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Résumé de l'article

Les soins de santé centrés sur la personne reconnaissent les patients comme des sujets de droits, tandis que le principe de continuité des soins est lié à la longitudinalité, établissant une relation thérapeutique à long terme tout au long du cycle de vie de l'individu. Ces principes du modèle de soins complets au Chili posent des défis éthiques aux équipes de soins de santé primaires. L'objectif de cet article est de décrire et d'analyser les principaux conflits éthiques délibérés par un comité d'éthique clinique de soins primaires, différenciés par cycle de vie. Une méthodologie qualitative a été utilisée, avec une approche d'étude de cas portant sur 30 des 70 requêtes reçues par le comité sur une période de sept ans. Les résultats montrent que les conflits éthiques durant l'adolescence et dans les soins aux personnes âgées génèrent de plus grandes difficultés pour l'équipe de santé. Les principales conclusions sont liées à la responsabilité de les traiter de manière appropriée et de contribuer à des plans de soins complets qui prennent toujours en compte les aspects éthiques des soins.

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ARTICLE (ÉVALUÉ PAR LES PAIRS / PEER-REVIEWED)

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Maggie Campillay^a, Carmen Nadal^b

Résumé

Les soins de santé centrés sur la personne reconnaissent les patients comme des sujets de droits, tandis que le principe de continuité des soins est lié à la longitudinalité, établissant une relation thérapeutique à long terme tout au long du cycle de vie de l'individu. Ces principes du modèle de soins complets au Chili posent des défis éthiques aux équipes de soins de santé primaires. L'objectif de cet article est de décrire et d'analyser les principaux conflits éthiques délibérés par un comité d'éthique clinique de soins primaires, différenciés par cycle de vie. Une méthodologie qualitative a été utilisée, avec une approche d'étude de cas portant sur 30 des 70 requêtes reçues par le comité sur une période de sept ans. Les résultats montrent que les conflits éthiques durant l'adolescence et dans les soins aux personnes âgées génèrent de plus grandes difficultés pour l'équipe de santé. Les principales conclusions sont liées à la responsabilité de les traiter de manière appropriée et de contribuer à des plans de soins complets qui prennent toujours en compte les aspects éthiques des soins.

Mots-clés

éthique institutionnelle, étapes du cycle de vie, soins de santé primaires, comités d'éthique clinique, santé familiale, Chili

Abstract

People-centred health care recognizes patients as subjects of rights, while the principle of continuity of care is related to longitudinality, establishing a long-term therapeutic relationship throughout the individual life cycle. These principles of the comprehensive care model in Chile pose ethical challenges to primary health care teams. The purpose of this article is to describe and analyze the main ethical conflicts deliberated by a primary care clinical ethics committee, differentiated by life cycle. A qualitative methodology was used, with a case study approach reviewing 30 of the 70 queries received by the committee over a period of seven years. The results show that ethical conflicts during adolescence and in the care of elderly people generate greater difficulties for the health team. The main conclusions are related to the responsibility of addressing them appropriately, and for contributing to comprehensive care plans that always consider the ethical aspects of care.

Keywords

institutional ethics, life cycle stages, primary health care, clinical ethics committees, family health, Chile

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INTRODUCTION

In Chile, the Comprehensive Health Model (MAIS, Spanish acronym) in Primary Health Care (PHC) highlights the principle of person-centred care that recognizes patients as subjects of rights. Therefore, health care must respect autonomy, encourage co-responsibility, and prioritize the needs of the person from a holistic perspective (1,2). In this regard, studies that have evaluated the progress of the model in primary care have agreed on the importance of continuing to implement actions centred on people, due to their positive effects in preventing health problems in the population (3). However, there remains a low participation and autonomy of patients in clinical decisions (4). In this context, patient autonomy is mainly relational under two arguments: The first is that the patient does not make decisions without considering their social and emotional environment, and on the other hand, the relationship between the medical team and the patient occurs in a context of continuous and historical care. This allows for the creation of a trusting relationship over time that is based on effective and confident communication, on a legitimate concern for the other, knowing the responses to critical events, and aspects of personality. The life history of a person contributes to the health team making better decisions, considering, for example, the when and how to give bad news. It also contributes to advanced directives of patients as people in trusting relationships can freely express their preferences before losing their abilities, thus favouring respect for active choosing about their care throughout their life cycle, and facilitating support for the caregiver (5).

According to Emanuel and Emanuel (6) the paternalistic model of care ensures that patients receive the necessary interventions to recover their health yet limits the exercise of patient autonomy and causes subordination to the authority of the doctor or health team. According to Pellegrino (7) autonomy refers to a sociopolitical, legal and moral concept that influences the way ethical decisions are made in care, respecting the patient in a "frank act" and respecting the dignity of people (p.379). Historically, patients were recipients of services, thus maintaining a passive attitude (8). However, greater access to information enables people to assume a more active attitude in making their own health decisions, influenced as mentioned by their values and preferences (9). Along with this, the incorporation of informed consent in clinical procedures has been an important tool to counteract the traditional paternalism of the health system (7,9,10).

In Chile, the MAIS life cycle and life course approach, responding to the principle of continuity of care (1), has provided primary care teams with a substantial framework for the study of cases and the monitoring of development tasks throughout people's lives. In addition, it has allowed the development of interventions and counselling through a process of accompaniment that

evolves permanently, responding to growing demands of cultural, family and social origin related to the population in receiving care (11). However, these advances in the Chilean health model are not sufficient to guarantee the resolution of problems that generate ethical challenges in primary care. Professionals may feel overwhelmed by the difficulty of making decisions that involve personal and institutional values and principles, and the customs and beliefs of patients (12). The WHO (13) recognizes the existence of ethical conflicts that arise from care in complex crisis contexts in which values associated with the individual dimension of care, the collective dimension and/or the global dimension are involved. In this regard, clinical ethics committees (CECs) have provided a valuable space for the development of ethical competencies in the healthcare team for ethical-legal reflection and deliberation, safeguarding the rights of patients, humanizing care, improving the quality of care and providing suggestions that guide towards healthcare practice with high ethical standards (12,14).

According to the United Nations Educational, Scientific and Cultural Organization (UNESCO) (15), CECs must have a defined mission statement that specifies their objectives distinct from those of other committees or institutional entities. The procedures for selecting members should be a formal and transparent, while informal recommendations and expressions of interest will occur naturally. Relevant basic representation should include health professionals, bioethicists, lawyers, patient advocates and laypersons, among others. It should also be determined whether members will serve for an indefinite period or fixed terms, and the process for their departure should be clarified. The Committee's agenda will depend on the consultations that prioritize certain issues occurring in the institution. Decisions regarding deliberation processes often involve dialogue with guidelines for conducting them and seeking consensus.

The context of this study is the trajectory of a CEC in primary care in the city of Rancagua, Chile, which was composed of nine individuals: a dentist, a social worker with a degree in philosophy as a second career, a physician beginning a Master's in bioethics, a lawyer, a therapist specializing in childcare, a physical rehabilitation specialist, a nutritionist, a licensed nursing technician and a community representative. The addition of a priest with theological studies was accepted to represent community interests that were important to consider in deliberations. At the beginning, the Committee used to have monthly meetings lasting one hour to analyze ethical conflicts identified by its members or the healthcare team in their daily practice. Those inquiries were submitted to the CEC by email. Patient or family inquiries were asked to be submitted in writing, in a sealed envelope. Occasionally, during regular meetings, the person submitting an inquiry to the CEC was invited to present relevant information for deliberation. This process followed a sequential model, beginning with the identification of facts, values, principles, or rights involved, identifying any extreme courses of action, and concluding with intermediate actions that protect the principles agreed upon by the Committee, and which would be recommended as optimal courses of action. Generally, despite discrepancies among CEC members during deliberations, recommendations with the greatest benefit and least risk to the patient were prioritized, along with the biopsychosocial approach inherent to the primary care model.

Based on the above, having access to a CEC is an opportunity to train the healthcare team, as they are constantly faced with difficult situations that may contravene their professional biomedical training. Special attention must be paid to the concepts of human dignity and vulnerability during the healthcare delivery process as individuals are more vulnerable when they are ill, during childhood or old age, or in proximity to death. The use of technology and advances in biomedical resources in those situations can be very challenging for the healthcare team, who seek to respect the dignity of people by considering their inherent value, not treating them only as sick bodies to be restored to health; paradoxically, in trying to do good health professionals can cause harm (16). Studies on ethical conflicts in the clinical environment have shown that these cases cause doubts about how to act in order not to harm the patient, and therefore, can generate discomfort, helplessness, and/or feelings of guilt in the members of the health team (17). Ethical conflicts are characterized by the uncertainty of not knowing what to do when faced with a complex situation, or a difficult decision in clinical practice, and that potentially affects the well-being of patients. These decisions are not only related to ethical values in dispute, but also to technical, bureaucratic, and organizational aspects that restrict, hinder, or limit decision-making at work (18,22). In this regard, ethical conflicts can cause moral anguish or moral suffering in primary healthcare teams, since decisions considered complex can produce negative psychological and emotional responses (23). Studies on this subject show that these feelings or psychological responses are consequences of believing that personal or professional values have been betrayed, which causes feelings of guilt, loss of meaning for work, lack of confidence in performance (17,23), desensitization, exhaustion, and demoralization that lead to a reduction in quality standards in patient care (24). In this regard, CECs in primary health care setting enable the healthcare team to address ethical issues in clinical practice, review institutionalized policies, and engage in ongoing training in bioethics (25). Additionally, healthcare institutions must cultivate responsible relationships with patients, carers, families, users of the health care system and society based on particular needs. This highlights the importance for the CEC to incorporate a life course perspective in their discussions, as it provides a comprehensive understanding of the health-disease trajectories of individuals and their families (26). Considering that almost all inquiries referred to a CEC are related to crises experienced by individuals and their families, those situations could complicate the relationship between the healthcare team and the families/carers involved (27). Those crises can be classified in biological, psychological, social, economic, political, and geographical (26). The significance of this point lies in the fact that the main ethical conflicts addressed by CECs arise within this context.

The following qualitative study sought to answer the question: *What are the main ethical conflicts encountered in a primary health care (PHC) CEC in Chile, following the life cycle and life course approach of MAIS?* Through this study, we aimed to present evidence and arguments that support the importance of institutionalizing CEC in PHC, recognizing the contribution of these committees to the ethical dimension of care and their role in promoting the transfer of competencies to PHC teams, and suggesting pertinent courses of action that improve the treatment of patients and enhance the quality of care.

METHODOLOGY

The research was approached from the interpretive paradigm, qualitative methodology and case study approach. The experience of a CEC in the city of Rancagua (capital of the O'Higgins Region) that operated continuously for seven years was collected. This is considered relevant, since in Chile, CECs in PHC are not mandatory (28). The case therefore has intrinsic value (28), since its development and process contribute to identifying, understanding and better guiding the ethical conflicts that affect the work of primary health teams, based on situations that arise in family interventions considering the life cycle and life course. In this regard, the principle of person-centred care requires the healthcare team to have a greater holistic understanding of the patients' biography, which can lead to potential ethical conflicts in clinical and therapeutic relationships, organizational matters, handling sensitive data and confidentiality, among others (29).

The study addressed a sample of 30 inquiries (from a total of 70) submitted by healthcare teams to the CEC during the period 2015-2022. Included were cases that reported family-based interventions which involved a multidisciplinary primary healthcare team, as this allowed for a deeper exploration of the conflicts that arose in the usual dynamics of the CEC. The analysis unit corresponds to the cases deliberated by the CEC, which were organized by life cycle of the index case. The data were accessed directly, since they were published and summarized in a publicly accessible book (14). They were transcribed in full, respecting anonymity, and shared among the researchers from a Google Workspace® drive document. A first analysis meeting was held to build a characterization of the 30 cases addressed by the CEC (Table 1), followed by a second round in which the cases were classified according to life cycle (Table 2). This was considered essential to determine the main themes that typically affect each life cycle, allowing for the establishment of common bases in the suggestions and guidelines given by the CEC, and to guide the discussion of the study. Life course was classified as follows: a) boys and girls, b) adolescents, c) adult women, d) adult men, and e) older people. A gender distinction was made in the case of adults, since in this life cycle stage there are differences in care delivery and diseases associated with this dimension (30).

In subsequent meetings, a) rounds of readings of the cases by life course were carried out, and b) analysis of the courses of action established by the CEC to organize the discussion. The criteria of rigour considered reliability, since the universe of cases deliberated by the CEC was used. For triangulation between the researchers during the analysis rounds, in-depth discussion enabled contrast of theoretical and interpretive approaches to the categorization process.

Available data corresponding to the annual activity reports of the CEC were used over a period of seven years. Information saturation was reached by reviewing the documents several times and not finding new emerging categories for each life cycle. The replicability and transferability of this study is possible by following the methodological aspects mentioned above, and possibly with similar results at the national level, since the functioning and level of knowledge of the primary care teams is similar due to the normative and technical strengthening of the PHC. The ethical aspects of the study were safeguarded by respecting the confidentiality and autonomy of the health professionals and the members of the CEC studied. The data were anonymized, and only part of the in vivo categories were used to identify the cases. The identities of the families, which were the subject of ethical conflict for the teams (31), were protected and designated as cases to organize the data based on the life course model. Approval was obtained from the independent Scientific Ethics Committee of the Araucanía Sur Health Service through official letter No. 170/2023.

RESULTS

As a result of the data analysis (cases), the following ethical conflicts were identified and considered by the Clinical Ethics Committee (Table 1).

Table 1. Characterization of the cases and ethical conflicts reported to the CEC in Rancagua

Nº	Case (In vivo code)	Conflicts and/or dilemmas identified by PHC team
1	"I can no longer attend this therapy, because I have to take care of my father" (Daughter caregiver abandons her treatment to care for her dependent father)	- Well-being of the caregiver vs. well-being of the dependent parent - Exercise of autonomy in vulnerable conditions
2	"I demand access to my son's medical record" (mother demands information about her teenage son's medical record)	Safeguarding the adolescent's privacy, the right to confidentiality of their data, and the request for information from their mother to protect the health of her child (charity)
3	"I am afraid to tell my partner that I have HIV" (partner confirmed with HIV refuses to allow informing his partner)	Right to confidentiality of the HIV patient vs not causing harm to the partner (non-maleficence)
4	"I need medication to deal with the problems in my life" (abandonment of psychological therapy to attend workshops for caregivers, since she prioritizes the care of her father and her young daughter)	- Well-being of the caregiver vs well-being of the dependent parent - Exercising autonomy in vulnerable conditions
5	"You should have preventive exams"	- Violation of the principle of autonomy of users of the health system. - Patient autonomy vs the potential benefit of preventive examinations - Exercise of autonomy in a context of medical paternalism, which predominates in the health system
6	"I can't take care of him. His father needs to be monitored by a specialist at the hospital."	- Violation of the right to health - Conflict between the principles of beneficence and non-maleficence

7	"This survey is very easy to answer, it will help me finish my master's degree"	• Violation of the principles of autonomy, beneficence, non-maleficence and justice of patients or users of the health system
8	"I do not authorize my daughter to be vaccinated"	• Violation of a girl's right to health • Delegated autonomy vs beneficence and non-maleficence of vaccines
9	"I will not stop eating what I like, I prefer that you prescribe me medication"	• Patient autonomy vs beneficence of care
10	"I will do everything possible to ensure that my father lives on"	• Patient autonomy vs caregiver values and beliefs; advance directives
11	"He told me how he wanted to live the last stage of his life"	• Patient autonomy vs caregiver values and beliefs; advance directives
12	"Don't tell my parents"	• Autonomy of an adolescent's sexual life vs legal responsibility of parents • Beneficence and non-maleficence of health actions
13	"This was put in me to prevent menstruation" (adolescent institutionalized in state protection homes with a subcutaneous method to prevent pregnancy)	• Autonomy of the sexual life of an institutionalized adolescent vs State responsibility • Beneficence and non-maleficence of health actions
14	"Adherence to pharmacological treatments has been difficult due to low awareness and responsibility" (adolescent institutionalized in state-protected homes with subcutaneous contraceptive method, with moderate cognitive deficit, and behavioural disorder)	• Autonomy of the sexual life of an institutionalized adolescent with cognitive disability vs legal responsibility of the State • Beneficence and non-maleficence of health actions
15	"She refuses any contraceptive method" (adolescent institutionalized in state-protected homes without contraceptive method, who refuses any possibility of treatment to regulate fertility)	• Autonomy of the sexual life of an institutionalized adolescent vs legal responsibility of the State • Beneficence and non-maleficence of health actions
16	"I only have a tourist visa and I don't have health insurance"	• Right to health of immigrant girls and boys without discrimination (justice) • Beneficence of health actions
17	Access to immediate care for adolescents at risk of suicide who belong to the private health system and who are detected in school screenings carried out by teams from health centres in the public system.	• The right to health of adolescents • Beneficence and non-maleficence of health actions in a mixed system (public-private) with different insurance plans and providers that do not work in a network
18	Is school a suitable place to administer rapid HIV tests to adolescents?	• Progressive autonomy of adolescents • Beneficence and non-maleficence of health actions
19	"They are denying me my father's death certificate"	• Rights and responsibilities of patients and family members in relation to health care
20	"I have the right to be a mother" (woman with a disability diagnosed with schizophrenia)	• Patient autonomy vs beneficence and non-maleficence of health actions • Stigmatization
21	"They didn't give me that test" (pregnant Haitian woman denies having tested HIV positive)	• Patient autonomy vs beneficence and non-maleficence of health actions in immigrant population
22	"I was not informed that my daughter was vaccinated"	• Delegated autonomy to the father and mother vs beneficence and non-maleficence
23	"We can take care of that child, there is no need to abort" (the teenager's mother does not want to terminate her daughter's pregnancy)	• Autonomy of adolescent rape victim vs beneficence and non-maleficence
24	"I know I'm pregnant" (woman makes up pregnancy)	• Right to health free from any form of discrimination • Beneficence and non-maleficence
25	"My mother has the right to her medicines" (daughter claims medicines from consultation supplanted by her mother)	• Justice in health care • Damage to the therapeutic relationship
25	"They discriminated against my father because he was old, bedridden and dying" (outpatient health team cannot assist patient at home and he dies)	• Justice in health care • Good death • Beneficence and non-maleficence
26	"The family must decide" (amputation in a frail, elderly person)	• Surrogated autonomy • Beneficence and non-maleficence
27	"These are confidential data" (mother insists on knowing the result of the PCR test taken by her 19-year-old son)	• Data autonomy and confidentiality
28	Working man asks for a certificate with the result of his PCR because his company requires it	• Data autonomy and confidentiality
29	Workers tested in groups with PCR are informed privately, but the rest of the workers demand to know the results	• Data autonomy and confidentiality
30	"The sterilization of our daughter (who is disabled) is my wife's wish before she dies"	• Surrogate autonomy • Beneficence and non-maleficence

Source: Nadal, 2021 (14)

The cases reviewed by the CEC (Table 1) correspond to consultations carried out by the primary care teams, which are mainly associated with processes that trigger personal and/or family crises. Normative crises are mainly described in cases where patients are children or adolescents, and are related to developmental crises in which the role of the father and mother as responsible for the health of their children is highlighted. In childhood, ethical conflicts were frequently associated with father and/or mother's refusal vaccine are common. While in the case of adolescence, consultations were oriented towards sexual and reproductive health in which the father and/or mother questioned the adolescent's ability to consent or make decisions, in addition to questioning the confidentiality of data in the context of health care.

In the adult phases, non-normative crises become more evident since most of the identified ethical conflicts were related to behaviours that could negatively affect people, such as being associated with the exercise of restricted autonomy due to a lack of health knowledge. In older people, the main consultations were associated with the condition of chronicity, fragility and loss of physical and mental functionality, which provoke paternalistic and overprotective attitudes in families and caregivers that threaten the exercise of the right to autonomy.

As summarized in Table 2, adolescents accounted for the majority of CEC consultations, together with dependent elderly people or those with multimorbidity. Subsequently, cases in the adult population were equal between men and women, and finally, the group in which fewer cases were recorded corresponds to boys and girls.

Table 2. Classification of cases deliberated by the CEC, according to life cycle

Group	Type of case according to life cycle	Nº
Boys and girls	Cases related to childhood health	2
Teenagers	Cases related to adolescent sexual and reproductive health	9
Adult women	Cases related to health behaviors of adult women	6
Adult men	Cases related to health behaviors of adult men	6
Elderly people	Cases related to the care of elderly people who receive home care and/or multimorbidity	7
Total		30

DISCUSSION

Development of an ethic of care based on human dignity

Based on the findings of our analyses of 30 cases and ethical conflicts reported to the CEC in Rancagua, we argue that MAIS and the principle of person-centred care offer the ideal theoretical and practical framework for primary care teams to provide comprehensive and continuous care, including guiding people and families in different periods of crisis.

Comprehensiveness allows care to be addressed from all human dimensions, and at all levels of care with an anticipatory focus while the continuity of care incorporates the vision of the life cycle and life course (1). Care from this comprehensive perspective goes beyond the mere delivery of actions by the health team; it necessarily requires a professional attitude that represents concern, responsibility and commitment to the other. Care therefore acquires a concrete moral body based on values, personal virtues and a positive disposition towards the subjects of care that must ultimately be reflected in the behaviour of the health team (32). A study carried out by the Chilean public organization, Superintendence of Health (33), on the dignified treatment of health system users following the 2012 Law 20,584, which regulates the rights and duties that people have in relation to actions linked to their health care, established that dimensions such as empathy, not being discriminated against, being treated as a person and without paternalism, respect for privacy/intimacy and having a comprehensive view of the patient, are associated with dignified treatment from the perspective of people who use the health system. These dimensions demonstrate the usefulness of identifying value characteristics of the ethics of care, since they allow the construction of quality indicators associated with dignified treatment, giving health teams the possibility of rationalizing these, identifying gaps and advancing in the development of skills to improve care.

The recognition of human dignity a human right has been declared in article No. 1 of the Universal Declaration of Human Rights (UDHR): "All human beings are born free and equal in dignity and rights and, endowed as they are with reason and conscience, they should behave fraternally towards one another." This fundamental feature for social coexistence is based on the philosophical tradition in which dignified treatment is associated with "key human capacities such as conscience, freedom and autonomy." It is also an intrinsic value that "belongs to each human being to the same degree throughout his or her life" (life cycle) (34, p.1160). This ontological vision of "being human" allows for the development of values that support the practice of care (35). Patient care is a practice motivated by the intention of seeking a benefit, thus responsibility and focused attention are assumed, which requires great intellectual and sensitive concentration to understand the needs of others (36). From this perspective, comprehensive care becomes difficult and complex, since in many cases it is not possible for health teams to respond unequivocally to a problem; rather, they are permanently faced with dilemmas or conflicts that generate doubts about how to act correctly to obtain the maximum benefit for people. In addition, they must consider that the socioeconomic conditions in which many patients live are not ideal, and that the health system does not always provide the resources to achieve therapeutic and care goals (37). This can be seen in that related dilemmas in the same life cycle may be similar, but their approach through a care plan will take into consideration the family and social context specific to each case (Table 2).

Care throughout the life cycle and life course

Analyzing the cases reviewed by the CEC (Tables 1 and 2), it is possible to affirm that the primary care team will always have doubts about how to act in certain situations of family crisis, and at different stages of a person's life cycle. In this regard, the theory of the personal life cycle is based on different stages of human development, expanding the notion of the phases of personal life from childhood to old age. Each stage follows a biologically influenced sequential maturation pattern that also recognizes the influence of the environment and context on the development of each person's personality. Each of these phases involves the resolution of certain crises or conflicts that must be overcome in order to best address the next phase, conditioned by the family and cultural environment that exerts powerful influences on people (38). Based on this, some crises

are predictable (normative) while others are unpredictable (non-normative), both having personal and family impacts associated with the stress of dealing with these events. Varied and complex aspects influence the adaptation of individuals and families to crises whose behavioural patterns have been learned generationally, and are in complex interaction with their support networks, forms of communication, family functionality, personal values and principles, socioeconomic factors, among many other factors that will make a crisis be experienced in a very particular way (1).

On the other hand, the life course approach promoted by the Pan American Health Organization (PAHO; 39), covers the entire life cycle, recognizing that there are life events, whether continuous or cumulative, that lead to adaptive changes that influence the health and development of individuals, families and communities, so that "health development can be enhanced, diminished, interrupted or recovered throughout the course of life" (p.43). Based on this, health problems from the MAIS perspective are addressed from different theoretical and practical approaches that provide tools to the primary care team so that people, families and communities can generate coping strategies in the face of a crisis, either focusing on the problem, the emotion, or the meaning that people and families give to each crisis. In this last point, there are beliefs, values, principles and existential objectives that contribute to finding positive aspects behind a stressful life situation, and that help sustain coping and well-being during a difficult-to-manage life event (40). To deal with any crisis due to illness of a family member, especially due to serious, chronic, debilitating, painful or terminal pathology, different adjustments are required in the lives of family members to be able to cope, since these will have important consequences in all spheres of life (40).

In person/family-centred care, one of the main objectives is to develop and implement comprehensive care plans aimed at the patient within their family context, a key component of which is facilitating care that includes ethical principles and values such as collaboration and solidarity between family members and health care providers (41). The study carried out by Anderson and White (42) in families with seriously ill patients and their caregivers describes how the caregiver families highlight in their stories, as do the CEC informants (Table 1), value aspects of care such as: "honoring the wishes of the loved one" which refers to respecting the patient's autonomy; "receiving help or support" from others, which refers to the principle of solidarity and compassion; and "acting together as a family", which refers to intergenerational solidarity and the feeling of compassionate love. The same study also describes barriers that hinder the care of patients with serious illnesses, such as female caregivers who report gender bias in carrying the "burden of the emotional work of caring," or "lack of support from health systems."

Proposals for ways to intervene with families in these events are quite varied and there are no universal formulas. However, the experience of some study groups at internationally continue to demonstrate the benefits of support during the family life cycle. Family interventions should be mainly aimed at preparing the family in advance for events specific to each life cycle, such as serious illness, considering probable results, providing complete information for making the best decisions, improving family satisfaction, especially psychological, ensuring that patients do not receive unnecessary treatments and that the family understands the limitations of care and life support (43).

In recent decades, health care systems have promoted attitudinal aspects of care such as empathy to establish the therapeutic and care relationship with people, which guides the social and therapeutic behaviour of the teams (44). To analyze some of these issues raised in the cases addressed by the CEC, and their contribution to the situation, in the following sections a case is presented for each life cycle.

Case associated with the life cycle of a young girl whose father refuses vaccination according to the normal schedule of the national immunization program

In this case, a father does not authorize the vaccination of his young daughter, generating debate regarding the decisions of the parents when these are based on erroneous beliefs about immunization, and the State's responsibility to guarantee the greater good of the child.

The International Convention on the Rights of the Child considers children and adolescents to be subjects of rights, and to be recognized as persons in development for the progressive exercise of their autonomy and in accordance with the evolution of their capacities (45). In this regard, health from a positive perspective is the physical, psychological and social state that allows children and adolescents to reach their maximum development potential, so generating healthy and safe environments is essential to achieve this state. In clinical practice, improving the health conditions of children and adolescents implies entering into conflict with the beliefs of some families or groups that hold alternative ideas about health: for religious reasons, such as Jehovah's Witnesses; for preferences such as vegan groups that reject products of animal origin; or are influenced by fake news on the Internet and so reject vaccines, among many other biomedical interventions. These families, from a practical perspective, may restrict the possibilities of access to adequate nutrition, treatments or immunization for their children and adolescents based on ideas that are far from conventional medicine. In addition, aspects such as the low level of education of the parents can make intervening or reversing these decisions very complex, which is why reduced access to healthcare accounts for a primary form of child abuse (46).

Immunization in Chile for children and adolescents reaches high coverage and constitutes one of the main axes of the dimension of the right to health of children and adolescents (47). In this sense, Law 21,430 on guarantees and comprehensive protection of the rights of children and adolescents (48), establishes that the care of children is a family responsibility, as the family is a fundamental unit of society and facilitator of the growth, development and well-being of children and adolescents. In addition, families are responsible for the protection of and guidance for the exercise of their children's rights. State

institutions, such as Family Health Centres (CESFAM, Spanish acronym), must ensure the best interests of children and adolescents, and when possible allow them to act autonomously, respecting their life path, considering their age, degree of development, maturity and/or emotional state. In addition, children and adolescents must be allowed to express their opinion on aspects related to their well-being whenever they wish and where possible. According to a study carried out in Chile by World Vision (49), the promotion of the principle of participation and progressive autonomy of children and adolescents has put conventional parenting models to the test. This study shows that children and adolescents have wide margins of participation in daily decision-making, and that authoritarian and violent parenting styles are maintained, which are characterized by the lack of recognition of children as subjects of rights in society.

In this case, the suggestions for the clinical team were to: engage in dialogue with the parents or other family members seeking to reverse the decision to reject immunization, look for other family members who support vaccination to generate new arguments for change and meaning for the parent, provide information on the rights to health of children and adolescents, develop an argument based on the collective (common good) and not only on the individual (autonomy) considering that the herd effect of immunization is what benefits the entire target population (14). As a last measure, if the father's attitude is not changed, civil justice mechanisms should be used to represent the right to health and the greater good for the child. According to Valera et al (50), the main ethical arguments for this measure are the certainty of harm to the girl from not receiving her age-recommended vaccines, the benefit of vaccination both individually and collectively, and the obligation to be vaccinated as is established as a State rule.

Case associated with the life cycle of a 12-year-old adolescent who wishes to abort a pregnancy resulting from rape

The case corresponds to the request made by a 12-year-old adolescent who goes to the CESFAM to request the interruption of her 13-week pregnancy, which was the result of repeated sexual abuse by a stepbrother (not proven). In this case, the mother is opposed to abortion, the socioeconomic conditions and the home environment are precarious. During a visit by the health team, the mother expressed wanting her daughter to have the child since she, the mother, has not been able to conceive with her current partner. Meanwhile, the adolescent appears scared and mentions that she no longer wants to terminate her pregnancy. This aspect is relevant to highlight since the health team can play a relevant role in providing information, identifying and managing the abuse of children and adolescents and its consequences (46). In a study carried out in Chile on adolescent pregnancy (51), one of the gaps in the exercise of the rights of adolescents was found to be associated with adult-centrism on the part of families, institutions and society as a whole. This then has an impact on low levels of participation of adolescents, since there is little access to information to form their own opinions, limited opportunities to being heard, and low consideration of their opinions in decision-making that concerns them, as in this case where the adolescent does not want to continue with the pregnancy.

Adolescence has been related to the tasks of searching for identity, marked by processes of cognitive, emotional and socio-sexual development. In the course of an adolescent pregnancy, the process of accepting to have a child has been described as the duality of being a father/mother and at the same time being an adolescent. For the proper development of this process, it is necessary to find the positive meaning of pregnancy and to have support networks that allow the adolescent to move forward with her life project (51). In the case presented, the violent circumstances that gave rise to this pregnancy are probably the reason why the adolescent wants to opt for abortion, in addition to the negative circumstances of her environment in which her mother does not respect the autonomy of her daughter.

In Chile, Law No. 21,030 on Voluntary Termination of Pregnancy for Three Reasons, refers to the possibility of abortion as a result of rape, provided that no more than fourteen weeks of gestation have elapsed, and for girls under 14 years of age. In the case presented, the adolescent is 12 years old, and her pregnancy is at 13 weeks, so she meets the requirements to be permitted to terminate the pregnancy expressly and voluntarily, given her explanation that it is the result of rape (52). Furthermore, this adolescent is in a vulnerable and disadvantaged condition, and thus there is an obligation on the part of the State to protect her integrity and to respect her will to terminate the pregnancy. This is anchored in the sexual and reproductive rights of women, which penalizes "forced pregnancy, denial or postponement of abortion, mistreatment of women and girls seeking information on health, sexual and reproductive goods and services, and qualifies them as forms of gender-based violence that, depending on the circumstances, may constitute torture or cruel, inhuman or degrading treatment" (53, p.7-8). In this situation, there is a crime that must be reported and the obligation to first protect the adolescent girl as a victim of sexual violence (53). Secondly, there is the obligation to guarantee the "right of women to access comprehensive abortion care services that are safe and legal, that protect their right to autonomy and reproductive freedom" (54).

The suggestions for the health team were: act with respect and compassion, prioritize the vulnerable adolescent and establish mechanisms for her protection, respect her progressive autonomy, avoid re-victimization as far as possible, report the case to the justice system, accompany her decision-making process so that she makes the decision to abort without coercion and in an informed manner, and ensure ongoing support from the psychosocial team.

Case of a 35-year-old male diagnosed with a chronic disease who decides not to adhere to healthy habits and requests drug treatment

A 35-year-old patient diagnosed with cardiovascular disease during a preventive check-up rejects the possibility of making changes towards healthier habits and requests medication from his primary care physician. The primary care team at the CEC argues that there is a conflict between the patient's autonomy to decide about his own health and justice in relation to what is therapeutically indicated for a patient in his situation of admission to the program and the progression of the disease. In this sense, the patient should start non-pharmacological treatment, making changes to his lifestyle which should be sufficient to improve his current cardiovascular risk. However, the patient does not accept the indications, generating a reaction of rejection in the medical team.

From the perspective of the life course, the trajectory of this patient's illness is influenced by his previous experiences, including negative experiences with his parents or a family member who is a carrier of an illness, losses, beliefs or another critical event that explains his negative attitude towards the counselling received. It should also be considered that changes in behaviour towards healthier habits occur late, progressively, and only once people understand and accept that the changes suggested by the primary care team produce benefits for them (39). This attitude of rejection towards non-pharmacological treatment should be considered a legitimate response that does not prevent the primary care team from accompanying the patient's adaptation process and promoting healthy lifestyles as a first measure. Disease triggers a non-normative crisis that begins with the diagnosis, progresses to the adjustments that must be made in daily life, and finally coping, when the problem is understood and the consequences for the patient are clarified. There are a series of tasks in the adaptation process in individual and family care, and the person diagnosed with a chronic disease must learn to relate appropriately with the health team. As such, the patient and his family can reorganize their goals to cope with an illness, integrating the patient's life cycle, the family life cycle and the cycle of the disease itself (55). In this case, the suggestions for the primary care team were: to conduct a family study, to respect the patient's initial decision, to identify support networks for care in the family, to accompany the crisis process respecting the adjustment and adaptation to changes in the patient's lifestyle. The frustration that these cases generate for the primary care team must also be managed.

Case of an elderly person who receives care from her only daughter, who declares herself overwhelmed

An elderly person with secondary dependency due to a stroke is cared for by her 30-year-old daughter, the latter who is separated from her husband and who helped her care for her father, and herself has a young daughter. As the daughter's siblings neglect the care of their father, she also manages her father's pension as the only family income. She does not attend the self-care workshops for caregivers offered by the CESFAM and has reported feeling overwhelmed. According to what was described by the CEC, the caregiving daughter of this elderly person matches the profile of people who perform this role: it is usually women, spouses or daughters, who perform informal care functions. In this regard, data from the National Disability Survey (2022) revealed the overload that occurs when there is a primary caregiver and care is not shared with other family members (56). When an elderly person begins to lose autonomy and functionality, they require support from a caregiver for daily living activities. This role implies assuming great responsibilities in relation to the care of others, which often reduces the possibilities of self-care, causing significant alterations in the mental and social health of the caregiver, since the adaptation process when assuming the role of caregiver can become a challenging life crisis (57,58).

This case highlights the impact of being a caregiver, and how this unrecognized work alters the daily life of a young woman who assumes the entire workload of caring for her father, while also having her own childcare responsibilities. Studies such as the one carried out by Aman et al. (58) show that the meaning of being a caregiver can vary between cultures, and that it does not always represent burden or stress. For some, caregiving can also be a source of satisfaction, especially when there are ties of filiation, the dependence of the person being cared for is partial, and the caregiver has a higher educational level. However, in Western cultures characterized by individualism, caring seen as is sacrificing oneself, which in a practical sense is a postponement of oneself with consequences that can be very negative both for the person who cares, as well as for the elderly person who receives care. Studies have shown that the quality of life of caregivers improved when coping is active and focused on emotions and social support (59), in addition to receiving training, coordinating periods of substitute caregivers, and balancing care tasks with other work, activity or social life (57). In this case, the CEC's suggestions were to: provide support for the caregiver through a comprehensive plan by the primary care team, identifying support networks to generate spaces for rest with alternating care for the parent, self-care, and permanent home visits to support care through formal instances.

CONCLUSION

In summary, the Primary Care Clinical Ethics Committee (CEC) constitutes a fundamental resource to advise primary care teams in the face of ethical conflicts in routine clinical practice, as well as in the context of emerging global crises that are increasingly complex. Wealthy countries in North America and Europe have made progress in other strategies, such as bioethical advice provided by professionals with specialized training, especially at the hospital context (60). By contrast, in developing countries such as Chile, these strategies receive little attention in public policies, depriving primary care teams of the opportunity to debate the ethical dimension of care or improve understanding of the therapeutic relationship and so develop greater skills for intersubjective people-focused care.

The findings of this study contribute to making visible the ethical dimension of care, and in particular, the importance of the CEC in contributing to the comprehensive health care model in dealing with conflicts presented by the primary health care teams of several family health centres in Rancagua, Chile. The CEC constitutes a fundamental support resource for the training and accompaniment of primary health care teams, favouring care plans with a rights-based approach in accordance with the family and individual life cycle. From this perspective, every action carried out by health teams has an ethical dimension to address. While families, regardless of their culture, combine their emotional dimension with the moral sense that characterizes them, health care teams require new skills to offer care focused on people. This aspect, often made invisible in health care, takes on meaning in the face of a crisis, especially as a response to illness, aging, a catastrophe, or palliative care.

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