>
<tr>
<td>Clarity of minor themes</td>
<td>3/9(33.3)</td>
<td>29,79,80</td>
</tr>
<tr>
<td>Data collection</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Interview guide</td>
<td>6/9(66.6)</td>
<td>27,29,46,47,50,53,</td>
</tr>
<tr>
<td>Repeat interviews</td>
<td>0/9(0.0)</td>
<td></td>
</tr>
<tr>
<td>Audio/visual recording</td>
<td>8/9(88.8)</td>
<td>27,29,46,50,53,78,79,80</td>
</tr>
<tr>
<td>Field notes</td>
<td>2/9(22.2)</td>
<td>79,80</td>
</tr>
</tbody>
</table>
Nine studies involving 167 nurse participants. From the 9 studies nearly all carried out in Norway (7) one in New Zealand and one in Cyprus.

Nurses’ Age varied from 28 to 59 years old, and had 1-35 years of experience. They work in various care units, and working places, ICU, Nursing homes, community, adult care

Mostly semi-structure interviews for data collection and hermeneutic approach to data analysis

<table>
<thead>
<tr>
<th>Study</th>
<th>Sample (n) sampling method</th>
<th>Nurses (Y) Age Range</th>
<th>Working setting</th>
<th>Nurses (Y) Working experience</th>
<th>Data Collection method</th>
<th>Data Analysis</th>
<th>Research Topic</th>
</tr>
</thead>
<tbody>
<tr>
<td>(0)</td>
<td>Physicians (n=21) ICU nurses (n=25)</td>
<td>28-57</td>
<td>ICU</td>
<td>1-26</td>
<td>Participant observation and semi-structured interviews</td>
<td>hermeneutical interpretation</td>
<td>To explore how limited resources influence nursing and medical treatment in intensive care</td>
</tr>
<tr>
<td>Norway*1</td>
<td>Physicians (n=20) nurses (n=25)</td>
<td>26-59</td>
<td>public hospitals and nursing homes</td>
<td>1-34</td>
<td>semi-structured interviews</td>
<td>Hermeneutical and content analysis</td>
<td>To explore how clinicians understand their professional role in clinical prioritizations for older patients</td>
</tr>
<tr>
<td>Norway*2</td>
<td>Physicians (n=20) nurses (n=25)</td>
<td>26-59</td>
<td>public hospitals and nursing homes</td>
<td>1-34</td>
<td>semi-structured interviews</td>
<td>Hermeneutical and content analysis</td>
<td>To explore what kind of criteria, values, and other relevant considerations are important in clinical prioritizations in healthcare services for older patients</td>
</tr>
<tr>
<td>(07)</td>
<td>Physicians (n=21) ICU nurses (n=25)</td>
<td>28-57</td>
<td>ICU</td>
<td>1-26</td>
<td>semi-structured interviews and participant observation</td>
<td>Hermeneutical interpretation</td>
<td>To examine how significant others (e.g. family) may affect the principles of justice in the medical treatment and nursing care of ICU patients</td>
</tr>
<tr>
<td>Norway*1</td>
<td>Nurses (n=17) Purposive</td>
<td>25-55</td>
<td>home-based care</td>
<td>1-35</td>
<td>Semi-structured interviews</td>
<td>Hermeneutical methodology</td>
<td>To investigate nurses’ priority decisions and the provision of home-based nursing care services</td>
</tr>
<tr>
<td>Norway*3</td>
<td>Physicians (n=6) nurses (n=5)</td>
<td>38-59</td>
<td>Nursing Homes</td>
<td>10-34</td>
<td>Semi-structured interviews</td>
<td>Hermeneutical methodology</td>
<td>To describe nurses’ and physicians experiences of prioritization factors in nursing homes</td>
</tr>
</tbody>
</table>

Abbreviations: ICU = intensive care Unit, NR = Not reported, Y = years, n = number, Notes: *1 possibly the same participants were enrolled, *2 Also, *3 Also.
Numbers in bracket above country = number of the study in reference list.
Results of the thematic synthesis

- Synthesis resulted in
  - 35 preliminary themes,
  - 14 descriptive themes and
  - four analytical themes
    - Professional challenges and moral dilemmas,
    - Dominating considerations when allocating resources
    - Perception of a morally ideal role – role conflict
    - Experiences of the ethical effects of rationing.

- Discussion of relationships between the themes revealed a new thematic framework.
Results - presenting analytical themes

1st Analytical theme – Challenges and ethical dilemmas (examples)

• To ensure adequate and comprehensive care, equal access to care, Ethical care.

• Some of the narratives
  • “...the interpersonal concern and care, this is what suffers”
  • “the things that aren’t about life and death, they have to be postponed”
  • “something of a medical nature, we pay attention”
  • “I think they’re not getting the care that they could be getting”
  • “Patients want nurses to talk to them, they need to feel safe”
  • It is unfair treatment, simply because a person is so strong that he may appear threatening…”
  • “patients sometimes have to be sedated a little longer, In order to handle the rest of the unit, something which I consider unethical”
2nd Analytical theme – Dominating considerations when allocating resources (examples)

- Dominating considerations of nurses when allocating scarce resources are related to *time constraints*, the *organizational structure* and *support* from the organization, the *care model*, *professional principles* and *values*, the *status* of *patients* and their *families*.

- **Some of the narratives**
  - ...“I feel that *the responsibility is taken away from us because of too many tasks*” (80). “*They organize the time* – (50). “there are many who want contact, but you can't. You work like a robot” (29).

  - “*I get a working list estimated on time*” (50)“. “*the duty manager said, “Oh you'll just have to manage*” and I just burst into tears” (78). “*it is not up to me to set priorities*,

  - “*the most acute first. I give high priority to medical treatment*” (47). “*We meet physical needs. Medicines, nutrition, purely practical tasks*” (50).

  - “*The ones who complain of course will be given more priority*” (46). “*The nice service user suffers*” (46).
The perception of nurses regarding their role when allocating resources in scarcity is related to the need for holistic, individualized and comprehensive care, the need for care based on equality and justice, the need to act as patients’ advocates, disclaimer of responsibilities in relation to allocating resources.

- **Some of the narratives**
  - “I feel that we do not prioritize social needs” (47). “I don’t prioritize the relational aspect of care” (27).
  - “I’m talking about quality time, where you can see that they enjoy having us there” (50). “It’s more a matter of adapting the job to the individual” (46).
  - “to give priority to those who haven’t been outside” (47). “It should be more like offering almost equal help to those in almost the same situation” (46).
  - “Then there is no one who stand in the breach for these people... ends up at the bottom of the priority list” (27)
  - “the duty manager said” (78) “obliged to keep to the assigned tasks” (50). “it is not up to me to set priorities, it depends on the manager” (29).
The perception of nurses regarding the effects of rationing to them is related to conflicts with professional standards and with the ethical dimension of nursing, moral burden, guilt feelings and moral distress.

Some of the narratives

...“There is so much to do, so you feel behind all the time…” (80).

“….it is difficult to say that I don’t have time to help you. It’s about ethics …” (27).

“you wonder if you did all the things you could have done” (29).

“That does something to you…” (53). “You really feel guilty…” (27). “and I just burst into tears…” (78)

“I think about it all the way home. I haven’t done my job properly and then I worry…” (78).

“I woke up in the middle of the night† because I remembered things that I left undone my mistakes and my inappropriate behavior….” (29).
Summary of key analytical themes, descriptive themes and narratives from participants in primary studies

<table>
<thead>
<tr>
<th>Table 4. Summary of main analytic themes, descriptive themes, and illustrative quotations across studies (N = 9).</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Descriptive themes</strong></td>
</tr>
<tr>
<td>Professional challenges and moral dilemmas</td>
</tr>
<tr>
<td>Challenges in securing adequate and comprehensive care</td>
</tr>
<tr>
<td>(risks for mishaps and neglect)</td>
</tr>
<tr>
<td>Challenges in securing equal access to care</td>
</tr>
<tr>
<td>Time constraints</td>
</tr>
<tr>
<td>Organizational schedule and support (unsupported feeling)</td>
</tr>
<tr>
<td>Model of care</td>
</tr>
<tr>
<td>Professional values and ethical principles</td>
</tr>
<tr>
<td>Patients’ and families’ status and position</td>
</tr>
<tr>
<td>Perception of professional and moral role</td>
</tr>
<tr>
<td>Need for holistic, individualistic, and comprehensive care</td>
</tr>
<tr>
<td>Need for equal care based on fairness and justice</td>
</tr>
<tr>
<td>Patients’ advocacy</td>
</tr>
<tr>
<td>Disclaimer of responsibility in rationing</td>
</tr>
<tr>
<td>Moral strain, feelings of guilt, and moral distress</td>
</tr>
</tbody>
</table>

Italicized quotations are from study participants. Only Quotations from nurses were used for the purpose of this synthesis (number near quotation) — study reference.
Developing an analytical thematic framework

The discussion of researchers in order to determine relationships between themes and subthemes as well as between themes and the judgments, reflections and ideas of researchers.

- revealed a new thematic framework to explain and offer a better understanding of the ethical dimension of nursing care rationing,
- thus extending the findings of the primary studies.
Results

Developing an analytical thematic framework

Securing Adequate and comprehensive care
- Securing Equal access to care
- Securing Ethical care

Model of care
- Professional Values and Ethical principles
- Patients’ and Families status and position
- Organizational schedule and support
- Time constraints

Need for Advocacy to patients
- Holistic, individualistic, comprehensive care
- Equal care based on fairness and justice

Disclaimer of responsibility

Moral conflicts
- Moral strain and distress

Professional challenges and moral dilemmas

Dominating considerations when prioritizing

A morally ideal role
Inability to fulfill moral role

Perception of professional and moral role
Experience of the effects of rationing

Figure 2: Thematic Analytic Schema of the ethical dimension of nursing care rationing.
Discussion

Developing an analytical thematic framework

- As shown in the above figure, nurses, in allocating scarce resources, are faced with certain professional challenges and moral dilemmas which in turn influence their considerations of prioritizing care as well as their perception, regarding their professional and moral role in relation to rationing.

- However, they may perceive their role in two distinct ways.
On one hand, they desire a morally ideal role - wishing to offer to patients holistic, individualized and comprehensive care based on equality, fairness and justice while accepting a responsibility to act as a patient advocate.

Thus, by being faithful to professional ideals and expectations, nurses wish to fulfill their role in the allocation of any resources in an ethical and professional manner, regardless of any other competing considerations.

This ethical approach to care obviously leads to positive patient outcomes and to professional satisfaction for nurses.
On the other hand, nurses may be not able to accept a role in rationing of nursing care, disassociating themselves from such a responsibility.

This may be justified on external factors, such as the dominating considerations, thereby providing various excuses for the nurse.

However, inability to accept such a role may inevitably lead to unfair and unethical distribution of nursing resources or unacceptable practices.
Developing an analytical thematic framework

- This, in turn, will affect their perceptions regarding professional and moral roles, as well as their personal role, within the healthcare context in which they work and in relation to nursing care rationing.

- Thus, if they feel that they are able to secure an appropriate care for their patients, they will provide this care and will feel professionally satisfied.

- Otherwise they will experience the negative consequences that rationing may have on them in relation to the ethical aspects of nursing, expressing moral strain, moral conflicts, or moral distress.
The ethical dimension of nursing care rationing: A thematic synthesis of qualitative studies

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Cyprus University of Technology, Cyprus

Abstract
Background: In the face of scarcity, nurses may inevitably delay or omit some nursing interventions and give priority to others. This increases the risk of adverse patient outcomes and threatens safety, quality, and dignity in care. However, it is not clear if there is an ethical element in nursing care rationing and how nurses experience the phenomenon in its ethical perspective.

Objectives: The purpose was to synthesize studies that relate care rationing with the ethical perspectives of nursing, and find the deeper, moral meaning of this phenomenon.

Research design: A systematic review and thematic synthesis of qualitative studies was used. Searching was based on guidelines suggested by Joana Briggs Institute, while the synthesis has drawn from the methodology described. Primary studies were sought from nine electronic databases and manual searches. The explicitness of reporting was assessed using consolidated criteria for reporting qualitative research. Nine studies involving 167 nurse participants were included. Synthesis resulted in 35 preliminary themes, 14 descriptive themes, and four analytical themes (professional challenges and moral dilemmas, dominating considerations, perception of a moral role, and experiences of the ethical effects of rationing). Discussion of relationships between themes revealed a new thematic framework.

Ethical consideration: Every effort has been taken, for the thoroughness in searching and retrieving the primary studies of this synthesis, and in order for them to be treated accurately, fairly and honestly and without intentional misinterpretations of their findings.

Discussion: Within limitations of scarcity, nurses face moral challenges and their decisions may jeopardize professional values, leading to role conflict, feelings of guilt, distress and difficulty in fulfilling a morally acceptable role. However, more research is needed to support certain relationships.

Conclusions: Related literature is limited. The few studies found highlighted the essence of justice, equality in care and in values when prioritizing care—with little support to the ethical effects of rationing on nurses. Further research on ethical dimension of care rationing may illuminate other important aspects of this phenomenon.

Keywords
Care rationing, ethical perspectives, ethics, nursing values, professional role, thematic synthesis