



Quality of life and ethics: A concept analysis

Lais Fumincelli and Alessandra Mazzo

University of São Paulo at Ribeirão Preto College of Nursing (EERP-USP), Brazil

José Carlos Amado Martins

Nursing School of Coimbra, Portugal

Isabel Amélia Costa Mendes

University of São Paulo at Ribeirão Preto College of Nursing (EERP-USP), Brazil

Abstract

Background: In health, ethics is an essential aspect of practice and care and guarantees a better quality of life for patients and their caregivers.

Objective: To outline a conceptual analysis of quality of life and ethics, identifying attributes, contexts and magnitudes for health.

Method: A qualitative design about quality of life and ethics in health, considering the evolutionary approach in order to analyse the concept. To collect the data, a search was done using the keywords *ethic**, *quality of life* and *health*. After, in total, 152 studies were found, finalizing seven relevant studies for the proposed concept analysis.

Findings and discussion: Of seven studies analysed, their main results were shown by means of antecedents, consequences and attributes of the concepts. The three final attributes that synthesize the concept of quality of life and ethics in health were highlighted: Ethics dilemmas and quality of life; Human ethics and quality of life; and Ethics of care and quality of life. In fact, the attributes and context clearly reveal that ethics and quality of life influence the ability to solve ethical dilemmas, guarantee human ethics in healthcare and impact ethics in healthcare for the production of effective health policies and care that encompasses professional quality of life as well.

Conclusion: The magnitude of ethical knowledge in each professional discipline permits cultivating a solidary attitude and developing the willingness to improve healthcare. The right to access, dignity and respect in care delivery are rooted in behaviours and are spontaneously applied in practice to the extent that they play an ethical role.

Keywords

Concept analysis, ethic, health, quality of life

Introduction

Ethics is an integral aspect of health practice. It affects the capacity to assist the other through critical–reflexive thinking, encompassing values, meanings and decision making.¹ Consequently, it remits to appropriate healthcare actions and a better quality of life for patients, family members and communities. Ethics involves theories, perspectives, principles, concepts of fundamental issues regarding values and meanings of human life.¹

Quality of life can be understood as the values, perspectives, satisfaction, living conditions, accomplishments, functionality, cultural contexts and spirituality.² In healthcare, ethical issues comprise the multiple dimensions of life, involve doing what is correct in terms of respect, dignity, principles and moral values.³ When they deliver ethical healthcare, the professionals can grant the patients appropriate therapeutic choices against the background of the realities experienced and thus guarantee a better quality of life.

In this context, quality of life in the health presented a more specific approach covering the individual satisfaction or well-being in front of the health condition, disease or treatment. Specially, also emphasized the concern of policy makers, researchers and health professionals to align the health care priorities and values of patients and society.⁴ In this search to understand the perspectives of patients, families and communities in clinical outcomes, effectiveness of the therapeutic processes and quality of health care, other names were defined as “health-related quality of life”, “perceived health-status” and “patient-reported outcomes”.^{4–6} These terms keep a close relationship between them, but should not be used as synonyms because not have the same meaning for health and patient professionals.

Considering that World Health Organization (WHO) defines health as ‘a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity’,⁷ the ethical dimension of health professionals is directly related to the responsibility for care activities, involving the different areas of life and reflecting in the care attitudes. The health professionals are responsible for guaranteeing a better quality of life to the patients through the guarantee of the right to healthcare and the absence of harm that denigrates the physical, mental and moral integrity, closely integrated into the right to life and human dignity.⁸

Since 1948, the Universal Declaration of Human Rights has guaranteed human right to all in the international sphere. Article 3 declares ‘Everyone has the right to life, liberty and security of person’.⁹ Around the world, health professionals work in suburbs, cities, rural communities, refugee hospitals, environmental disasters, war zones, hospitals, homes, clinics, political organizations, among others. They deliver care in different places, contexts and life perspectives and in common, routine or atypical situations and incorporate ethics and quality of life in the performance of actions that promote access, security, efficiency and qualification.^{1,3,8}

When applied in combination in healthcare practice, quality of life and ethics permit the achievement of better therapeutic and access outcomes in health services. Quality of life particularly affects healthcare. Magnanimous ethical work, then, is fundamental for the professionals, mainly when making decisions in situations of conflicts or emergencies. In that sense, through a theoretical literature review, this study aims to outline a conceptual analysis of quality of life and ethics, identifying attributes, contexts and magnitudes for health.

Methods and results

This study was based on the evolutionary method of Rodgers. According to this method, the concepts could be dynamic, broad, absolute and clear. This type of analysis enables the clarification, refinement and development of knowledge about a particular concept.¹⁰

In this sense, this method requires some primary activities, such as: identification of the concept of interest and associated expressions; identification and selection of appropriate field to collect relevant data; data collect regarding the attributes of the concept, antecedents, consequences and surrogate terms; analyse data regarding the characteristics of the concept; identification of example of concept, if necessary; and identification of implications and hypotheses for concept development.¹⁰ However, in this study only the first four approaches were followed.

In this study, the concepts of interest were quality of life and ethics in health, considering discussions about them and their relevance to health care practice, the objective was to outline and clarify the phenomenon in the contexts and magnitudes for health.

To collect the data, were searched in the National Library of Medicine (PubMed), SCOPUS, Cumulative Index to Nursing and Allied Health Literature (CINAHL), Literatura Latino-Americana e do Caribe em Ciências da Saúde (LILACS) and Web of Science. In the selected studies, a search was done using the keywords “*ethic**”, “*quality of life*” and “*health*”. The inclusion criteria were original studies with quantitative and qualitative approach, systematic/integrative reviews and theoretical articles; in English, Spanish and Portuguese; and without any time limit. Excluded studies were studies related to health-related quality of life; book reviews; theses or dissertations; abstracts of scientific events; expert opinion; editorials; and websites.

In total, 152 studies were found. After exhaustive reading of titles and abstracts, 25 were selected to read the complete version. Among these 25 articles fully read, seven complied with the study objectives and were included for concept analysis. The seven relevant studies for the proposed concept analysis¹⁰ were published between 1990 and 2015 in English.

The seven studies selected were investigated using exhaustive and intuitive reading. The data were synthesized and analyzed according to the inherent characteristics of the concept (attributes, antecedents and consequences). The selected studies were identified as Studies, followed by a number from 1 to 7.

Table 1 describes the included studies by author, year of publication and main excerpts extracted.

After the analysis of the studies and consensus by the researchers, three attributes that synthesize the concept of quality of life and ethics in health were highlighted: ‘Ethics dilemmas and quality of life’, ‘Human ethics and quality of life’ and ‘Ethics of care and quality of life’. The antecedents and consequences elements are presented in Table 2.

The main ethical dilemmas discussed and conclusions presented are demonstrated in Table 3.

Discussion

Ethical dilemmas and quality of life

Every day, health professionals are confronted with complex challenges related to life, and the requirement to make decisions remits them directly to their ethical principles. These choices can compromise or improve the quality of life of patients, families and communities and can be more complex in marginalized populations with low life expectancies or reduced quality of life scores.

The analysed studies highlighted ethical dilemmas in patient care, for example, in situations of reduced life expectancy or lack of responses to a treatment, insufficient mental healthcare, among others, which present clear negative quality-of-life scores.^{11,12,14} Under these conditions, the group of people, generally older individuals with mental disabilities, unconscious or in the end-of-life stage, who demand more costly therapeutics from the health systems and intense nursing care. Nevertheless, independent of the situation a person is in, the universal right to health is guaranteed, in compliance with Article 1 of the Universal Declaration of Human Rights: ‘All human beings are born equal in dignity and in rights’.⁹

Table 1. Distribution of studies according to author, year of publication and main excerpts.

Study	Author and year	Title	Statement of the main text
1	Dean HE, 1990 ¹¹	Political and ethical implications of using quality of life as an outcome measure	<p>'The lack of consensus about its definition [quality of life] and the problems inherent in its measurement render quality of life a poor choice as a criterion for decision-making regarding health policy'.</p> <p>'Two core questions remain: How do we use the concept of quality of life for the benefit of individuals and society without compromising the integrity of either? How do we make ethical decisions for the aggregate good without violating the rights of individuals and without devaluing life, either by forcing someone to live who does not want to or by refusing treatment to someone who wants it?'</p>
2	Ketefian S, 1995 ¹²	Individual versus community: ethical issues in quality of life	<p>'Ethical problems arise when expensive treatments are provide with unknown or marginal utility, or when quality of life following a given treatment is diminished without the promise of improvement'.</p> <p>'[. . .] the caring for the aged the goal should be improving quality of life rather than seeking ways to extend life'.</p> <p>'Permanently unconscious or demented patients who are not terminal [. . .] those who are terminally ill who will die with or without care [. . .] quality of life for both groups as poor'.</p> <p>'[. . .] individuals, in the exercise of their autonomy, need to place self-restraint on their behaviour for the common good'</p> <p>'[. . .] there is a collective professional responsibility to promote the common good'</p>
3	Aroskar MA, Moldow DG, Good CM; 2004 ¹³	Nurses' voices: policy, practice and ethics	'Consider quality of life in policy development, including adequate pain management'.
4	Ghebrehiwent T, 2012 ¹⁴	Reflections on nursing ethics	<p>'In order to resolve ethical dilemmas, nurses need direction on ethical decision making'.</p> <p>'[. . .] we can ensure that nursing is grounded in ethical principles compatible with human dignity, quality of life and patient safety'.</p>
5	Milton CL, 2013 ¹⁵	The ethics of defining quality of life	<p>'Recently, quality of life has been linked to issues of patient safety in diverse healthcare settings and institutions'.</p> <p>'[. . .] all human life is to be revered and all human experience is incarnated with intrinsic value'</p> <p>'[. . .] human dignity is "an august presence, a noble bearing of inherent uniqueness" (citation Parse, 1996)'</p>
6	Milton CL, 2014 ¹⁶	Straight thinking and ethics in nursing	'Professional nurses engage with persons as they face myriad health decisions and desire to have straight thinking about issues involving choices of human health and quality of life'.

(continued)

Table 1. (continued)

Study	Author and year	Title	Statement of the main text
7	Kim K, Han Yonghee, Kim Ji-su; 2015 ¹⁷	Korean nurses' ethical dilemmas, professional values and professional quality of life	'The professional quality of life (ProQOL) of nurses refers to the quality of positive and negative emotions they feel in the professional context of helping others'. 'Professional values affect the nurse's quality of life because they determine the motives of someone who is attempting to deal with an ethical dilemma'.

Table 2. Antecedents and consequences and their respective frequencies of citations in the studies.

Antecedents	Frequencies	Consequences	Frequencies
Health decision	31	Ethical dilemma	45
Discipline of nursing and other health areas	15	Professional quality of life	34
Health policy development	14	Straight think	16
Human rights	7	Public policy	14
Quality of life for individual and community	6	Human life	13
Pain and suffering	5	Safety	7
Elderly	5	Human dignity	6
Groups which diminished life	4	Ethical problems	5
Integrity	3	Common good	2
Ethical action	2		

In view of this statement, the health professionals play a fundamental role to guarantee the democratic and moral deliberation of the human rights to health,¹² and in that sense, measures need to be recognized and taken. Ageing is a contemporary reality of the global population. According to estimates, between 2010 and 2050, the number of people over 65 years of age will increase from 524 million to 1.5 billion.¹⁸ In most countries, health policies and services work to prevent mainly chronic conditions like Alzheimer's disease, cardiac diseases, diabetes and cancer. Recommendations for healthy lifestyles are developed, in accordance with the countries' different economic stages and available resources, in order to guarantee a better quality of life to the older population.¹⁹

What mental health is concerned, for example, in some countries of the European Union (EU), Iceland, Norway and Switzerland, about 30.0% of the adult population (18–65 years) has already experienced a mental disorder (related to drugs use, psychoses, depression, anxiety and eating disorders).²⁰ In the United States, millions of people have a mental disorder each year and only about half of them receive appropriate treatment.²¹ Around the world, there are thousands of people with mental disorders, most of them have been deprived of their human rights. These are marginalized and stigmatized people, victims of physical and emotional abuse in the community they live and even in health services.²²

The violation of the respect for human diversity demonstrates the lack and qualification of health professionals and systems in mental healthcare. The dignity of mental patients is internationally recommended, so as to promote their autonomy and independence in daily activities and a dignified quality of life. As a whole, each sphere of the health careers should guarantee these persons and their relatives the political and legal orientations on their human rights, besides respect for informed consent with the treatment,

Table 3. Selected studies according to ethical dilemmas and proposed conclusions.

Study	Ethical dilemmas	Main conclusions
1	Political and ethical implications of using quality of life	'Forums should be organized at multiple levels involving nurses, physicians, other health care providers and the general public. (...) We should be aware of the political scene and the research scene to guard against the potential misuse of study findings in the establishment of public policy. We should seek information for ourselves and our patients; we should provide the highest quality of care we can that is aimed at providing patients the possibility of fulfilling their own goals for their lives'.
2	Situations of costly treatments for unknown and marginalized patients or patients with low quality of life undergoing treatments without perspectives of improvement	'The professions can promote and enhance civic discourse about society's goals and can contribute to the process of democratic deliberation and moral debate; they can play an important role in guiding the terms of the dialogue for addressing and resolving compelling social issues'.
3	Development and implementation of health policies	'Health and patient care policy development and implementation without a nursing voice is policy that lacks a critical element [...] Nurses provide "the cement" that holds care for patients together'.
4	Confrontation of health professionals with daily ethical issues, such as complaints of irregularities and access to healthcare	'Nurses [...] have the knowledge, versatility and the skills to lead in an ethical direction. [...] to provide ethical voice and ethical policies to transform health systems for the benefit of our populations'.
5	Patient safety and dignity in healthcare	'[...] quality of life ought to be studied with formal disciplinary research methods that expose an ethos of human dignity and advance nursing knowledge. The findings of these paths of inquiries should inform and be regarded for future healthcare policy'.
6	Complexity of global health aspects and immediate decision making in difficult situations	The straight thinking can be to understand 'guide future nurse practice and global health policy'.
7	Quality of life of health professionals	'Nursing is a profession with a high probability of experiencing a low ProQOL' [...] 'hospital administrators and nurses should continue to conduct educational programmes to enhance nursing professional values [...] and reduce the degree of exhaustion of nurses'.

inclusion in health programmes, access to public information and understanding of the proposed therapeutics.^{21,22}

The ethical responsibility for healthcare remains intrinsically linked with means to relieve pain and suffering at the end of life. The demand for palliative interventions is complex, but comfort and the quality of care delivery improve the patients' quality of life and influence the psychosocial reaction of their caregivers and/or relatives. The repercussions in the caregivers' psychological well-being are essential to better cope with death later and the circumstances surrounding the patient's loss.^{12,23}

One aspect the studies in this analysis did not address is the recent situations of migrations and refugees that have currently influenced the global public health and raised ethical and quality-of-life dilemmas of human beings. It is estimated that there are 214 million people living outside their countries of origin. There are different reasons for departure, such as civil conflicts, natural disasters, political persecution, poverty, discrimination, lack of access to basic health services and search for new opportunities in terms of work or education.²⁴

Recently, a staggering number of refugees and immigrants have reached Europe by sea or land. The number of refugees and immigrants by sea in Europe in 2015 was 589,285, of these 3095 died while crossing the Mediterranean.²⁵ Unfortunately, these individuals were submitted to multiple forms of discrimination, violence and exploitation, which often directly affect their physical and mental health. In many cases, the worsening of the problems continues due to the legal, socioeconomic, cultural and linguistic barriers that impede them to access the health services.^{24,25}

In that sense, the professionals are ‘the lenses’ that reflect the living conditions¹⁵ and ‘the voices’¹³ for these populations. As they are that close to the reality these people experience, they are able to promote the autonomy and right to have access to health independent of the social, cultural and economic conditions of these populations, with a view to furthering a better quality of life.^{11,12}

Human ethics and quality of life

Guaranteeing the access to health means promoting people or communities’ safety. Nevertheless, to establish safety in healthcare, it is fundamental to understand human ethics.¹⁵

Human life consists of experiences, beliefs and values intrinsic to the experiences, contexts and knowledge. The theories and philosophies adopted in health guide the professionals towards further knowledge on the person’s beliefs and values. In nursing, for example, the professional discipline encompasses health in human beings, in the context and in quality of life.^{15,16} The International Council of Nurses – Code of Ethics for Nurses establishes the following four universal responsibilities of nurses: promote health, prevent illnesses, re-establish health and relieve suffering. According to the nurse, ‘Inherent in nursing is a respect for human rights, including cultural rights, the right to life and choice, to dignity and to be treated with respect’. Nursing care should be compatible with safety, dignity and people’s rights, maintaining an ethical posture and clear and objective dialogue, besides respect for the person receiving care.^{26,27}

Besides safety, dignity also comprises the human ethics of care. According to WHO, dignity is ‘[...] to an individual’s inherent value and worth and is strongly linked to respect, recognition, self-worth and the possibility to make choices’.²² Patient safety is related to the collective responsibility of the health team to promote dignity and, thus, the patient’s ‘common good’.¹² The guarantee of rights, safety and ethics in healthcare comprises the dignity of the human being, who in the vulnerability of the biopsychosocial status feels safe and confident to choose and comply with the proposed treatment.²⁸

It should be highlighted that most healthcare contexts currently present scarce criticism on professionals, with emphasis on the nursing professionals, to attend to the patients’ multiple health needs. An ethical issue may occur in any health situation where profound moral issues and decision making are necessary and urgent.⁸ Therefore, new professionals need to be attracted through actions that value the profession, and appropriate training and qualification of existing human resources are needed through tools and structures that support the ethical issues in health services.¹⁴ Through knowledge, versatility and skills to cope with an ethical orientation, the health professions can promote the ethical visibility that transforms political and healthcare systems and benefit the quality of life of the attended populations.^{11,29}

Ethics of care and quality of life

The development and implementation of health policies challenge the ethics and values of each professional. The policies in force are detached from the patient's true needs and compromise the quality of the care practice. In a study on the nurses' perspectives on the quality of care, one of the points highlighted was 'Consider quality of life in policy development [. . .]'.¹³

WHO defines quality of life as 'an individual's perception of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards and concerns'.³⁰ In that context, the lack of the patients' perspectives and the health professionals' considerations in the development and implementation of policies turns into an ineffective tool in healthcare and compromises the care network in the contexts of emergency care, health promotion, prevention, treatment or rehabilitation in health.

Among the studies analysed, one tool was proposed to develop effective policies and care for the populations, 'straight thinking'. In that tool, the author proposes the application of 'straight thinking' in an interdisciplinary moment of policy development, conducted by a multidisciplinary team in the analysis of health data deriving from a health database for decision making and policy formulation. This proposal rests on the notion of dignity, singularity and context of each person and health services, which the professionals respect.¹⁶

Another aspect that influences ethical care and which was surveyed in the studies analysed is the professional's quality of life. A health professional's attitudes are inseparable from his ethical values. The ethical issues emerging in daily healthcare can generate different stressors that also affect the professionals' quality of life.¹⁷ Professional quality of life remits to the combination of perceptions, emotions and positive or negative physical and psychosocial effects in the work context. This refers to the experience, for example, of coping with an ethical dilemma that can relate to professional stress.¹⁷ When confronted with ethical dilemmas that are difficult to solve, professional accountability remits to personal problem-solving philosophy, values and ideologies.³

The ability to solve ethical issues demonstrates personal satisfaction and happiness, offering a better professional quality of life. When ethical dilemmas remain unsolved, the acknowledgement and respect for human life and death are appointed in coping with situations.¹⁷ In that context, the ethical dilemmas include decision making associated with respect for human life in the conception of its values and meanings, giving rise to an expected ethical care for the quality of life of professionals and patients–family–community.

Conclusion

Quality of life and ethics are fundamental aspects in the discussion of the health process. In this study, in view of the presented categories, the attributes and context clearly reveal that ethics and quality of life influence the ability to solve ethical dilemmas, mainly when involving marginalized populations, human ethics in the guarantee of safety, dignity of healthcare for people's common good and the impact of ethics in healthcare for the production of effective health policies and care that encompasses professional quality of life as well.

Ethical education provides the health professionals with tools to reflect on and criticize their practice and its impact on the quality of life of the people they assist. The magnitude of ethical knowledge in each professional discipline permits cultivating a solidary attitude and developing the willingness to improve healthcare. The right to access, dignity and respect in care delivery are rooted in behaviours and are spontaneously applied in practice to the extent that they play an ethical role.

Conflict of interest

The author(s) declared no potential conflicts of interest with respect to the research, authorship and/or publication of this article.

Funding

The author(s) disclosed receipt of the following financial support for the research, authorship, and/or publication of this article: This research received a specific grant from the São Paulo Research Foundation (FAPESP).

References

1. Gallagher A and Hodge S. *Ethics, Law and Professional Issues: A Practice-Based Approach for Health Professionals*. Basingstoke: Palgrave Macmillan, 2012.
2. Moridi H, Ghasemi P, Nikrang M, et al. A systematic review on the concept of quality of life. *J Soc Issues Hum* 2015; 3: 173–178.
3. Wyndaele JJ. Ethics, healthcare and spinal cord injury: research, practice and finance. *Spinal Cord* 2011; 49: 161–174.
4. Bakas T, et al. Systematic review of health-related quality of life models. *Health Quality of Life Outcomes* 2012; 10: 1–12.
5. Moons P, Budts W and De Geest S. Critique on the conceptualisation of quality of life: a review and evaluation of different conceptual approaches. *Int J Nurs Stud* 2006; 43: 891–901.
6. Doward LC and McKenna SP. Defining patient-reported outcomes. *Value in Health* 2004; 7: 4–8.
7. World Health Organization. *Constitution of the World Health Organization*. Geneva: World Health Organization, 1946.
8. Ulrich CM, et al. Everyday ethics: ethical issues and stress in nursing practice. *J Adv Nurs* 2011; 66: 2510–2519.
9. United Nations. *The Universal Declaration of Human Rights*. Geneva: United Nations, 1948.
10. Rodgers BL. Concept analysis: an evolutionary view. In: Rogers BL and Knafel KA (eds) *Concept Development in Nursing: Foundations, Techniques, and Applications*. 2nd ed. Philadelphia: Saunders, 2000, pp.77–92.
11. Dean HE. Political and ethical implications of using quality of life as an outcome measure. *Semin Oncol Nurs* 1990; 6: 303–308.
12. Ketefian S. Individual versus community: ethical issues in quality of life. *Nurs Sci Q* 1995; 8: 98–99.
13. Aroskar MA, Moldow DG and Good CM. Nurses' voices: policy, practice and ethics. *Nurs Ethics* 2004; 11: 266–276.
14. Ghebrehwt T. Reflections on nursing ethics. *Nurs Ethics* 2012; 19: 313–315.
15. Milton CL. The ethics of defining quality of life. *Nurs Sci Q* 2013; 26: 121–123.
16. Milton CL. Straight thinking and ethics in nursing. *Nurs Sci Q* 2014; 27: 201–203.
17. Kim K, Han Y and Kim J. Korean nurses' ethical dilemmas, professional values and professional quality of life. *Nurs Ethics* 2015; 22: 467–478.
18. World Health Organization. *Global Health and Aging*. Geneva: World Health Organization, 2011.
19. United Nations. Department of economic and social affairs population division. *World Population Ageing*, 2013.
20. World Health Organization (WHO). *Data and Statistics of Prevalence of Mental Disorders*. Geneva: World Health Organization, 2014.
21. The National Institute of Mental Health. *Statistics*. United States, 2015.
22. World Health Organization (WHO). Mental health. *Mental Health: World Mental Health Day*. Dignity and Mental Health, 2015.
23. Abbott CH, et al. The influence of patients' quality of life at the end of life on bereaved caregivers' suicidal ideation. *J Pain and Symptom Manage* 2014; 48: 459–464.

24. International Organization for Migration of WHO. *International Migration, Health and Human Rights*. Geneva: International Organization for Migration, 2013.
25. World Health Organization. Regional Office for Europe. *Refugee Crisis*, 2015.
26. International Council of Nurses. *The ICN Code of Ethics for Nurses*. Geneva: International Council of Nurses, 2012.
27. Horton R and Das P. Global health security now. *The Lancet* 2015; 385: 1805–1806.
28. Gastmans C. Dignity-enhancing nursing care: a foundational ethical framework. *Nursing Ethics* 2013; 20: 142–149.
29. Mendes IAC, et al. Professional marketing and social visibility in nursing: a strategy to value human resources. *Texto & contexto enfermagem* 2011; 20: 788–795.
30. World Health Organization (WHO). *WHOQOL-BREF Field Trial Version: Introduction, Administrations, Scoring and Generic Version of the Assessment*. Programme on Mental Health, 1996.