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Contents / Sadržaj

Editorial

It is with great satisfaction to present the 15th number of *Jahr – European Journal of Bioethics*. There is almost a pattern of having a more miscellaneous first issue every year, without special sections. It is the same again this year. The only section we always try to promote as a particular encouragement for our youngest colleagues is the one devoted to making space for student contributions. This time two papers are co-written with students, thus even not formally structured as a section, student work is taking place again in our journal.

In the current issue you can read about the highly important medical-law topic at the level of the European Union concerning the Patient's Right Directive, an affirmative answer to the question if palliative care needs distinct ethical guidelines, a new discussion about human dignity and the right to live, the importance of the assessment of quality of life in glaucoma patients, and some introductory words about holistic environmentalism. These topics are brought through one original scientific article, two preliminary communications, one review scientific article and one essay.

Several book reviews as well as two scientific meeting reviews are also a part of this issue, but we also bring information about The Annual Fritz Jahr International Award for Research and Promotion of European Bioethics, which this year went to Jose Roberto Goldim. Feel free to pass on the information about the Award.

I would like to thank the members of the Editorial Board, peer-reviewers and all other associates included in the creation of this issue. I owe special thanks to our Language Editors for the extraordinary help given to me again.

Enjoy reading *Jahr*!

Igor Eterović

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Klea Vyshka*

The exclusion of the long-term services from Patients' Rights Directive – the issue of an ageing population

ABSTRACT

This paper presents some of the main aspects of the Directive 2011/24/EU of the European Parliament and of the Council of 9 March 2011 on the application of patients' rights in cross-border healthcare, commonly known as the Patients' Rights Directive, and as well treats the problematic exclusion of the long-term services from its scope. This Directive represents the latest EU initiative in regard to the European Health Care and the Single Market, but it is observed that the exclusion made by the Member States might lead to conclusions that the PRD is biased against the chronically ill and patients seeking long-term care, especially in an ageing Europe background that emerges in nowadays society.

Keywords: Patients' Rights Directive, cross-border healthcare, healthcare services, internal market law, long-term healthcare services, long-term care patients.

1. Introduction

In early July 2008, the European Commission introduced a proposal[1] for a Directive of the European Parliament and of the Council on the 'application of patients' rights

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1 COM (2008) 414 final. Available at: http://ec.europa.eu/health/ph_overview/co_operation/ healthcare/docs/COM_en.pdf. (last consulted 08/10/2016)

in cross-border healthcare'. Such a proposal was truly deemed as 'daring'[2] due to the fact that Member States regarded healthcare problems as an issue that should remain within the context of national policy, and because of the earlier failed attempt of the Commission to originally include healthcare services in the Services Directive 2006/123.[3] Eventually, years later this specific directive has been adopted, as a part of a broader social agenda,[4] with the ensemble of measures on healthcare which again proved the art of codifying complex case law.[5]

No doubt that health policies throughout Europe were (and maybe still are) in a 'chaordic'[6] state of being, situation which resulted from the factors such as dualism of competent authorities, both the European and national working in the field of health policies, the quite sensitive character of the health sector and rather vague treaty provisions. However, the acceptance that healthcare and other social services are services provided for the general interest, is approximated by a growing recognition at the international and national level that those rights are 'fundamental' and capable of enforcement at an individual level.[7] The Court of Justice of the European Union has already made clear[8] that market freedoms are also applicable to those areas of public policy that most national governments had explicitly excluded from the market. Therefore, healthcare is no exception and there is, as such, an EU wide access for union citizens to medical services and freedom of services which allows cross-border delivery of medical, dental, and other health services.

There was a confused conceptual background,[9] but the Commission tried to codify the Court's case law under the free movement provisions which created opportunities

2 W. Sauter, Harmonisation in Healthcare: The EU Patients' Rights Directive, p. 4.

3 See Directive 2006/123/EC OF THE EUROPEAN PARLIAMENT AND OF THE COUNCIL of 12 December 2006 on services in the internal market, Article 2 (2) (f), where healthcare services are namely excluded from the scope of the directive. For the exclusion see also S.J.H Evans, *The Services Directive: (too) great expectations? An initial overview of the rights and obligations under the Services Directive*, based on an earlier publication by E. Belhadj, S.J.H. Evans and J.W. van de Gronden, "*De Dienstenrichtlijn: de gebreken van de deugden? Een eerste verkenning van de Dienstenrichtlijn*", SEW 2007, pp. 141-153.

4 Commission Communication of 2 July 2008 on the Renewed Social Agenda: Opportunities, Access and Solidarity in 21st Europe, COM (2008) 412 final.

5 Terms used in S. De La Rosa, The Directive on Cross-Border Healthcare or the art of codifying complex case law, (2012) 49 CMLRev. 15.

6 Term borrowed by Hock, Dee W. Birth of the Chaordic Age Berrett-Koehler Publishers; 1st Edition/ 1st Printing edition (January 1, 2000) p. 67.

7 In the academic literature, this has been called 'market citizenship', see Everson M (1995) The legacy of the market citizen. In: Shaw J, More G (eds) New legal dynamics of European Union. OUP, Oxford

8 Case C-158/96 Kohll, Case C-120/95 Nicolas Decker v Caisse de maladie des employés privés, Case C-358 Müller Fauré, Case C-208/07, Petra von Chamier-Glisczinski v Deutsche Angestellten-Krankenkasse (non-exhaustive list).

9 See for more E. Szyszczak, 'Patients' rights: a lost cause or missed opportunity?', in J. Van de Gronden, E. Syszczak, U. Neergaard and M. Krajewski, Healthcare and EU Law, Legal Services of General Interest (The Hague, Asser Press, 2011) pp. 105-108.

for patients to travel abroad and receive medical treatments, and to be able to recover all or at least some of the costs from the respective Member State of affiliation. The aims of using a Directive on the Patients' Rights (PRD) are numerous and obviously deemed as very specific, which is one of the reasons why the European Parliament successfully excluded healthcare from the application scope of the Services Directive. The PRD aims to establish the general framework for efficient and accessible cross-border healthcare, also backed up by a reimbursement scheme by the Member State of affiliation of the healthcare obtained abroad. Most importantly, the PRD creates an EU set of procedural rights and guarantees for patients seeking healthcare outside of the state of affiliation. According to the PRD,[10] the cooperation between Member States on cross-border healthcare is one of the main objectives which basically transfers the sole 'patients' rights' ideas into Union principles for healthcare and further Europeanisation of healthcare issues, which became too big and important to be sheltered by only strict national outlines.

Applying the free movement principles to health care issues has actually received different approaches and interpretations, from viewing the adoption of PRD as a 'small miracle'[11] and as a major step towards harmonisation in the context of a single market, to a challenge that Member States' autonomy will face in the area of healthcare. A cursory examination through academic titles reflects this judgement: 'the virus of cross-border patient mobility...'[12]; 'Killing National Health and Insurance Systems'[13]; 'Patients' Rights: a lost cause or missed opportunity?'[14] These are just some of the titles that indicate not such a friendly approach towards the matter.

Not putting into question the steps towards building a vast single market taken by PRD, nevertheless, we might further argue in favour of several cogent arguments that seemingly remained intact by PRD's provisions. While looking at the subject matter and scope of the Directive enunciated in Article 1, we notice that actually the PRD keeps several barriers towards its aim still high, considering both recent and near future demographic changes and problems.

10 Directive 2011/24/EU OF THE EUROPEAN PARLIAMENT AND OF THE COUNCIL of 9 March 2011 on the application of patients' rights in cross-border healthcare, preamble, recital (10)

11 M. Peeters, 'Free Movement of Patients: Directive 2011/24 on the Application of Patients' Rights in Cross-Border Healthcare', 2012 European Journal of Health Law, no. 1, p. 60.

12 Kostera T (2007) Unwelcome Europeanisation—the development of cross-border patient mobility, master of European studies thesis, 2007, College of Europe, Bruges.

13 V.G. Hatzopoulos, 'Killing National Health and Insurance Systems but Healing Patients? The European Market for Health Care Services After the Judgments of the ECJ in Vanbraekel and Peerbooms', 2002 Common market law review, no. 4, p. 683.

14 E. Szyszczak, 'Patients' rights: a lost cause or missed opportunity?', in J. Van de Gronden, E. Syszczak, U. Neergaard and M. Krajewski, Healthcare and EU Law, Legal Services of General Interest (The Hague, Asser Press, 2011).

Given the above context, the purpose of this paper would be to argue about the exception that PRD is deemed not to apply to services in the field of a long-term care, which support people in carrying out routine and everyday tasks. So, it appears that the exception is aimed at individuals who find themselves in long-term care facilities, residential or nursing homes, which consequentially fall outside the scope of PRD.[15] In other terms, it means that this category of individuals have the right to travel for these purposes to another Member State, but have no right in the union law to be reimbursed for the treatment. Consequently, a protection gap towards this specific category emerges, which is only likely to increase as a result of ageing European population, taking into account demographic data and recent population studies. The main reason for applying the exclusion of services in the field of a long-term care can be found in the nature or characteristics of such services provided to the elderly population. Namely, they are not a pure form of health services, but a mix of social services as well, while the Directive has been put to regulate the domain of the health care services in particular.

It could also be argued that since the PRD is in its core a balancing act that encourages national health systems to retain their own character, this exclusion is in fact a possibility Member States to retain control over a large amount of their social security budgets.[16] But on the verge of an ageing population, which would increase the above-mentioned category, is this absolute exemption fruitful? One of the main recommendations that this paper wishes to elaborate, would be to examine possible future solutions which would balance the Member States' needs to control their social security budgets and requesting cross-border assisted living care. The PRD indeed offers much more than cross-border healthcare and finally some clarity about reimbursement entitlements. But is the PRD biased against the increasing number of that ageing category, suffering from chronic diseases and in need for long-term care, irrespective of geographical barriers? This paper will aim to answer this question in specific.

In the second section of this paper we discuss the political, legal, and economic context of the Directive and the contention of the Member States regarding the long-term care issue. After examining Article 1 (3) of the Directive, which deals with its scope and application, we will assess the legal base of this Directive, to see if we are really considering exclusion in the light of the Treaties and the case law. Indeed, in the third section we will dive more deeply in the case law built up by CJEU, starting with the leading *Luisi and Carbone* and ending with a rather questionable

15 Directive 2011/24/EU on the application of patients' rights in cross-border healthcare, Article 1

16 P. Quinn, The European Patients' Rights Directive: A Clarification and Codification of Individual Rights Relating to Cross Border Healthcare and Novel Initiatives Aimed at Improving Pan-European Healthcare Co-Operation, p.45.

judgment in *Von Chamier Glisczinski*. There are also lots of issues that long-term care services pose today. Therefore, we will discuss those issues and some attempts to possible alternatives in the fourth section, which undoubtedly will be followed by some conclusions and recommendations.

2. Political, legal and economic context of the Directive and the contention of Member States on long-term care

2.1 Background context

The regulation of healthcare issues in the EU has been since the beginning, an area of multiple discussions and reluctant behaviour from the Member States. The original EEC Treaty did not even contain any specific provisions related to health issues, whereas the Treaty of Maastricht 1992 created only a limited competence of the Community to regulate the area of public health (Article 192 EC). During the long process of evolution, the special contribution was the old Article 152 EC of Amsterdam Treaty, stating that any action by the Community in the field of public health shall fully respect the responsibilities of the Member States for the organization and delivery of health services and medical care.[17] The picture that Article 168(7) TFEU created, however, seems to expand the limits of EU in public health. Although Member States are still responsible for the definition of their health policies and the delivery of health services, they will have to include the management of health services and the allocation of resources assigned to them while performing the relevant tasks.

In this background, we can argue that the legal competence for legislation regarding public health issues at the EU level was limited, although this area was of cross-border concern. But on the other hand, social services were depicted as core values of the new vision for Europe and were included in the Lisbon Agenda 2000-2010. The Health Council as well agreed, that social services, in particular healthcare, were part of 'European Values', though without underestimating the challenges that lie ahead in reconciling individual needs with the available finances, as the population of Europe ages, expectations rise, and medicine advances.[18]

The background did not seem to be very clear at the time when the Commission attempted to deepen the codification of the Court's case law under the free movement principles, which had already created a right of patients to seek healthcare

17 The Treaty of Amsterdam 1997 raised the profile of public health issues by adding it to the list of activities of the Community in the Article 3(1) (p) EC. It also introduced a "high level of human health protection" through Community policies.

18 Statement on Common Values and Principles in EU Health Systems, Health Council 1 June 2006

in other Member States and subsequently, reclaim some, or all, of the costs of the treatments by their Member State of affiliation. And indeed, this patients' right has shown to be different from time to time. From the dual system of access to care of Regulation 1408/71/EC,[19] to the freedom to receive services in another Member State using the Article 56 TFEU[20] and more recently to Article 35 of the Charter of Fundamental Rights, which provides a right to preventive health care for everyone. Therefore, it is thought that the PRD is a step towards creating a broader framework for healthcare policy despite the few EU legislative competences to do so. During the discussion of the proposed Directive, Member States were understandably concerned about the difficulties that further developments aimed by the PRD would pose to actually accommodate its provisions with the diversity of existing national systems of healthcare.[21] Furthermore, some aspects are considered as discriminatory, especially when it comes to dealing with chronically ill patients and the long-term sick who need longer and perhaps more complex forms of long-term social and healthcare, and social security support. And in fact, during the discussion of the proposed Directive, it was difficult to find consensus within the Council on three main points, namely, legal basis for the Directive, whether long-term healthcare services (LTHC) should be included in the scope of the Directive, and the situations in which Member States can refuse prior authorisation for the hospital treatment sought abroad. Subsequently and respecting this scope of this paper, we will further discuss the now excluded long-term healthcare services and the numerous problems which this situation arise and may appear in the not too distant future.

19 For more on this see, F. Pennings 'The Draft Patient Mobility Directive and the Coordination Regulations of Social Security' in in J. Van de Gronden, E. Syszczak, U. Neergaard and M. Krajewski, Healthcare and EU Law, Legal Services of General Interest (The Hague, Asser Press, 2011).

20 The starting point is case law from CJEU, in the joined cases 286/82 and 26/83 *Graziana Luisi and Giuseppe Carbone v. Ministero del Tesoro* [1984].

21 Healthcare systems in Member States are organized according to two main models a) National Health Systems – based on the Beveridge model – which recognize a universal right for the whole population to receive (nearly) free medical care, financed from tax revenues; such systems are to be found in the UK, Ireland, Spain, Italy, Portugal, Greece, Denmark, Finland and Sweden and b) Social Insurance Systems – based on the Bismarck model – where coverage is dependant mainly upon payment of premiums. Such systems may be divided further into "benefits in kind" where the health provider gets paid indirectly by the social security institution, scheme to be found in Austria, Germany and the Netherlands and into "reimbursement systems" where the patient pays the fees but later gets reimbursed by the social security institution; such systems are present in Belgium, France and Luxembourg. By this whole picture, it is clear that National Health Systems leave very little room for the application of the free market principles. See further on this issue Jorens, *European integration and healthcare systems: EC Regulation 1408/71 between Status Quo and Upgrading*, paper delivered at the Conference: "European Integration and National Health Care Systems: A Challenge for Social Policy", Gent 7-8 Dec. 2001.

2.2 Article 1(3) (a), the exclusion of services in the field of long-term care

While drafting the PRD, one of the hottest topics of the debate was whether to include or not LTHC in the patient mobility principle. And actually, the very recognition itself of a concept such as 'long-term care' in EU's social services is a part of a long process, culminated by the emergence of new social risks which come as a result of demographic changes in the EU, further discussed in this paper. In the draft proposal, the Commission used the definition of long-term care offered by the Organisation for Economic Co-operation and Development (OECD) as 'a cross-cutting policy issue that brings together a range of services for persons who are dependent upon help with basic activities of daily living over an extended period of time.'[22] Thus, the concept of LTHC derives from the long-term care (LTC) because it would be provided to an individual patient. It is indeed difficult to set boundaries between social care and healthcare, not only towards the nature of the activity, but also the means of funding, especially when the state uses social security benefit systems to fund the possible provision of LTHC. Member States change their policies related to long-term care over time, accentuating institutional care of LTC in home care supported by professionals and community care services.[23] The degree of modernisation of LTC has therefore, posed challenges to Member States in relation to new policy designs alongside new structures for the organisation of the services. As a result, there is a great diversity in the concept of LTC in Member States, mostly because of different traditions and historical evolution, rather than strategic planning. To illustrate, in some Member States there is no definition of LTC at all,[24] whereas in other Member States there is an even more detailed definition than the one provided by OECD.[25] And of course, there are also Member States in between these limits, but which still provide a vague definition of the matter.[26] Overall, there are differences between Member States on how to provide and fund LTC but this should not be regarded as unexpected, since after all, legislative initiatives of the Commission hope to further harmonise Member States' laws and policies.

At this point, numerous questions arise. What is the nature of LTC in terms of the intramural/extramural division? Is it a social security or a health care system? How

22 The OECD health project, 'Long-term care for older people', published in 2005, available at http://www.euro.centre.org/data/1216815268_61772.pdf [last consulted 15/10/2016].

23 European Commission, *Long-term Care in the European Union,* 2008.

24 Bulgaria, Greece, Hungary, Malta, Romania, Slovenia, United Kingdom.

25 For example, in Spain LTC is defined as "the situation of a person who, on account of age, disease or incapacity and linked to lack or loss of physical, mental, intellectual or sensorial autonomy, requires assistance from (an)other person(s) or considerable help to carry out essential daily activities or, in the case of persons with a mental disability or illness, other forms of support for their personal autonomy." European Commission, *supra* n. 23.

26 For example, LTC is defined in Cyprus as "need of care due to mental or physical incapacity or social distress." European Commission, *supra*, n. 23.

should individualised care work? Should it be provided through State resources or through accredited bodies? Of course the answer to these questions requires more time but until now, the EU's response has been to monitor the Member States' approaches to LCT by collecting data through MISSOC.[27] But the Member States final choice to exclude LTHC from the scope of the PRD may not be the best option, having in mind also the fact that more cases emerge before CJEU raising issues of payments under the social security Regulation or where long-term care patients choose to seek this treatment in other Member States relying upon the free movement provisions.[28]

The exclusion of LTHC from the scope of the proposed Directive was agreed by the Commissioner for Health Vassiliou at the June 2009 Council meeting. In the 2009 version, the definition of LTHC excluded from the Directive is as follows: 'This Directive does not apply to services whose primary purpose is to support people in need of assistance in carrying out routine, everyday tasks. More specifically, this refers to those long-term care services deemed necessary to enable the person in need of care to live as full and self-determined life as possible. Thus, the Directive shall not apply, for example, to long-term care services provided in residential homes or housing ('nursing homes') by home care services or assisted living facilities.'[29]

In later versions of the draft Directive, the above mentioned exclusion was reduced to the following: 'Article 2.1 This Directive shall not apply to (a) services in the field of long-term care whose purpose is to support people in need of assistance in carrying out routine, everyday tasks,' amendment which successfully became part of the adopted PRD, and more specifically, in Article 1 (3) (a).

2.3 Legal base of the Directive and the Treaties: Are we really talking about exclusion?

The decision regarding the choice of a legal base to sustain the Directive was again one of the discussions proven to be strongly debated between the Commission and the European Parliament. Article 114 TFEU, represented the first proposed legal basis, which went through all the stages until adoption. The use of Article 114 shows that PRD aims to secure the establishment and functioning of the internal market,

27 Mutual Information System on Social Protection in the EU Member States, the EEA and Switzerland; http://www.missoc.org/index.htm [last consulted 09/10/2016]

28 Case C-70/95 *Sodemare SA, Anni Azzurri Holding SpA and Anni Azzurri Rezzato Srl v. Regione Lombardia* [1997].

29 Recital 9b COREPER draft of 26 November 2009. Subsequently, article 2(2)(a) of the revised draft Directive and finally recital 14 of the Directive 2011/24/EU OF THE EUROPEAN PARLIAMENT AND OF THE COUNCIL of 9 March 2011 on the application of patients' rights in cross-border healthcare.

and since in paragraph 3[30] it contains requirements that any harmonisation measure should guarantee a high level of protection of human health, it was initially regarded as sufficient to serve as a legal basis for the Directive. However, we could argue in favour of interest groups, which expressed their concern about the explicit linkage of Article 114 TFEU to the free movement right to healthcare services as a purely economic right, blurring as such the social character intrinsic to the idea of healthcare services.[31] In other words, if only Article 114 was used as a legal basis for PRD, this would mean a constant domination of economic integration issues, over recognising the, albeit limited, EU competence in the area of healthcare worded in Article 168 TFEU.[32] The Commission supported the idea of using a joint legal base and so did the Committee of the Regions. It was proved to be impossible to use only Article 168 as a legal basis, since the PRD aims to go beyond public health improvement measures. In fact, looking at paragraph 5,[33] it seems that there is a certain inconsistency, because it explicitly deals with the exclusion of the harmonisation of the laws and regulations of Member States.[34] It remains to be seen if this choice is going to be unquestioned by CJEU, since it has already expressed preference for only one legal basis to be used for EU legislation,[35] with an exception that two legal bases may be used only where a proposed legal instrument has two parallel aims equally binding.[36] But judging from

30 Article 114 reads: (1) Save where otherwise provided in the Treaties, the following provisions shall apply for the achievement of the objectives set out in Article 26. The European Parliament and the Council shall, acting in accordance with the ordinary legislative procedure and after consulting the Economic and Social Committee, adopt the measures for the approximation of the provisions laid down by law, regulation or administrative action in Member States which have as their object the establishment and functioning of the internal market. (2) Paragraph 1 shall not apply to fiscal provisions, to those relating to the free movement of persons nor to those relating to the rights and interests of employed persons. (3) The Commission, in its proposals envisaged in paragraph 1 concerning health, safety, environmental protection and consumer protection, will take as a base a high level of protection, taking account in particular of any new development based on scientific facts. Within their respective powers, the European Parliament and the Council will also seek to achieve this objective.

31 At the time of the draft proposal, the old Article 16 EC did not provide a legal base for legislation in the area of services of general economic interest. After the Treaty of Lisbon 2009, Article 14 TFEU allows the European Parliament and the Council to use the ordinary legislative procedure to enact regulations.

32 The reaction of national responses also ignores problems faced by regional governments in the EU. For example, in Scotland, the Scottish Parliament legislated with the NHS Reform Act 2004 to abolish the English NHS market-oriented healthcare system and re-introduced an integrate public healthcare system for Scotland, which is opposed using commercial healthcare providers in Scotland.

33 Article 168 (5) TFEU reads: The European Parliament and the Council, acting in accordance with the ordinary legislative procedure and after consulting the Economic and Social Committee and the Committee of the Regions, may also adopt incentive measures designed to protect and improve human health and in particular to combat the major cross-border health scourges, measures concerning monitoring, early warning of and combating serious cross-border threats to health, and measures which have as their direct objective the protection of public health regarding tobacco and the abuse of alcohol, excluding any harmonisation of the laws and regulations of the Member States.

34 See for this purpose also the note of the Committee of Permanent Representatives to the Council, delivered on 26 November 2009.

35 Case C-377/98 *Netherlands v. European Parliament and Council* [2001], paragraph 27.

36 Case C-165/87 *Commission v. Council* [1988], paragraph 11.

the above arguments, proving the harmony between the two Articles in this case is going to be a difficult task for the Court.

At the same time, the Directive is required to respect other Treaty provisions, namely the general subsidiarity provision in Article 5 TFEU, but also provisions such as Article 6(a); 2(5) and 168(7), which contains a special subsidiarity clause with respect to the responsibility of Member States for the organisation and delivery of healthcare. Nevertheless, CJEU has already clarified in *Müller-Fauré* and *Watts* that this provision does not mean that adjustments to national systems may not be required by other Treaty provisions, such as Article 56 TFEU on the freedom to provide and receive services.[37]

However, according to the previous case law of CJEU, the relationship between Treaty provisions and the Directive is going to be even broader than this. To explain the following, let us draw some parallels regarding Regulation 1408/71, subsequently replaced by Regulation 883/2004,[38] the core subject matter of *Kohll* and *Decker* case law, which according to the legal scholars' opinion opened up the market[39] of healthcare services. Briefly, these cases concerned the possibility of persons who had not obtained the prior authorisation provided in the Regulation, to receive refund of health expenses incurred in another Member State. The Court stated that the existence of the Regulation does not preclude the application of Treaty rules and went on to interpret the two in a complimentary way. So, the authorisation procedure provided in the Regulation allows the patient 'to receive sickness benefits in kind, on account of the competent institution but in accordance with the provisions of the legislation of the State in which the services are provided... without that person incurring additional expenditure.'[40] On the other hand, relying on the Treaty provisions alone, someone may claim 'reimbursement of costs incurred in connection with treatment provided in another Member State,' but only at the tariffs in force in the State of insurance.[41] Therefore, the Court treats the Regulation as a specific application of the general Treaty rules on free movements and not as the only occasion in which social security funds may be called upon to reimburse expenses incurred in other Member States. This logical sequence might follow also the interpretation of the PRD in relation to long-term healthcare patients who seek treatment abroad. Since the PRD does not grant the right to have such treatment

37 Case C-358/99 *Müller-Fauré*, paragraph 102 and Case C-372/04 *Watts*, paragraph 147.

38 Regulation (EC) No 883/2004 of the European Parliament and of the Council of 29 April 2004 on the coordination of social security systems (OJ L 166 of 30 April 2004, p. 1).

39 Barnard C, *The substantive law of the EU: the four freedoms* (Oxford University Press 2016), p. 315-316.

40 *Kohll paragraph 26* and *Decker* paragraph 28.

41 *Kohll* paragraph 27 and *Decker* paragraph 29.

reimbursed,[42] patients might try to obtain this reimbursement consequently, relying on the general Treaty rules. It remains to be seen if this is going to be successful and effective, having also in mind the previous case law of CJEU on this matter, which we will discuss in the next section. But overall, having in mind the close relationship between the PRD and Regulation 883/2004,[43] the existence of which basically sets two alternative procedures of reimbursing costs of cross-border healthcare, the above argument might effectively be used in favour of such long-term healthcare patients, trying to invoke their rights against the exclusion.

3. The art of codifying complex case law

3.1 Brief analysis of leading cases *Luisi and Carbone* and *Kohll and Decker*

In order to better understand the background of the PRD and perhaps to hollow out the roots of the long-term healthcare exclusion, let us turn briefly into explaining some pivotal judgments delivered by the Court of Justice in respect of opening the internal market as well the healthcare services. Maybe the line of case law would have been hard to follow without the *Luisi* and *Carbone* judgment of 1984,[44] in which the Court held that 'freedom to provide services includes the freedom for the recipients of such services to go to another Member State in order to receive them there, without being obstructed by restrictions, even in relation to payments and that tourists, person receiving medical treatment, and persons travelling for the purpose of education or business are to be regarded as recipients of services.'[45] The deep meaning of this judgment can be traced in the Court's endeavours to change its perspective, moving beyond the merely economic dimension of trade in services and opening a door towards the subjective rights of citizens as such. The mentioning of education and medical treatment as examples of services seems to further strengthen the above argument. However, after the *Luisi* and *Carbone*, the possibility created by the Court remained open for many years, without anybody making use of it. This was until 1998 when the Court had another chance to move forward with the *Kohll* and *Decker* cases.[46]

42 It should be noted that there is nothing in the Directive 2011/24/EU to stop national social security systems or local organisations with such responsibilities to negotiate their own agreements with organisations that provide services in other Member States if they wish to.

43 See for this matter M. Peeters, 'Free Movement of Patients: Directive 2011/24 on the Application of Patients' Rights in Cross-Border Healthcare', 2012 European Journal of Health Law, no. 1, pp. 29-60.

44 Joined Cases 286/82and 26/83 *Luisi and Carbone* [1984].

45 *Luisi and Carbone*, paragraph 16.

46 Case C-158/96 *Kohll* and Case C-120/95 *Decker* [1998].

Since the *Luisi* and *Carbone* was a breakthrough case, it did not really give too many details for the subject matter. It was with the following *Kohll* case, that according to the academic opinion, shivers passed through all social security and healthcare funds.[47] According to the Court, 'the special nature of certain services does not remove them from the ambit of fundamental principle of movement.'[48] In the *Decker* judgment, the Court ruled that the free movement of goods should also be respected by national social security and healthcare schemes. The clear confirmation from the Court's side that Regulation 1408/71 on social security does not exhaust the field and has to be compatible and interpreted in accordance with the free movement rules that were mentioned even earlier in this paper.

In such cases, Member States should reimburse the patient on the same terms as if the treatment had been received within the territory. Prior authorisation according to the Court, could not be either justified by the need to preserve the financial balance of the medicinal and hospital system of the Member States, because since the reimbursement scheme is governed by the Member State's of affiliation policies, the cost of treatment remains constant regardless of the place where Mr. Nicolas Decker bought his glasses, or where Aline Kohll had a dentist visit. What still was not clear after the *Kohll* and *Decker* judgment was to what extent these rules would be applicable in treatment offered in a hospital infrastructure.[49] Nevertheless, the Court confirmed and extended the ambit of *Kohll* judgment in *Vanbraekel and Peerbooms*.[50]

Von Chamier-Glisczinski

Until now, we have seen approaches of CJEU towards both extramural and intramural cases of healthcare services. But where did then the exception that Member States included in the PRD, to exclude long-term healthcare services from the harmonisation aims of the present directive originate? It is difficult to be sure,

47 V.G. Hatzopoulos, 'Killing National Health and Insurance Systems but Healing Patients? The European Market for Health Care Services After the Judgments of the ECJ in Vanbraekel and Peerbooms', 2002 Common market law review, no. 4, p. 688.

48 Case C-158/96, *Kohll,* [1998] ECR I-1931, paragraph 20. This line has afterwards been repeatedly cited by the Court in following judgments.

49 Opinion of Advocate General Saggio, delivered on 18 May 2000, for the *Vanbraekel* case C-368/98, paragraph 11.

50 The Court confirms its expansive approach to the notion of economic activity when confronted also with health services provided in hospitals with this case. The Court also introduced a number of well-known procedural requirements to be fulfilled if a prior administrative authorisation is deemed to be justified. These can be found at Case C-368/98 Vanbraekel and others [2001] ECR I-5363; ECJ, Case C-157/99 Smits and Peerbooms [2001] ECR I-5473, paragraph 90.

but the exception according to some authors[51] intends to reflect the judgment in Von Chamier-Glisczinski.[52] This lady, a German national, received from the Deutsche Angestellten-Krankenkasse combined benefits in kind and cash, as provided in the German law. When her husband decided to move to Austria, Mrs Von Chamier-Glisczinski also was put in a care home in the same state. At this point, the Krankenkasse continued delivering the monetary benefits, but stopped the full in-patient care, since that was a benefit in kind which could not be exported to Austria. After this, Mrs Von Chamier-Glisczinski sought in German courts the right to reimbursement of the costs linked to her stay in the Austrian care home, with the main argument that benefits in kind after all correspond to cash benefits and that they can be converted. Therefore, according to this point of view, there is no actual prevention for the possibility of exporting them. The German court decided to refer a preliminary question to CJEU asking whether social security regulation or the provisions on the free movement were opposed to such situation.

The Court basically stayed in line with its previous case law *Molenaar,*[53] stating that in-house care is a benefit in kind and that Regulation 1408/71 does not impose obligations to the State of affiliation to continue serving it. However, this does not mean that the competent institution is exempted of its duties to grant it, probably meaning that the Regulation remains neutral towards this matter. Subsequently, the Court recalls the Kohll and Decker principles, stating that the situation existing at the main proceedings does not prevent the person concerned from claiming, pursuant to primary law, the payment of certain costs relating to care received in a care home situated in another Member State.[54] However, provisions on the free movement of workers and services were not applicable, because first, there was no element proving Mr Von Chamier-Glisczinski as a worker and second, Mrs Von Chamier-Glisczinski had moved to Austria on a permanent basis. It looked that the judgment would make a positive turn for the German lady, when the Court mentioned that she nevertheless, enjoyed the status of an EU citizen, but CJEU instead of applying the test of barrier, justification and proportionality, it said that Article 42 EC,[55] provides for coordination and not harmonisation of the Member States' legislation. Therefore, this cannot guarantee that a move of an insured person to another Member State would be neutral as regards social security.

51 P. Quinn, P. de Hert, The European Patients' Rights Directive: A Clarification and Codification of Individual Rights Relating to Cross Border Healthcare and Novel Initiatives Aimed at Improving Pan-European Healthcare Co-Operation, p. 45.

52 Case C-208/07, von Chamier-Glisczinski [2009] ECR I-6095.

53 Case C-160/96 Molenaar [1998] ECR I-843.

54 Case C-208/07, von Chamier-Glisczinski [2009] ECR I-6095, paragraph 66.

55 Now Article 48 TFEU on social security of migrant workers; see also Case C-208/07, von Chamier-Glisczinski [2009] ECR I-6095, paragraph 84.

The Court's legal persuasiveness in this point appears to be vague, since there is a sort of contradiction between the earlier statement and what was said in paragraph 66 to the effect that the Regulation does not interfere with the application of primary law. Why did the Court accept this argument now, instead of following the usual line, stated also on the *Vanbraekel* case? There is not much choice, but to wait and see if CJEU will develop further practice in the light of the strict as opposed to the more lenient approach.

4. Issues that the LTHC poses today

4.1 Demographical changes, the future of an old Europe

'Driven by population ageing, the big challenge of long-term care systems is to meet the needs of a growing number of older people at risk of suffering from frailty and disability, while keeping costs affordable and public finances sustainable.'[56] This is the opening sentence of the joint report on healthcare and long-term care systems, prepared by the staff of European Commission's Directorate General for Economic and Financial Affairs and the Economic Policy Committee. The fact that the size and age structure of Europe's population is going through important changes was and still remains an uncomfortable truth, reckoned by the highest Union institutions. Although it is true that all age groups can benefit from long-term care services, the majority of the patients consist of those in retirement age.[57] According to the joint report on healthcare and long-term care systems, the development of LTC policies is facing three big challenges today.[58] First, as estimated, the number of Europeans aged +80 will be constantly increasing and being in such conditions, this specific population will most likely require a combination between both medical and social care in a continuous basis. Second, according to studies, a foreseeable shift from informal house care towards formal care-giving is expected, forwarding such bill from family members of the patient, to the state's social security systems. Lastly, LTC makes an unquestionable growing share of GDP and public spending,[59] which is not

56 Joint Report on Health Care and Long-Term Care Systems and Fiscal Sustainability Prepared by the Commission Services (Directorate-General for Economic and Financial Affairs), and the Economic Policy Committee (Ageing Working Group) Volume 1, chapter 5, p. 155.

57 Report of the European Social Network, *Services for older people in Europe*, published October 2008, page 2.

58 Joint Report on Health Care and Long-Term Care Systems and Fiscal Sustainability Prepared by the Commission Services (Directorate-General for Economic and Financial Affairs), and the Economic Policy Committee (Ageing Working Group) Volume 1, chapter 5, p. 155.

59 Joint Report on Health Care and Long-Term Care Systems and Fiscal Sustainability Prepared by the Commission Services (Directorate-General for Economic and Financial Affairs), and the Economic Policy Committee (Ageing Working Group) Volume 1, chapter 2, pp. 16-37.

a rather easy challenge for Member States, construing as such one of the reasons why there is an exclusion in respect of LTC in the Directive scope of this paper.

The above mentioned joint report frames the main policy elements, referring as such categories of budgeting and performance assessment, institutional arrangements, and specific policy tools for LTC system design. Overall, the joint proposal concludes that driven by population ageing, the challenge of LTC services is to meet the demand consequently in rise, while still keeping the costs affordable and public finances sustainable. The government officials stress that demographic changes have caused increasing costs of LTC services and as well the population expectations for better care services do not seem to help much in solving the issue. The core problem though, seems to be the huge discrepancies that exist among Member States. They have different approaches towards LTC services, different descriptions of what falls under a long-term service or not, different traditions into offering such care, different governance, which might be centralised or decentralised, and many different ways in which they finance LTC services, including the public-private financing mix, the sources of public funding and the levels of governments involved in the financing of services. The picture, as it stands, is indeed chaotic.

Demographic change happens at a different pace in each country. According to the OECD, it is estimated that by 2050 one third of the population in Poland, Italy, and Germany will be over 65 years old. In that time, the share of the elderly population in Belgium, Sweden and the UK will be around 25% of the total population.[60] Basically, it is expected that by 2040 those older than 80 years will constitute a share of the total population which will be more than twice the current proportion.[61] Also, while translating this into costs and expenditure for the Member States, the Economic and Financial Affairs Council (ECOFIN) requested the Economic Policy Committee (EPC) to provide age-related public expenditure projections, and it resulted that in all cases long-term care expenditure increases more than that of the health care, based on estimations carried out previously.[62] In the end, it is clear that now Europe is facing a major natural challenge, which is exactly the ageing of its population. As mentioned, this is a purely natural process, albeit influenced by low birth rates and increased life expectancy, which is not necessarily deemed to be a totally negative phenomenon. On the contrary, a possible further harmonisation of policies and

60 OECD Demographic and Labour Force database (July 2006), accessible at https://data.oecd.org/pop/elderly-population.htm#indicator-chart [last consulted 11/10/2016].

61 The Survey of Health, Ageing and Retirement in Europe (SHARE), which is the main source of comparable data on the number of old people that cannot perform activities of daily living due to physical limitations. http://www.share-research.org/ [last consulted 11/10/2016].

62 Accessible at http://ec.europa.eu/economy_finance/publications/publication922_en.pdf [last consulted 11/10/2016].

legislation towards these services on a Union scale by the Member States will put the European Union at the front line of protecting this category of persons in need of care, setting such a good example of what good and enjoyable ageing should be.

4.2 More challenges to the exclusion principle

Given the above arguments, we might think that after all, Member States had their own strong reasons for being reluctant into including the LTC services in the scope of the Patients' Rights Directive. According to the above mentioned arguments, something needs to be done and some harmonisation needs to prevail into Member States' national policies and laws regarding elderly care and LTC services, if the Union wishes to remain faithful to its social agenda. On 25 October 2013, exactly the deadline for transposition of the PRD into national law, the European Commissioner for Health, Tonio Borg, made a public statement, stating among others that: 'Today is an important day for patients across the European Union. As of today, EU law in force enshrines citizens' right to go to another EU country for treatment and get reimbursed for it. From today, all EU countries should have transposed the Directive on Patients' Rights in Cross-border Health Care, adopted 30 months ago, into their National law. For patients, this Directive means empowerment: greater choice of healthcare, more information, easier recognition of prescriptions across-borders (...). For patients to benefit from the rights granted by EU law, the law needs to be properly transposed and enforced. The Commission has provided a great deal of support to Member States during the transposition period. Now I urge all Member States to deliver on their obligations and fully transpose this Directive.'[63]

Clearly, the last sentence is a very diplomatic one, suggesting that not all Member States had completed the transposition process, which is something that happens rather frequently in most of the cases. But the true 'problem' is that although the PRD is binding in all its legal contents, the very fact that we are dealing with a directive, leaves the door opened to its implementation by the Member States. In our context, as we have mentioned before, it is true that LTC services do not fall within the scope of PRD, but this anyway does not prevent Member States or social security institutions in concluding agreements between them, as long as they are in conformity with the Treaties, and in principle with all primary legislation of EU law. Maybe a few good examples in the future will pave such a way.

63 Available at http://europa.eu/rapid/press-release_MEMO-13-932_en.htm [last consulted 11/10/2016].

Additionally, some legal scholars,[64] acknowledging the fact that the Directive itself is not free of ambiguity, draw our attention at the preamble (Recital 14) which is very 'vague and short' regarding the exclusion of the long-term services from the general scope of the PRD: 'This Directive should not apply to services where the primary purpose is to support people in need of assistance in carrying out routine, everyday tasks.' Righteously, the author argues that this formulation seems to target social care and support, which in the end are not part of healthcare at all. While the second part of the recital is to clarify the ambiguous first statement, it actually creates more confusion. It seems that also a care of mixed nature (healthcare and social care) is excluded on the basis of being a long-term one. As we have already mentioned, the number of patients seeking these services is growing and due to their special circumstances, it is difficult to distinguish a line between *social* and *health* care. In this sense, the PRD may be seen as discriminatory[65] and create a new line of case law in the bench of CJEU.

4.3 Impact analysis of PRD and some discussions on alternatives

Given the enthusiasm with which a Directive on patients' rights was awaited, it is normal to expect also a certain degree of curiosity in the legal opinion[66] concerning the results of its transposition into national law. Has the patient mobility increased after the adoption and if so, to what extent? Will healthcare actors adopt the cooperation opportunities and will this lead to an accessible European system of healthcare? On September 2015, the European Commission drew a report[67] on the operation of the Directive, highlighting the main issues in the course of the transposition years and most importantly, the features of current patient mobility.

The report states that the transposition process was somehow neglected by the Member States, since infringement proceedings were launched against twenty six of them on the grounds of late or incomplete notification of the measures adopted.[68] However,

64 Herman Nys, editorial of the European Journal of Health Law 21 (2014), The Transposition of the Directive on Patients' Rights in Cross-Care Healthcare in National Law by the Member States: Still a Lot of Effort to Be Made and Questions to Be Answered, pp. 1-14.

65 E. Szyszczak, 'Patients' rights: a lost cause or missed opportunity?', in J. Van de Gronden, E. Syszczak, U. Neergaard and M. Krajewski, Healthcare and EU Law, Legal Services of General Interest (The Hague, Asser Press, 2011), page 111; See also P. Quinn, P. de Hert, The European Patients' Rights Directive: A Clarification and Codification of Individual Rights Relating to Cross Border Healthcare and Novel Initiatives Aimed at Improving Pan-European Healthcare Co-Operation, p. 46.

66 M. Peeters, 'Free Movement of Patients: Directive 2011/24 on the Application of Patients' Rights in Cross-Border Healthcare', 2012 European Journal of Health Law, no. 1, pp. 50-51.

67 Commission report on the operation of Directive 2011/24/EU on the application of patients' rights in cross-border healthcare, COM(2015) 421 final, Brussels 04/09/2015.

68 COM(2015) 421 final, p. 3.

subsequently only four of these proceedings remained open and all four Member States had made commitments to fix the problems as soon as possible. In later years, the correctness of the transposition will be assessed by the Commission. The feature that needs to be looked upon with interest in the report is the data collection of patient flows. The Commission says that patient flows for healthcare abroad under the Directive are low. But this seems to be the issue concerning even the Social Security Regulation, whilst patient mobility, in terms of unplanned healthcare, is higher. The exceptions of this general observation are only France, Luxembourg, and to some extend Finland and Denmark, but generally, the usage of planned healthcare is far below the number suggested by Eurobarometer of people that expressed their interest in experiencing cross-border healthcare.[69]

This might come as a surprise, but we still have to bear in mind that a number of Member States were late with the implementing process and that the data was collected during 2014, meaning that the transposition deadline had not expired yet. Secondly, as indicated by Eurobarometer,[70] the number of citizens who are well-informed about their right to reimbursement is very low. There are also some natural reasons for this, including the unwillingness to travel due to family proximity, language barriers or acceptable waiting times in the national health system.

According to Article 20 of the Directive,[71] the Commission will draw similar reports every three years, so for a full picture of the facts and figures, we would have to wait until September 2018. By the above data, if we were to make a parallel line to the LTC service seekers, we would expect nevertheless a constant growth of their willingness to receive such treatment abroad, also due to the facts already mentioned earlier. Also, when there is an identification of such patients by the National Contact Point, data should be recorded in order to fill out further impact assessments.

Authors[72] call the PRD 'waiting time Directive', in principle entitling patients only to reimbursement for treatments (when they are subject to prior authorisation, but most hospital treatments are) that cannot be provided within a reasonable time in the Member State of affiliation. If this is the case, would it be appropriate to adopt the same approach towards LTC services? After all, it should be noted that the exclusion of LTC from the scope of the Directive, does not mean that care-homes or even Member States cannot conclude cross-border agreements to facilitate this type of

69 Special Eurobarometer 425 / Wave EB82.2 – TNS Opinion & Social, available at http://ec.europa.eu/public_opinion/archives/ebs/ebs_425_sum_en.pdf [last consulted 12/10/2016].

70 *Ibid.*

71 Directive 2011/24/EU OF THE EUROPEAN PARLIAMENT AND OF THE COUNCIL of 9 March 2011 on the application of patients' rights in cross-border healthcare, Article 20.

72 M. Peeters, 'Free Movement of Patients: Directive 2011/24 on the Application of Patients' Rights in Cross-Border Healthcare', 2012 European Journal of Health Law, no. 1, p. 57.

patient mobility. Maybe a local action would be followed by a more 'European' one. Also, another thing we should bear in mind is that 'negative' judgments by CJEU such as Von Chamier-Glisczinski were issued before several developments reinforcing Europe's social dimension occurred. Thus, with entry into force of TFEU introducing the social progress clause in Article 9 or Article 168 expanding Union's competences in the field of public health and by a legally binding Charter of Fundamental Rights, the outcome of the ruling, might have been different.

5. Conclusions and recommendations

Predominantly, this article tends to agree that the adoption of Patients' Rights Directive is a crucial event in the cross-border healthcare area. With a correct transposition of this Directive, European patients can expect some clarity with respect to reimbursement proceedings and of course, more detailed information and support regarding their rights to cross-border healthcare. Overall, there is a diversity of services (health and/or social) and in this case they posses different natures, modes of application and reimbursement processes, which are equally a matter of assessment. An important relationship between national legislation and European regulations (minimum harmonisation regulations) can also be observed, as there is a different degree of development of health systems between Member States, and otherwise unified solutions could create problems. In the end, if this Directive is deemed to be biased against chronically ill patients and LTC seekers, this is for CJEU to decide after the transposition transitional period has ended and first cases come to knock on the Court's door.

After the exclusion of healthcare services from the scope of the Services Directive, it is natural that the PRD now presents itself as one of the most important legislative measures adopted by European health law. Coming to the end of this paper, we would recommend that in subsequent developments, EU's actions should respond to the new challenges brought in the table by social and demographic changes, considering drafting a specific proposal with regard to cross-border long-term care services.

And probably this should be the way to approach this exclusion. The fact that it was particularly difficult to find a political will of Member States, given the diversity of their national healthcare systems, and the not so supported idea to share their competences in organising healthcare systems provides a strong argument in favour of the LTC exclusion. But in the light of future developments, maybe this should be approached as an EU's intent to give more time and focus primarily on harmonising LTC policies within Member States, and then decide to adopt a harmonising legislation in cross-border LTC. The population of Europe is in a continuous ageing

process; therefore measures should be taken with regard to providing LTC and making them accessible through the internal market, backed up by reimbursement schemes or social security ones.

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Isključenje dugoročne skrbi iz Direktive o pravima pacijenata – pitanje starenja stanovništva

SAŽETAK

Rad predstavlja neke od glavnih aspekata Direktive 2011/24/EU koju su Europski parlament i Vijeće donijeli 9. ožujka 2011. Direktiva se odnosi na primjenu prava pacijenata u prekograničnoj zdravstvenoj skrbi, uobičajeno poznatoj kao Direktiva o pravima pacijenata, i tretira problematično isključivanje dugoročnih usluga iz svog djelokruga. Ova Direktiva predstavlja najnoviju inicijativu Europske unije u odnosu na europsku zdravstvenu skrb i jedinstveno tržište, ali se primjećuje da bi isključivanje od strane država članica moglo dovesti do zaključaka da je Direktiva pristrana prema kronično bolesnim pacijentima i pacijentima kojima je potrebna dugoročna skrb, osobito u europskoj pozadini sve starije populacije koja se pojavljuje u današnjem društvu.

Ključne riječi: Direktiva o pravima pacijenata, prekogranična zdravstvena zaštita, zdravstvene usluge, zakon o unutarnjem tržištu, dugoročne zdravstvene usluge, pacijenti kojima je potrebna dugoročna skrb.

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Does the Distinctiveness of Palliative Care Research Require Distinct Ethical Guidelines?

ABSTRACT

Palliative and end of life care is changing, becoming more widespread and improving for patients. Yet, the current literature in the field suggests that the evidence for palliative and end of life care is somewhat limited. Research on treatment decisions, family care, and advance directions are just a few of the areas that need rigorous research efforts. Palliative care research is essential in order to continue providing effective treatments to those suffering in the last stages of life. Indeed, the goal of good palliative care research is to relieve suffering and to improve quality of life. Similar to any other field, palliative care programs must develop on a research base, and patient care will suffer if it is not backed by sound research. However, weighted against this need are some who maintain that the ethical and practical challenges of palliative care research are unique and insurmountable. This analysis considers if distinct ethical guidelines are needed for palliative care research.

Keywords: palliative care; palliative sedation; vulnerability; end-of-life care; risk-benefit analysis; decision-making capacity.

Introduction

Palliative and end of life care is changing in many parts of the world, becoming more widespread and improving for patients. The current literature in the field of palliative medicine suggests that the evidence for palliative and end of life care is limited.[1] The American Academy of Hospice and Palliative Medicine released a statement

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1 Marcia Grant, Ronit Elk, Betty Ferrell, R. Sean Morrison, and Charles F. von Gunten, "Current Status of Palliative Care—Clinical Implementation, Education, and Research," *CA: A Cancer Journal for Clinicians,* 59 (2009), 332.

in late 2014 emphasizing that many palliative care decisions and interventions lack sufficient evidence to either recommend or not recommend.[2] Research on treatment decisions, family care, and advance directions are just a few of the areas that need rigorous research efforts. Resources for such research, although limited, have begun to fund needed studies.[3] Palliative care research is essential in order to continue providing effective treatments to those suffering in the last stages of life. Indeed, the goal of good palliative care research is to relieve suffering and to improve quality of life.[4] Similar to any other field, palliative care programs must develop on a research base, and patient care will suffer if it is not backed by sound research.[5] However, weighted against this need are some who maintain that the ethical and practical challenges of palliative care research are unique and insurmountable.[6]

While we must not take lightly the fact that palliative care researchers confront an array of ethical dilemmas, does the distinctiveness of palliative care research require distinct ethical guidelines? That is, do the ethical issues that arise in palliative care research extend beyond those of standard research trials? Thus, at the heart of this debate is the question of whether palliative care research creates new or unique ethical challenges. The answer to this question will have significant implications for the design and conduct of palliative care research.[7]

This analysis will consider three arguments that may be raised to support the claim that palliative care research raises distinct ethical issues. The three arguments that will be considered are that: 1) Palliative care patients are especially vulnerable; 2) Research investigators must obtain consent from patients and families; and 3) The risks and benefits of palliative research are difficult to assess. These three arguments are considered here because the literature suggests they are the issues that are most disturbing to investigators, healthcare providers, and the public.[8] All three of the arguments outlined above may create considerable challenges for palliative care investigators. Nonetheless, the central thesis of this analysis is that the

2 American Academy of Hospice and Palliative Medicine, Statement on Palliative Care Research, November 2014: http://aahpm.org/positions/research-ethics

3 Grant, et. al., "Current Status of Palliative Care—Clinical Implementation, Education, and Research," 332.

4 David Casarett, "Ethical Issues in Palliative Care Research," in *Oxford Textbook of Palliative Medicine*, 4th edition, edited by Geoffrey Hanks, Nathan Cherny, Nicholas Christakis, Marie Fallon, Stein Kaasa, and Russell Portenoy, 416-21, (New York: Oxford University Press, 2011) 416.

5 Neil MacDonald and Charles Weijer, "Ethical Issues in Palliative Care Research," in *Oxford Textbook of Palliative Medicine*, 3rd edition, edited by Derek Doyle, Geoffrey Hanks, Nathan Cherny and Kenneth Calman, 76-83. (New York: Oxford University Press, 2004), 77.

6 A.M. Jubb, "Palliative Care Research: Trading Ethics for an Evidence Base," *Journal of Medical Ethics* 28, no. 6 (2002): 342.

7 David J. Casarett and Jason H.T. Karlawish, "Are Special Ethical Guidelines Needed for Palliative Care Research?" *Journal of Pain and Symptom Management* 20, no. 2 (2000): 130-31.

8 Casarett and Karlawish, "Are Special Ethical Guidelines Needed for Palliative Care Research?" 131.

issues of vulnerability and informed consent do not merit requiring distinct ethical guidelines. However, there does appear to be distinct ethical challenges in analyzing risks and benefits in palliative care research, though it does appear these challenges are surmountable. This analysis will proceed by initially providing an overview of the research process and its relation to palliative care. It will then analyze the human rights concerns of vulnerability and informed consent that come into focus when conducting research on palliative care patients. An examination of the argument that assessing risks and benefits in palliative care research is difficult, which is somewhat distinct to this field, follows. Lastly, further considerations to protect research participants, including the ideas of compassion and vigilance, are brought forward.

Research Ethics

The development of contemporary research ethics has been quite difficult. From a historical perspective, paternalism has held a prominent place in healthcare for the majority of its past. Further, the crimes against humanity committed by the Nazi regime under the guise of human research, and more recent offenses such as the Tuskegee syphilis experiments that were not concluded until 1972, still resound clearly in the field of research ethics. It is against this challenging background that research ethics evolved.[9] This section considers the research process and its application to palliative care.

The Research Process and Palliative Care

Clinical trials provide the strongest evidence for the effectiveness, efficiency, and acceptability of clinical interventions. Without evidence from clinical trials, clinicians lack an important source of information to guide their practice. This may be a particular issue in palliative medicine where clinical research has not evolved at the same pace as palliative care programs. The result of this has been limited evidence for many of the interventions used in palliative care. Indeed, many pharmacological interventions that are in common use in palliative care have not been robustly tested in broad clinical trials.[10] Yet, as in any other healthcare field, clinicians have

9 Franz-Josef Illhardt and Henk ten Have, "Research Ethics in Palliative Care," In *The Ethics of Palliative Care: European Perspectives*, edited by Henk ten Have and David Clark, 198-211, (Buckingham, England: Open University Press, 2002), 202.

10 Yolanda Zuriarrain Reyna, Michael I. Bennett, and Eduardo Bruera, "Ethical and Practical Issues in Designing and Conducting Clinical Trials in Palliative Care," in *Research Methods in Palliative Care,* edited by Julia M. Addington-Hall, Eduardo Bruera, Irene J Higginson, and Sheila Payne, 27-41, (New York: Oxford University Press, 2007), 27.

an obligation to provide the best possible treatment and care to patients at the end of their lives. The only way to ensure that high medical standards are established and maintained is through an understanding of the pathophysiological processes in patients with advanced disease and by evaluating the treatments that are employed using the most robust methodology possible.[11] Therefore, if palliative care patients are to receive the best imaginable care, an appropriate evidence base that is grounded in clinical research must be furthered. Hence, clinical trials are a key part of good clinical practice, even in the palliative care setting.[12]

The first question that palliative care investigators face in designing an ethical research study is whether it is research or quality improvement (QI). This decision is very significant and has profound implications for both the study's design and the ethical standards to which it will be held. For example, US federal law requires research projects be approved by local IRBs to ensure that informed consent is obtained from each subject, that research risks are reasonable in relation to expected benefits, and that subjects are recruited in an equitable fashion. In comparison, there are few widely accepted standards that govern QI. In many situations this delineation is clear. However, QI activities often share many of the characteristics of research. For instance, both QI and research involve systematic data collection methods, both may apply statistical methods to test hypotheses, establish relationships among variables, and evaluate outcomes, and both are designed to produce knowledge that could benefit patients other than those directly involved in the activity. Therefore, QI and research activities can at times be difficult to distinguish, and may be particularly difficult in end-of-life research. This may result in confusion and conflicting opinions from IRBs that review study protocols.[13]

The research process in the healthcare setting unfolds within a series of particular stages. The basic idea and hypothesis must first be elaborated. Despite having a clear hypothesis about the outcome of the trial, it is essential that this is merely an assumption and the investigator does not have evidence or an overwhelming belief to the contrary. Indeed, there is a consensus that at the beginning of a trial that compares two or more treatments, an honest null hypothesis must exist.[14] This state of not knowing the outcome is called "equipoise," and it is an essential component

11 Geoffrey Hanks, Stein Kaasa, and Karen Forbes, "Research in Palliative Care," in Oxford Textbook of Palliative Medicine, 4th edition, edited by Geoffrey Hanks, Nathan Cherny, Nicholas Christakis, Marie Fallon, Stein Kaasa, and Russell Portenoy, 361-74 (New York: Oxford University Press, 2011): 362.

12 Reyna, et. al., "Ethical and Practical Issues in Designing and Conducting Clinical Trials in Palliative Care," 27.

13 David Casarett, "Ethical Considerations in End-of-Life Care and Research," *Journal of Palliative Medicine* 8, no. supplement 1 (2005), S149.

14 MacDonald and Weijer, "Ethical Issues in Palliative Care Research," 80.

of ethical research.[15] Once a research goal has been identified, it is then necessary to work out how to achieve it in a reliable way.[16] This is followed by the design of the methodological procedure and creating the research study protocol. An ethics review board must then approve the research protocol. The purpose of these reviews is to safeguard the rights and welfare of human research subjects. They examine risks to human subjects, ensure that consent is properly attained, and certify that the overall design of the study is scientifically sound.[17] Once the protocol has been approved it may then be carried out. The results of the study, which may take a significant amount of time to collect, will be analyzed. New medical interventions and treatments may be developed on the basis of what is learned by the study.[18] Palliative research does present unique issues over other forms of medical research. The end result of palliative care is always the same: a deceased patient, and family and friends that are left in mourning. In palliative research, it is unlikely that the patient and his family would experience any benefit from presumed new interventions as patient's lifespan is very limited, and this perspective should be described in detail in the research design. For healthcare providers, one of the hardest questions in palliative medicine is how to tell the truth but leave room for hope.

Research in healthcare is distinguished from research in other areas because it has a particular objective and because it typically involves the participation of human subjects. The objective of research in healthcare is focused on finding novel or better methods of treatment. To achieve this aim, there must be a continual effort within the healthcare sector to generate new data that can be applied to the medical care of patients who are suffering due to limited treatment options and a deficiency of medical knowledge. Thus, new studies must be constantly initiated in order to improve the current standards of treatment and better patient care. Further, the participation of human subjects is a distinguishing mark of medical research. Prior to clinical research on humans, animal experiments are performed and their results are analyzed and the drug or new therapy must be approved for clinical trials in human subjects.[19]

As this analysis shifts to palliative care research in particular, it is important to clarify what is meant by the term. The World Health Organization defines palliative care as "an approach that improves the quality of life of patients and their families facing the

15 Michael I. Bennett, "Principles of Designing Clinical Trials in Palliative Care," in *Research Methods in Palliative Care,* edited by Julia M. Addington-Hall, Eduardo Bruera, Irene J Higginson, and Sheila Payne, 13-26, (New York: Oxford University Press, 2007), 14.

16 Claire Foster, *The Ethics of Medical Research on Humans*, (New York: Cambridge University Press, 2001), 21.

17 U.S. Food and Drug Administration. "Institutional Review Boards Frequently Asked Questions – Information Sheet." http://www.fda.gov/RegulatoryInformation/Guidances/ucm126420.htm

18 Illhardt and ten Have, "Research Ethics in Palliative Care," 200.

19 Illhardt and ten Have, "Research Ethics in Palliative Care," 200-01.

problem associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual".[20] This article is particularly concerned with the physical aspect of palliative care and its research. The benefits of palliative care research to future patients seem fairly obvious, for if palliative care research is designed to produce knowledge that will advance end of life care, then implicit in this goal is the expectation that this knowledge will improve care for future patients. These benefits to future patients may be described in terms of the study's validity and value. Palliative care researchers must use methods in their research that can be agreed upon by peer reviewers; thus, their study methods must be valid. All studies must further be designed in such a way as to produce knowledge that is generalizable. That is, the research findings need to be able to be extended to the population at large. Validity is a threshold requirement for all research, because, as it has been recognized, it is unethical to expose participants to research risks that peer reviewers agree cannot answer a research question.[21]

Moreover, the study's value must be taken into account. As defined broadly, value can be taken as the likelihood that the study's results will improve the health and wellbeing of future patients. Validity is an important measure of both a study's scientific and ethical quality. One reason why patients participate in research is to generate knowledge that will benefit those patients who come after them. Because subjects are willing to accept risks and burdens of research in order to benefit future patients, investigators have an ethical responsibility to maximize the possibility that a research study will do so.[22] However, it must also be considered whether there are benefits to those who participate in research, which will be examined in section 4 of this analysis.

Nonetheless, some commentators, such as Jeanne Quint Benoliel, suggest that there is merit in raising the general question as to whether dying patients should ever properly be subjects for scientific study.[23] Similarly, Munhall argues that all research turns people into mere means, regardless of whether or not the research participant is expected to benefit from the experience.[24] Additionally, Louise de Raeve has supported the argument that strong moral grounds exist for objecting to research in

20 http://www.who.int/cancer/palliative/definition/en/

21 Casarett, "Ethical Issues in Palliative Care Research," in *Oxford Textbook of Palliative Medicine*, 416.

22 Casarett, "Ethical Issues in Palliative Care Research," in *Oxford Textbook of Palliative Medicine*, 416.

23 Jeanne Quint Benoliel, "Research with Dying Patients," in *Patients, Nurses, Ethics,* edited by A. J. Davis, J. C. Krueger (New York: American Journal of Nursing, 1980): 119-28.

24 P. L. Munhall, "Ethical Considerations in Qualitative Research," *Western Journal of Nursing Research* 10, no. 2 (1988), 150-56.

palliative care. De Raeve argues from both a Kantian and risk-benefit perspective.[25] While the Kantian argument will not be addressed in this analysis, the question of risk-benefit will be examined at length. At this juncture it should be noted that it is currently generally accepted that, whatever the sensitivities around palliative care research, in the long run palliative care patients will be disadvantaged if there is a lack of evidence to support improvements and initiatives in palliative care. Therefore, though palliative care research poses many challenges from an ethical point of view, this should not discourage researchers from undertaking research in this field. The remainder of this analysis will consider these ethical issues.[26]

Universal Human Rights Considerations

Numerous ethical concerns are present in palliative care research, which should not be diminished. Indeed, there have been concerns raised from several commentators about whether it is ever appropriate to allow patients near the end of life to participate in research.[27] These arguments have considerable intuitive appeal and must be seriously addressed.[28] However, it must also be understood that overly strict limits on palliative research can also cause harm by impeding the establishment of new knowledge that will improve future patient care.

In order to be valid, arguments against research in a palliative setting must demonstrate that dying patients constitute a special class of research subjects, for whom research raises distinct ethical challenges that are insurmountable. From this stance, one may argue that special, distinct restrictions, protection, and guidelines are necessary to direct research. In contrast, if patients near the end of life are not subject to unique ethical constraints, then research may be acceptable within the context of strategies devised to protect subjects who pose similar challenges.[29] This section examines the two major human rights considerations in the context of research ethics, and specifically, palliative care research: vulnerability and informed consent.

Vulnerability

One reason to consider special ethical guidelines for palliative care patients is that they may be considered a vulnerable population. Surely palliative care patients are

25 Louise de Raeve, "Ethical Issues in Palliative Care Research," *Palliative Medicine* 8, no.4 (1994), 298-305.

26 Scottish Partnership for Palliative Care, *A Beginner's Guide to Successful Palliative Care Research*, (Edinburgh: Scottish Partnership for Palliative Care, 2011), 17.

27 de Raeve, "Ethical Issues in Palliative Care Research," 298-305.

28 David Casarett, "Ethical Issues in Palliative Care Research," in *Oxford Textbook of Palliative Medicine*, 416.

29 Jubb, "Palliative Care Research: Trading Ethics for an Evidence Base," 343.

not a homogenous group, yet they are a group for whom there is often no second opportunity to improve care.[30] Due to disease processes and the effects of palliative medicines there also may be some degree of decisional impairment. The Institutional Review Board Guidebook developed by the Department of Health and Human Services lists terminally ill patients as a special class of subjects, along with children, prisoners, and the mentally handicapped.[31] A simplistic definition of vulnerability is that, it describes a group of subjects who may be relatively or absolutely incapable of protecting their own interests.[32] The UNESCO *Universal Declaration on Bioethics and Human Rights* has provided an expanded definition of vulnerability. Article 8 asserts that when applying scientific knowledge and medical practice to individuals, the vulnerability of men and women must be taken into account. That is, individuals and groups of distinct vulnerability should be protected and respected. UNESCO defined vulnerability broadly as the susceptibility of being wounded.[33]

The notion of human vulnerability should not merely be applied to individuals in lower income lands. It is now widely accepted that vulnerability is universal in scope. That is, at some time in life, all humankind is vulnerable, regardless of social status, intelligence, authority, or economic power.[34] For many, the state of vulnerability is transient or contextual rather than inherent. However, it is to those individuals, groups, or communities for whom vulnerability is not a transient state that attention is particularly important.[35] For example, by definition, being a terminal patient is not a transient state, until death occurs. To be certain, the notion of vulnerability is a criticism of the conventional emphasis on individual autonomy as insufficient, and that attention should be directed towards the conditions for humanity's flourishing.[36] What is more, the principle of respect for human vulnerability should be linked to that of human dignity, which reinforces the notion of the unconditioned value of humankind by demanding their inviolability.[37]

Palliative care patients may encounter vulnerability because they lack decision-making capacity or because their choices are not truly voluntary. Decision-making capacity describes the ability of a person to understand given information and make

30 Reyna, et. al., "Ethical and Practical Issues in Designing and Conducting Clinical Trials in Palliative Care," 28.

31 U.S. Department of Health and Human Services, "Institutional Review Board Guidebook, Chapter VI, Special Classes of Subjects," http://www.hhs.gov/ohrp/archive/irb/irb_chapter6.htm

32 Casarett, "Are Special Ethical Guidelines Needed for Palliative Care Research?", 131.

33 H. ten Have, Michèle Jean, *The UNESCO Universal Declaration on Bioethics and Human Rights*, 155-64.

34 ten Have and Jean, *The UNESCO Universal Declaration on Bioethics and Human Rights*, 158.

35 Sheila .A.M. McLean, "Respect for Human Vulnerability and Personal Integrity," in *Handbook of Global Bioethics*, edited by Henk ten Have and Bert Gordijn (New York: Springer, 2013), 108.

36 Henk ten Have, "Vulnerability as the Antidote to Neoliberalism in Bioethics." Revista Redbioetica 2014; 1 (9): 87-92.

37 ten Have and Jean, *The UNESCO Universal Declaration on Bioethics and Human Rights*, 161-62.

a cogent choice. The concern is that this capacity may be impaired in patients near the end of life, which is based largely on observations that terminal patients regularly have evidence of cognitive impairment. To be sure, this has the ability of leading to impaired decision-making capacity and inadequate informed consent. Though not all patients with cognitive impairment will lack decision-making capacity, informed consent for these patients will be more difficult or impossible. Since cognitive impairment appears to be quite common in this population, palliative care researchers may often have difficulty identifying those patients who lack decision-making capacity and cannot provide consent.[38]

It must be recognized that this is a real challenge; however, the challenge is not unique to palliative care research. Hence, because it is not unique to palliative care research, it does not appear to provide grounds for distinct ethical guidelines. Investigators working in fields of research involving patients with dementia, psychiatric illness, and similar settings have developed strategies for assessing the decision-making capacity of such patients. Guidelines such as those provided by the National Bioethics Advisory Committee (NBAC) can be applied to palliative care research studies. The NBAC recommends that capacity should be assessed formally whenever research subjects are likely to be cognitively impaired and the research poses greater than minimal risk. Risks are determined to be greater than minimal if they are greater than those encountered in everyday life, or routine medical care. Indeed, as research risks increase and the chance of benefit decreases, decision-making capacity becomes increasingly essential. For instance, in high risk, low benefit research, to incorrectly assume that a patient is competent would be a grim mistake. This strategy is reasonable in palliative care research because the risks to which subjects are exposed are highly variable. While some studies involve only questionnaires or surveys, others involve experimental medications or risky procedures. When palliative care research involves only minimal risks, such as those posed by questionnaires, formal capacity assessments may not always be required. However, capacity assessment is more significant for studies that carry greater risks, such as those that involve a placebo when an effective agent is available, or an invasive intervention.[39]

Voluntariness is a second concern about vulnerability that must be considered. The voluntariness of a subject to consent to research participation has been at the forefront of research ethics since the Nuremberg Trials. In general terms, a choice is said to be voluntary if it is made without significant controlling influences.[40] The issue with palliative care research is that a subject's choice to participate may

38 Casarett, "Are Special Ethical Guidelines Needed for Palliative Care Research?" 131.

39 Casarett, "Are Special Ethical Guidelines Needed for Palliative Care Research?" 131-32.

40 Casarett, "Ethical Issues in Palliative Care Research," in *Oxford Textbook of Palliative Medicine*, 419-20.

be limited if their suffering has created a sense of desperation. If this concern is legitimate, voluntary consent in palliative care research may be confounded by the uncontrollable symptoms that are common in patients near the end of life.[41] What is more, a patient may feel some compulsion or obligation to participate in a research study, especially if they rely on a research institution or investigator for their care. This influence may be powerful in a palliative care setting and constitute some manner of involuntariness on the part of the patient.[42]

Though it is reasonable to suspect that these influences exist in palliative care settings, it is not at all clear that they present more of a danger than they do in other fields of human research. As has been recognized in the prevailing literature, a sense of desperation is not unique to palliative care patients. Oncology patients may feel a similar manner of desperation that influences their decision to enroll in phase I oncology clinical trials, even though the likelihood of attaining a medical benefit is remote. Therefore, it does not appear that these risks are unique to palliative care research. Further, the principle of respect for patient autonomy supports the potential involvement of patients in research that may not be of immediate benefit to themselves.[43] The voluntariness of a participant can be protected by ensuring that a participant's decision to enroll in a study is made with full knowledge of available alternatives and with the knowledge that he or she may withdraw at any time without penalty.[44] This is required by US law and the regulations of many other states, though it may not be emphasized sufficiently. Even more, palliative care researchers may find it beneficial to recruit participants through a third party. This serves to underscore the distinction made between research and clinical care, and may clarify to patients that they can decline participation without jeopardizing their clinical care.[45]

Informed Consent

A second reason to support the claim that palliative care research raises unique ethical issues is that investigators must obtain consent from patients. The notion of informed consent, similar to voluntariness, has been near the forefront of the concerns of medical ethics since at least the Nuremberg Trials in 1945-46. Informed consent refers to an individual's autonomous authorization of a medical procedure or of involvement in research. This involves more than a simple agreement or complying

41 Casarett, "Are Special Ethical Guidelines Needed for Palliative Care Research?" 132.

42 Russell Portenoy and Mitchell Max, "Pain Research—The Design of clinical trials," in *The Oxford Textbook of Clinical Medicine*, 3rd edition, edited by Derek Doyle, Geoffrey Hanks, Nathan Cherny and Kenneth Calman, 144-53, (New York: Oxford University Press, 2004), 143.

43 MacDonald and Weijer, "Ethical Issues in Palliative Care Research," 80.

44 Casarett, "Ethical Issues in Palliative Care Research," in *Oxford Textbook of Palliative Medicine*, 419-20.

45 Casarett and Karlawish, "Are Special Ethical Guidelines Needed for Palliative Care Research?" 132.

with a proposed medical intervention, for informed consent is a process, not a document. Explicit authorization of a medical intervention or research involvement through an act of informed and voluntary consent is essential. This can occur only if the patient or human research subject has gained substantial understanding of the proposed action and are void of substantial control by others.[46]

Even after the establishment of the Nuremberg Code, it has been shown that certain medical experiments in the US were conducted without the informed consent of patients. Examples of this abound and include the Willowbrook State School experiments in Staten Island of the 1950s and 1960s[47], as well as open-air tests of biological weapons over the US cities from 1949 to 1969 which resulted in the death of a man from San Francisco.[48] Subsequently, the principle of informed consent was incorporated into the Declaration of Helsinki, and the World Medical Association proposed the need for ethics review committees to evaluate and control medical research. Thus, the Declaration of Helsinki was revised in 1975, in part, to urge the scientific community to look to ethics review committees for guidance prior to beginning a research project.[49]

Palliative care researchers may face a number of challenges in the area of informed consent, however, none of these challenges are unique to palliative care.[50] Some have attempted to argue that informed consent in palliative care research is problematic because the stability and duration of consent are uncertain.[51] Patients nearing the end of life may lack decisional capacity or may experience fluctuating and/or declining capacity.[52] The issue of whether patients are competent to give informed consent is one that needs to be taken seriously by all palliative care researchers.[53] The dying person's freedom to choose their own course of treatment should be protected as long as they are competent to decide such matters. Several commentators have noted that the medical profession itself may complicate this. The weaker and more ill a patient becomes, the more they will require the assistance of a caregiver. The

46 Tom L. Beauchamp and James F. Childress, *Principles of Biomedical Ethics*, 7th ed. (New York: Oxford University Press, 2013), 120-25.

47 Frederick Adolf Paola, Robert Walker, Lois Lacivita Nixon, ed.. *Medical Ethics and Humanities,* (Sudbury, MA: Jones & Bartlett Publishers, 2009), 185–186.

48 Jonathan D. Moreno, *Undue Risk: Secret State Experiments on Humans*, (New York: Routledge, 2001) 233-34.

49 Illhardt and ten Have, "Research Ethics in Palliative Care," 202.

50 Meera Agar, Danielle N. Ko, Caitlin Sheehan, Michael Chapman, and David C. Currow, "Informed Consent in Palliative Care Clinical Trials: Challenging but Possible," *Journal of Palliative Medicine* 16, no. 5 (2013), 485.

51 MacDonald and Weijer, "Ethical Issues in Palliative Care Research," 79.

52 Susan Hickman, Juliana C. Cartwright, Christine A. Nelson, and Kathleen Knafl, "Compassion and Vigilance: Investigators' Strategies To Manage Ethical Concerns in Palliative and End-of-Life Research," *Journal of Palliative Medicine* 15, no. 8 (2012): 882.

53 Reyna, et. al., "Principles of Designing Clinical Trials in Palliative Care," 31-33.

medical profession tends to create a paternalistic attitude in such circumstances. For irreversibly ill patients, treatment generally involves both the compensation for lost functions and the mobilization of remaining functions. Hence, while some paternalistic intervention may be necessary, many patients retain the freedom to choose and act, though this range may become increasingly restricted as the illness progresses. Although personal autonomy may gradually diminish, patients will rarely lose freedom completely. Hence, medical research in the field of palliative care should acknowledge the freedom of a patient, and the research ought to be compatible with it, otherwise it ought not to be done.[54]

Furthermore, obtaining informed consent for palliative care research may be particularly delicate because participants may find it difficult to make such decisions at such a distressing point in their lives. Deciding how to describe the research trial also presents challenges, for certainly not all patients and families will have had full and open conversations with the physician about the patient's current condition and prognosis. Another complication and reason why it has been suggested that palliative care research deserves distinct ethical guidelines is that investigators must often obtain consent not simply from patients, but also from families. Including families as subjects in the clinical research is a logical extension of hospice and palliative care, for the aim is often to provide family-centered care. Studies have explored not only new drugs or therapies on the patient, but also include issues such as family functioning, family perceptions, and the effect of the patient's illness on the family. Indeed, there is reason to believe that families may become increasingly involved in palliative care research studies in the coming years. The Institute of Medicine and the National Institutes of Health have each called for more research on the experience of the families in distress.[55]

In these types of studies, both the patient and the family are "subjects" because they are the focus of the research. These studies may create complex administrative challenges because of the need for investigators to generate an effective informed consent process tailored to meet the difficult needs of both patients and families. It is important to note, though, that these are administrative challenges created by the ethical obligation to obtain informed consent, and are not created by palliative care research itself. Indeed, investigators may look to the field of dementia research for some solutions. In dementia research studies, investigators often obtain a "dual consent". That is, investigators obtain informed consent from both patients and family members simultaneously. This dual consent has the ability of assuring that family members understand the research and what is required of them to fulfill their

54 Illhardt and ten Have, "Research Ethics in Palliative Care," 202-03.

55 Casarett, "Are Special Ethical Guidelines Needed for Palliative Care Research?" 133.

responsibilities. In dementia research, as in palliative care research, the responsibilities of the family or caregiver can be substantial, including transportation to the study site, giving medications, and assessment participation.[56]

Thus, though the informed consent process in palliative care research may be challenging, overcoming these difficulties is possible. Each clinical trial in palliative care must carefully develop an appropriate protocol to solve the specific problems the trial will bring.[57] What is more, although research that includes multiple subjects does pose a real challenge for palliative care investigators, these are administrative challenges rather than purely ethical challenges. The situation of dementia research shows that the informed consent process in palliative care research is not unique in its complexity. Hence, palliative care researchers may learn from other fields of research, such as dementia research, the strategies to obtain consent from multiple subjects.[58]

In summary, though issues of vulnerability, voluntariness, and informed consent may present ethical challenges to research in the palliative care milieu, it does not appear that they raise distinct challenges that merit distinct ethical guidelines. Though none of these challenges is unique to palliative care research, the combination and frequency with which they are encountered does require systematic and considered solutions.[59] Thus, while these issues must not be taken lightly, it appears that the principles of research ethics are sufficient to protect human research participants from harmful practices.[60]

Distinct Research Considerations for Palliative Care

Above has been presented that issues of vulnerability and informed consent, though raising significant challenges for IRBs and investigators, are not unique to palliative care research. Further, there seems to be manners of overcoming these challenges. Therefore, neither issues of vulnerability nor informed consent appear to justify special restrictions, protections, or guidelines, as the principles of research ethics can protect patients. However, this section examines the question of risk-benefit analysis, which may provide such a justification.

56 Casarett, "Are Special Ethical Guidelines Needed for Palliative Care Research?" 133.

57 Reyna, "Ethical and Practical Issues in Designing and Conducting Clinical Trials in Palliative Care," 31.

58 Casarett, "Are Special Ethical Guidelines Needed for Palliative Care Research?" 134.

59 Agar, et. al., "Informed Consent in Palliative Care Clinical Trials: Challenging but Possible," 485.

60 Illhardt and ten Have, "Research Ethics in Palliative Care," 207.

Risk-Benefit Analysis is Difficult to Assess

Estimation of the anticipated risks and benefits is critical in the evaluation of any research project, but it is also one of the least developed areas in research ethics.[61] This issue may be more clearly unique to palliative care research.[62] To be sure, clearly articulating expected risks and benefits in palliative care research poses specific challenges.[63] Indeed, the NBAC has affirmed that properly assessing risk versus benefit is difficult in research studies.[64] One issue with risk-benefit analysis in palliative care research is the distinction between therapeutic and non-therapeutic medical research. This distinction was made in order to differentiate the scope, the participants involved, and the context in each of the two categories. In therapeutic research, the goal is to treat an individual's illness with the hopes he/she will recover. The context is usually in the hospital, utilizing the hospital's equipment and the experience of the research team. Non-therapeutic research involves the use of healthy subjects and seeks to obtain basic scientific data. This is often done for financial compensation and the context is the research site, such as a laboratory.[65] Thus, therapeutic research is designed with the intention of yielding benefit to participants, while non-therapeutic research seeks to derive knowledge without direct benefit to participants. This distinction can be useful in the ethical assessment of an acceptable balance for research participants, between the benefits and the risks of research.[66] Further, it has been recognized that when the distinction between therapeutic and non-therapeutic research with respect to the irreversibly ill patient disappears, the principle of beneficence may be in danger. Thus, we must ask whether palliative care patients can ethically be involved in non-therapeutic research trials.[67]

Moreover, another reason that the risks and benefits of palliative care research are often hard to assess comprehensively is due to limited preexisting evidence. The frequent heterogeneity of study populations has also been perceived as making the weighing of

61 M. Agrawal, "Voluntariness in Clinical Research at the End of Life," *Journal of Pain and Symptom Manage*ment 25 (2003), S25–S32.

62 Robert S. Krouse, Alexandra M. Easson, and Peter Angelos, "Ethical Considerations and Barriers to Research in Surgical Palliative Care," *Journal of the American College of Surgeons* 196, no. 3 (March 2003), 470.

63 M. Masso, *Ethical Research in Palliative Care: A Guide Through the Human Research Ethics Committee Process*, (Canberra: National Palliative Care Program, 2004), 18.

64 National Bioethics Advisory Committee, "The Assessment of Risk and Potential Benefit," in Research Involving Persons with Mental Disorders That May Affect Decisionmaking Capacity," 1998, https://bioethicsarchive.georgetown.edu/nbac/capacity/Assessment.htm

65 Illhardt and ten Have, "Research Ethics in Palliative Care," 203.

66 Masso, *Ethical Research in Palliative Care: A Guide Through the Human Research Ethics Committee Process*, 18-19.

67 Illhardt and ten Have, "Research Ethics in Palliative Care," 203.

risks and benefits difficult.[68] To be certain, it is an ethical duty of all investigators to maximize research benefits and minimize research risks. This obligation is expressed in US federal guidelines as the requirement that risks to subjects are reasonable in relation to anticipated benefits and to the anticipated value of knowledge generated by the study.[69] For example, this requirement is clearly stated in the Department of Health and Human Services IRB guidelines.[70] Nonetheless, this goal is often difficult to achieve, but is crucially important because the balance of risks and potential benefits is a main reason why subjects participate in clinical research. When palliative care investigators attempt to meet this challenge they may encounter difficulties in two issues: defining research risks and benefits, and measuring them against an appropriate standard.[71] Each of these will be examined in this section.

In the majority of research studies that involve either healthy participants or patients with a known and well-defined medical problem, the benefits and risks of research are fairly clear. Medical ethicist and physician David Casarett illustrates this by providing an example of a clinical trial comparing two forms of treatment for an acute myocardial infarction that might offer potential benefits of improved survival or improved cardiac function. The risks of such a trial might include bleeding, infection, or death. There ought to be general agreement that these are important risks and benefits to be balanced, and should be dutifully explained to the patients. However, the issue in palliative care research is that the benefits and risks that are important to patients near the end of life may be difficult to assess and define because an individual's goals may change as they near death. It has been suggested that, broadly defined, these changes can be characterized by a decreased emphasis on survival, and an increased push for pain management, symptom relief, retention of dignity, and maintaining social relationships and a semblance of control in their lives. Thus, it may be likely that patients' preferences regarding the potential risks and benefits of research may change as well.[72]

As patients approach the end of life, they may increasingly emphasize qualities such as pain management, dignity, social relationships, and control, as noted above. For instance, patients close to death may perceive the time spent answering questionnaires, surveys, or doing interviews for research as detrimental to the time

68 Jonathan Koffman and Fliss Murtagh, "Ethics in Palliative Care Research," in *Textbook of Palliative Medicine,* edited by Eduardo Bruera, Irene Higginson, Charles F. von Gunte, 192-201 (Boca Raton, FL: Taylor and Francis, 2006), 196.

69 Casarett, "Are Special Ethical Guidelines Needed for Palliative Care Research?" 135.

70 U.S. Department of Health and Human Services, "Institutional Review Board Guidebook. Chapter III, Basic IRB Review," http://www.hhs.gov/ohrp/archive/irb/irb_chapter3.htm

71 Casarett, "Are Special Ethical Guidelines Needed for Palliative Care Research?" 135.

72 Casarett, "Are Special Ethical Guidelines Needed for Palliative Care Research?" 135.

they could spend strengthening social relationships and addressing any "unfinished business" with family members, friends, and associates, while the identical protocol may not prove so onerous to patients with a curative disease.[73] Thus, palliative care patients may prefer to spend their time in ways other than research and may even be reluctant to impose any additional burdens on family members.[74] Additionally, a dying patient's emphasis on control may have important implications for their assessment of research risks and benefits. If the patient's control over medications and dosing is very important to them, any loss of control may be viewed as a significant risk. Conversely, a trial that gives patients an increased control over "as needed" medication dosing may be viewed as beneficial by patients who value control.[75]

The second issue is that measuring the risks and benefits in palliative research against an appropriate standard may prove especially challenging for IRBs. IRBs, per US federal guidelines, are required to measure the risks of research against the risks encountered in daily life or during the performance of routine physical or psychological examinations or tests.[76] Therefore, even if patients clearly understood the risks and benefits of research, it is not clear how investigators and ethics committees should balance them in determining whether a proposed research study offers an ethical balance of risks and benefits. This task may prove difficult in palliative care research because it may be either overly permissive or overly restrictive. For example, questionnaires or surveys that are time-consuming may cause little discomfort and pose a minimal risk in most research settings. However, for patients near the end of life who wish to spend quality time with family members rather than completing lengthy surveys, such research may become quite burdensome. Further, it has been suggested that judging risks to terminally ill patients by the standards of risks encountered in daily life may be misleading and unhelpful, because patients who are terminally ill face daily risks of death and suffering that are far greater than those faced by other research subjects.[77] What is more, in a 2015 research survey of the delegates at the 7th Pediatric Palliative Care Conference, approximately one-third of respondents in the study identified the IRB approval process as a major barrier

73 Jubb, "Palliative Care Research: Trading Ethics for an Evidence Base," 344.

74 Blair Henry and Damon C. Scales, "Ethical Challenges in Conducting Research on Dying Patients and Those at High Risk of Dying," *Accountability in Research* 19, no. 1 (2012): 7.

75 Casarett, "Are Special Ethical Guidelines Needed for Palliative Care Research?" 135-36.

76 U.S. Department of Health and Human Services, "Institutional Review Board Guidebook. Chapter III, Basic IRB Review," http://www.hhs.gov/ohrp/archive/irb/irb_chapter3.htm

77 Casarett, "Are Special Ethical Guidelines Needed for Palliative Care Research?" 136.

to palliative care research, citing the approval process as "arcane", "challenging," and "restrictive".[78] This would be worth examining in further research.

Response to the Difficulty of Assessing Risk-Benefit Analysis

As stated briefly above, Louise de Raeve has argued that strong moral grounds exist for objecting to palliative care research based on a risk-benefit perspective. De Raeve asserts that it is not clear from the outset of the study that participants will get anything out of the experience, which may be unethical. The author couples this argument with describing the "seductiveness" of palliative care research. That is, the researcher often provides a nonjudgmental listening ear, interest, and close attention to the patient, which is something the patient may not have received in a very long time, making a continued relationship with the investigator very enticing.[79] However, this second issue is not unique to palliative care research and, thus, should not be grounds for disqualifying research in that field. Further, it is not altogether clear that palliative care patients do not benefit from research.

At least two benefits of palliative care research to participants have been identified. During the course of the research study, investigators may have several opportunities to maximize the potential benefits of research to participants. In an interventional study, participants may be free to choose their own intervention. While, ideally, a new intervention should have a reasonable chance of success, more important may be that it offers to participants a significant potential benefit or improvement over other interventions that are available to patients outside the study. Further, potential benefits of a study can be enhanced by choosing an active control design, rather than a placebo. It must be noted that these suggestions ought to be tempered by realizing that potential benefits of research are never certain. If they were completely certain, equipoise could not be maintained. Nonetheless, investigators generally design trials of interventions for which there is at least some evidence of effectiveness. Moreover, palliative care studies may also benefit participants by the data gathering that occurs. This data collected during a descriptive study may identify inadequately treated pain, dissatisfaction with pain management, or related problems such as depression or anxiety. Investigators can then use this data to improve the participant's care. Therefore, it does not seem true that palliative care patients cannot benefit at all from research studies.[80]

78 Emma Beecham, Briony F. Hudson, Linda Oostendorp1, Bridget Candy, Louise Jones, Vickey Vickerstaff, Monica Lakhanpaul, Paddy Stone, Lizzie Chambers, Doug Hall, Kate Hall, Thines Ganeshamoorthy, Margaret Comac, and Myra Bluebond-Langner, "A call for increased paediatric palliative care research: Identifying barriers," *Palliative Medicine* 30, no. 10 (2016): 979-80.

79 de Raeve, "Ethical Issues in Palliative Care Research," 303.

80 Casarett, "Ethical Considerations in End-of-Life Care and Research," S-152-53.

Therefore, as has been identified in the above section, the weighing of risks and benefits in palliative care settings may present distinct ethical considerations that merit special attention. This judgment seems correct, especially when we consider that the risks and benefits that are important to patients near the end of life may be much more difficult to define because their goals may change significantly as they near death. Further, as has been explained above, it can be difficult to measure risks and benefits against the risks of everyday life because palliative care patients are in a unique phase of life. However, it should not be concluded that these challenges are insurmountable.[81] Robert Krouse, Ira Byock, and others have echoed this sentiment by affirming that barriers in palliative care research can be overcome with well-constructed studies carried out by thoughtful research teams. Indeed, the methodological difficulties in palliative care research are all surmountable through existing techniques and appropriately careful scientific design.[82]

In order to demonstrate that these concerns are surmountable, at least two strategies are essential to this endeavor. First, in order to define and weigh risks and benefits properly, data that describe how patients perceive the risks and benefits of research are necessary.[83] If palliative care researchers hope to find a balance between risks and benefits that participants will find acceptable then these data are essential. Researchers should also try to consider these risks and benefits in relation to those that patients near the end of life typically experience in their daily routines. A second strategy is that when IRBs review the protocols for palliative care research studies examining the physical aspects of palliative care, they will be better prepared to assess and weigh the risks and benefits of research if they include at least one healthcare professional with expertise in the field of palliative care. Indeed, IRB reviews have been considered to be a significant impediment to conducting quality research in palliative care because they are often ill-equipped to handle such protocols and, thus, promote a natural protectiveness towards what is perceived to be a vulnerable population.[84] Involving a healthcare professional with expertise in this area might curtail this. The Common Rule recommends that this be done for other vulnerable populations such as children. The IRB guidelines of the NIH extend this suggestion to palliative care research as

81 Jubb, "Palliative Care Research: Trading Ethics for an Evidence Base," 344.

82 Robert Krouse, Kenneth E. Rosenfeld, Marcia Grant, Noreen Aziz, Ira Byock, Jeffrey Sloan, and David Casarett, "Palliative Care Research: Issues and Opportunities," *Cancer Epidemiology, Biomarkers & Prevention,* 13, no. 3 (March 2004): 337-39.

83 J.H.T. Karlawish, "Permissible Risk and Acceptable Benefit (The Ethics of Research Involving the Cognitively Impaired)," *Forum* 7 (1997): 277–285.

84 P.W. Keeley, "Improving the Evidence Base in Palliative Medicine: A Moral Imperative," *Journal of Medical Ethics* 34, no. 10 (2008), 758.

well. Thus, this person may be very helpful in focusing the IRB on the risks and benefits that are likely to be most important to patients in their stage of life.[85]

In summary, palliative care research does seem to be unique because the evaluation and parameters of the risk benefit analysis, as well as the burden of the research upon the patient, may change significantly as patients near death. What is sure is that physicians and caregivers have the moral duty to support research, but in each case this must be done on the basis of a concrete risk-benefit analysis. The greater the risks are predicted to be, the greater the concrete benefits for the involved participant should be. Hence, studies that are likely to provide small benefit can only be justified if they bear low risk. While these concerns may be difficult to manage, the majority of literature appears to conclude that they are surmountable because of medicine's commitment to regarding irreversibly ill patients as autonomous and capable of freely consenting to research participation.[86]

Further Considerations to Protect Research Subjects

As has been presented in this analysis, there does not appear to be a compelling case for believing that research in palliative care is significantly more distinct than research in other fields as to require distinct ethical guidelines. Thus, patients suffering from an irreversible disease can be involved in medical research because the principles of research ethics seem to be appropriate for their protection.[87] However, this does not mean that there are no serious ethical concerns that need to be taken into consideration. This section will consider how further to safeguard palliative care patients who are involved in research and mitigate ethical concerns. The first subsection will consider specific suggestions to enhance ethical conduct and protect patients, and the second will look at the notion of compassion and vigilance as strategies to manage ethical concerns in palliative care research.

Specific Suggestions to Enhance Ethical Conduct

Franz-Josef Illhardt has recognized that, commonly, pharmaceutical companies will enroll critically ill patients into clinical trials if they meet the following criteria: 1) a life expectancy of more than three months, 2) informed consent for the trial, and 3) no other concomitant life-threatening diseases. As has been reported, these criteria have been applied frequently to studies in the second-line treatment of cancer.

85 Casarett and Karlawish, "Are Special Ethical Guidelines Needed for Palliative Care Research?" 136.

86 Illhardt and ten Have, "Research Ethics in Palliative Care," 209-10.

87 Illhardt and ten Have, "Research Ethics in Palliative Care," 207.

However, there are many items to consider, for we must question whether these guidelines are sufficient to protect vulnerable persons such as the incurably ill.[88]

When analyzing the first criterion regarding the life expectancy, problems may arise as we recognize that patients who come close to the threshold of three months of life expectancy should be protected against any kind of exploitation. This is true both in the research context and out of it. Indeed, caregivers have the moral and legal obligation to safeguard the interests of the patients. As death draws near, patients require the devotion and support of their families and other professionals to help them in coping with their fate. We must question whether they also need the progress of science from which they may never receive benefits.[89]

The second criterion also poses problems. Physicians have reported that many terminally ill patients agree to participate in research trials simply out of a sense of altruism. However, an altruistic attitude can be a sign of moral pressure when patients in the last stages of life opt for this moral mechanism. Patients may believe that they are burdens to their family and caregivers, and that they can enhance the value of their lives by participating in research. To be certain, this is not a mark of moral freedom. It is the duty of the caregiver to make the differentiation between a free altruistic attitude and the fear of not being free disguised as altruism.[90]

The final criterion that has been presented was an absence of concomitant life-threatening diseases. This is also often problematic. While only having the disease that is the prerequisite of the research aids the investigator in gaining control over the project, those patients who are incurably ill typically have multiple diseases and affected organs. It has been recognized that, due to this, research with patients in palliative care facilities can easily create situations in which the endpoints of research put risks upon the patient's process of treatment or bring about more inconveniences to the patient than the caregivers can ethically accept.[91]

There are a variety of ways to enhance the ethical conduct of palliative care research. This section will discuss specific suggestions in regards to how patients are enrolled, how the study is designed, and how it is conducted. In regards to patient enrollment, potential palliative care research participants ought to be advised to discuss their participation in a research trial with family members or other close friends. As has been briefly mentioned, palliative care stresses the importance of families and that they represent the fundamental unit of care. Because of this, the patient's family

88 Illhardt and ten Have, "Research Ethics in Palliative Care," 207-08.

89 Illhardt and ten Have, "Research Ethics in Palliative Care," 208.

90 Illhardt and ten Have, "Research Ethics in Palliative Care," 208.

91 Illhardt and ten Have, "Research Ethics in Palliative Care," 208.

or close friends should be involved in discussions on the decision to participate in research trials to the degree the patient will allow. It is also not uncommon that the family members will share research burdens due to the transport needs of the patient, medication arrangements, and other qualities of the study. It is reasonable for the family members or close friends who share these burdens to have their input recognized and honored as well. Further, as has been held throughout this analysis, there does not seem to be a valid reason to exclude potential research participants on the basis of age, frailty, or mental or physical disability. Members of society should not be unfairly excluded from the potential benefits of research participation. It is not ethically acceptable to stigmatize or stereotype an individual's rights because of a perceived attribute.[92]

The design of the clinical trial should also be formulated in such a way as to maximize ethical conduct. Research protocols should be written in such a manner as to encourage understanding and participation by members of the palliative care team who work with the research participant. This is grounded in the basic principle of palliative care as a multidisciplinary activity. Further, the trial methodology must emphasize the maintenance of patient comfort and dignity through the routine inclusion of assessments of the factors which contribute to this goal. Certainly, the recognition and alleviation of suffering is the primary reason for palliative care. Clinical trials that reflect this goal must be designed. Practical expressions of this concept include routine use of symptom control and quality of life assessments.[93]

During the conduct of clinical trials, particularly in studies that involve greater-than-minimal risk, it is recommended that tests of cognitive status be repeated at regular intervals. Palliative care patients may become incompetent subsequent to enrollment in a research trial and their continued participation should be dependent upon a surrogate's consent and the demonstration of continued patient benefit while on the experimental therapy, as well as the evidence that the therapy is not the cause of their development of incompetence. Conversely, if an incompetent patient should gain competency during a study, they should only continue in the study upon directly attaining their informed consent.[94]

Compassion and Vigilance as Strategies to Manage Ethical Concerns

In a recent empirical study, investigators found that when clinical researchers and their protocols reflected an environment of both compassion and vigilance, ethical concerns can be managed. In the study, the concept of compassion was reflected

92 MacDonald and Weijer, "Ethical Issues in Palliative Care Research," 82.

93 MacDonald and Weijer, "Ethical Issues in Palliative Care Research," 82.

94 MacDonald and Weijer, "Ethical Issues in Palliative Care Research," 82.

in strategies that represented heightened sensitivity to the needs of the research participants, such as allowing extra time to solicit consent, gently building up to sensitive questions, developing backup protocols, careful attention to the use of language, and methodological flexibility. Further, compassion was coupled with exercising heightened vigilance during every step of the research process about the possible effects of study participation on the participants' emotional and physical well-being, ensuring the research did not interfere with clinical care.[95]

Compassion has been recognized by numerous commentators to be a great virtue, if not a duty, of all physicians.[96] This easily transfers to the clinical trial investigator. The compassionate behavior of a physician or investigator is not only desired because it is nice for the patient; it is taken as a sign of an authentic attitude that underlies the fiduciary relationship between physician and patient.[97] When one examines the definition of compassion, we see how important this is to ethical palliative care research. The relevant literature on the etymology and meaning of the word provides slightly nuanced conclusions. The etymology of the two Latin roots suggests that the term means the ability to share or to enter into another's experience of suffering.[98] While it has been described as the participation in the suffering of others, it can also be thought of as something spontaneous and benevolent.[99] Working with this definition in mind, it seems desirable to have compassionate healthcare professionals who sense that compassion is one of their professional virtues.

To be a concerned, compassionate physician or investigator means to be involved, and to say that compassion is a physician's duty, a point that will be elaborated below, is to assert an obligation to employ some of humankind's natural ability to feel with the sufferings of others.[100] The obligation to relieve human suffering is virtually synonymous with the practice of medicine, and the suffering of the patient and the compassion of the physician are intimately related. Eric Cassell has asserted that there are three goals which would, if met by the actions of physicians, promise better care and result in lessened suffering for patients. The first goal is that all diagnostic or therapeutic plans be made in terms of the sick, suffering person, not the disease. The second goal is to maximize the functions of the patient, their quality of life, not

95 Hickman, et. al., "Compassion and Vigilance: Investigators' Strategies To Manage Ethical Concerns in Palliative and End-of-Life Research," 888.

96 C.J. Dougherty, and R. Purtilo, "Physicians' Duty of Compassion," *Cambridge Quarterly of Healthcare Ethics* 4, no. 4 (Fall 1995): 426.

97 P. Gelhaus, "The Desired Moral Attitude of the Physician: (II) Compassion," *Med Health Care Philos* 15, no. 4 (Nov 2012): 403.

98 Dougherty and Purtilo, "Physicians' Duty of Compassion," 427.

99 Gelhaus, "The Desired Moral Attitude of the Physician: (II) Compassion," 401.

100 Eric J. Cassell, *The Nature of Suffering and the Goals of Medicine*. 2nd ed. (New York: Oxford University Press, 2004), 290.

length of life. The third goal is to minimize both the patient's and family's suffering. As Cassell affirms, these aims are interlocking in that they arise from the more basic idea that physicians and other healthcare professionals should focus primarily on the best interests of the patient rather than treatment of the disease.[101]

The physician's duty to provide due care requires them to maintain a judicious range of professional skills and use them with appropriate diligence. Due care bars the deliberate or negligent imposition of unreasonable risks on patients. Although compassion provides no guarantees in this arena, compassion certainly makes it more likely that a healthcare provider will act with due care as changing circumstances require. Indirect evidence for this claim can be found in the legal arena where lawsuits for malpractice, which is the alleged violation of a standard of due care, often seem more closely linked to failed relationships with patients than to inadequate technical skills.[102]

While there are exceptions to nearly every rule, generally speaking, a physician's or investigator's duties are more readily satisfied when they bring a sense of compassion to their encounters with patients and research subjects. To contrast this, the physician or investigator who lacks compassion is more likely to be unaware of a patient's interest and less motivated to place it first in situations of conflict. Due care that is void of compassion is subject to compromise in various scenarios in which standards are implicit and unenforceable, and the uncompassionate physician or investigator is less likely to appreciate and protect patient's vulnerability. It can be assessed that the connection of compassion to the satisfaction of the core duties of physicians and investigators is so close as to make compassion itself a duty.[103] Indeed, principles of medical ethics are sterile if not applied within a compassionate environment by wise, charitable, and moral investigators.[104] Therefore, provided investigators compassionately apply ethical principles to their work, there is no justification for not endeavoring to improve the quality of palliative care through research.[105]

Conclusion

This analysis has examined the question of whether the distinctiveness of palliative care research requires distinct ethical guidelines. The analysis first provided an

101 Eric J. Cassell, *The Nature of Suffering and the Goals of Medicine*. 2nd ed. (New York: Oxford University Press, 2004), 282.

102 Dougherty and Purtilo, "Physicians' Duty of Compassion," 429.

103 Dougherty and Purtilo, "Physicians' Duty of Compassion," 429.

104 MacDonald and Weijer, "Ethical Issues in Palliative Care Research," 80.

105 Jubb, "Palliative Care Research: Trading Ethics for an Evidence Base," 345.

overview on the history of the research process. Then, three arguments were presented that have been used to support the conclusion that palliative care does in fact raise distinct ethical questions that may merit distinct ethical guidelines. The issues of vulnerability and informed consent were examined in detail, and it was determined that though these topics are serious, the principles of research ethics are sufficient to protect participants. Section 4 examined the issue of risk-benefit analysis and discussed the difficulties of this assessment. It was concluded that risk-benefit analysis in palliative care research might be distinct from other fields of research. However, these issues appear to be surmountable. Lastly, section 5 examined further considerations to protect research subjects, including the notions of compassion and vigilance.

To be certain, research is essential to improve medical care and increase our knowledge base. Dying patients or those at high risk of dying should not be denied the valuable opportunity to participate in such research. However, such research should always adhere to accepted ethical principles. Research must respect the dignity of patients, it must be scientifically valid, it should have the potential to benefit the targeted population, and it should minimize any potential for harm. Research involving patients that are at the end of life should be designed considering their emotional, social, physical, and spiritual taxing situations. Particularly, provisions should be taken to ensure that informed consent is obtained from patients who are capable, free from coercion, and not harboring false expectations about the likelihood of benefiting from the study intervention. Adhering to these principles will help ensure that patients can ethically participate in research that has the potential to advance knowledge and improve future patient care.

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Zahtijeva li profiliranost istraživanja o palijativnoj skrbi različite etičke smjernice?

SAŽETAK

Palijativna skrb i skrb na kraju života doživljava promjene, postaje sve rasprostranjenija i poboljšava se za pacijente. Ipak, trenutno dostupna literatura iz tog područja navodi da su materijali o palijativnoj skrbi i skrbi na kraju života donekle ograničeni. Istraživanja o odlukama o liječenju, obiteljskoj skrbi i naputku za buduću zdravstvenu njegu u određenim okolnostima samo su neka od područja koja zahtijevaju velike istraživačke napore. Istraživanje o palijativnoj skrbi bitno je zbog stalnog pružanja učinkovitih tretmana onima koji pate u posljednjim fazama terminalne bolesti. Doista, cilj dobrog istraživanja palijativne skrbi ublažavanje je patnje i poboljšanje kvalitete života. Slično kao i u bilo kojem drugom području, programi palijativne skrbi moraju se razvijati na istraživačkoj osnovi, a njega pacijenata će patiti ako nije potpomognuta znanstvenim istraživanjem. No, oni koji su protiv ove potrebe su oni koji ostaju pri mišljenju da su etički i praktični izazovi istraživanja palijativne skrbi jedinstveni i nepremostivi. Ova analiza razmatra jesu li različite etičke smjernice potrebne za istraživanje palijativne skrbi.

Ključne riječi: palijativna skrb; palijativna sedacija; ranjivost; skrb na kraju života; analiza rizika i koristi; sposobnost odlučivanja.

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Dostojanstvo ljudske osobe i pravo na život

SAŽETAK

Današnje suvremeno društvo stavlja nam rješenja mnogih proturječja društvene slike kakva danas vlada. Potrebno je samo malo dublje zahvatiti ispod površine da bi nam se otvorio širi horizont stvarne društveno-političke slike. Sastavni dio ljudskog društva jest i pravo, odnosno zakoni, prvo kao običajno pravo, a kasnije kodificirano pravo. U povijesti, možemo kroz pravne norme različitih pravnih sustava promatrati slike društva te kakve je poglede na život, na pravo na život, u konačnici na ljudsko dostojanstvo imala određena civilizacija. Kao postulat ovoga rada svrha je prikazati ljudska prava, ljudsko dostojanstvo i pogled na život, a posebno kroz učiteljstvo Katoličke Crkve, osvrćući se kratko i na učenje u Židovstvu u Tori, na rimsko pravo, te dakako na pozitivne pravne propise i pravne običaje uz slijed razvoja govora o dostojanstvu i pravu na život ljudske osobe, počevši od općeg pogleda na govor o ljudskom životu, preko promišljanja prvih kršćanskih vremena, do govora o dostojanstvu i čovjeku stvorenom na sliku Božju. Govoriti o ljudskim pravima i o dostojanstvu ljudske osobe nije nimalo zahvalna tema. Kroz povijest su ljudska prava i dostojanstvo ljudske osobe uvijek bili kamen spoticanja. U slučajevima takvog poremećaja, a mogli bismo čak reći i grubih povreda ljudskog dostojanstva i ljudskih prava, evanđeoski nauk kao objava koju Katolička Crkva baštini jest ključ u obrani i zaštiti onih koji su slabiji.

Ključne riječi: osoba, ljudsko dostojanstvo, život, pravo, čovjek slika Božja.

Uvod

Današnji moderan čovjek sa svojim načinom života nastoji se odmaknuti od okvira koje mu postavlja društvo, bilo kroz moralne bilo kroz državne zakone. Mogli bismo reći da nam mediji nude upravo takvu sliku društva bez ikakvih okvira,

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prenaglašavajući osobnu slobodu pojedinca i upravo tako (pre)odgaja se čovjeka, napose mladog čovjeka u kojem izaziva bunt. Takav se protivi zakonu koji promatra kao element ograničavanja njegove slobode. Zato ima ljudi koji misle da se zakon suprotstavlja slobodi i sanjaju o vremenu kad će čovječanstvo živjeti sređeno i radosno bez ikakvih zakonskih pravila. Je li istina da nam zakon sputava slobodu? Činjenica jest da postoji određena napetost između slobode i zakona. Sloboda je mogućnost izabrati ovo ili ono, a zakon je usmjeravanje prema jednome, prema činidbi ili propuštanju činjenja. Zapravo ta napetost pretpostavlja slobodu kao mogućnost odlučivanja pred silom zakona i tu dolazimo do konkretnog odnosa u zakonu: sila, sankcija – uvjetno ograničavanje slobode. Problematika odnosa zakona i prava jest ta da je pravo osnova zakona.[1] No, da se bilo koje pravo ostvari kroz zakon potrebna je sila, moć, vlast. Onaj koji primjenjuje silu nad drugim ne traži njegov pristanak. Očituje se određeni stupanj gubitka slobode onoga koji je nadvladan, silovan, takva osoba je zapravo prisiljena na prihvaćanje stanja koje joj je nametnuto. Ako određena osoba i u najmanjoj mjeri gubi slobodu i moć odlučivanja o sebi samome, tada takvim stanjem u ustavnopravnom smislu i prestaje biti osobom; upravo stoga što je sloboda odlučivanja temeljno pravo na ljudsko dostojanstvo. U slobodi osoba ima moć izbora, prava i, dakako, odgovornosti, ali primjenjujući silu osoba postaje ta koja slama volju drugoga jer za sebe jest osoba, a drugoga ne poštuje kao osobu. Dolazi do objektivizacije drugoga, gdje taj drugi postaje samo stvar; u konačnici u Kantovom smislu subjekt postaje objekt.[2] Članak 3. Opće deklaracije o ljudskim pravima navodi: „Svatko ima pravo na život, slobodu i osobnu sigurnost."[3]

Koliko god je današnjem čovjeku zakon teret, toliko je za razumijevanje problematike odnosa zakona i prava u našoj civilizaciji najbolje istaknuti razmatranje jednoga pitanja - pitanja djeteta. Dijete ima pravo, a nema nikakve sile, moći ili vlasti. Stoga se dijete može zaštititi samo zakonom, a nikakvom vlastitom obranom. Dijete koje je rođeno donekle ima svoj "glas", može vikati, drugi ga čuju, no ono nerođeno ostaje posve bespomoćno. I u tom smislu u zaštiti nerođenoga jest samo zakon Božji osnovan na njegovu vlastitom pravu na život.[4]

Razmatrati ljudska prava i dostojanstvo ljudske osobe, danas, u svjetlu kršćanske teologije, za sobom povlači određene konotacije koje mogu u određenom krugu ljudi izazvati predrasude, koje se najčešće javljaju iz neznanja. Neznanje i nepoznavanje

1 Usp. Arhiv OFMCAP, *XXIV Sloboda zakon sila,* propovijed Tomislava Janka Šagi-Bunića održana u Zagrebačkoj katedrali 1963. godine.

2 Usp. Friedrich MÜLLER, *Pravo - Jezik - Sila; Utemeljenje suvremene lingvistike prava*, Osijek, 2013., 31.

3 *Opća deklaracija o ljudskim pravima* (10. 12. 1948.), u: *Narodne novine*, http://narodne-novine.nn.hr/clanci/medunarodni/2009_11_12_143.html (19. 6. 2017.)

4 Usp. Arhiv OFMCAP, *XXIV Sloboda zakon sila,* propovijed Tomislava Janka Šagi-Bunića održana u Zagrebačkoj katedrali 1963. godine.

prava u pravnom sustavu ne oslobađa nas krivnje (*ignorantia iuris nocet*), a to je postulat još iz rimskoga prava. Stoga bi cilj ovog rada bio osvijetliti ljudska prava i dostojanstvo svake osobe, a na prvom mjestu pravo na život, kako ga promatra učiteljstvo Katoličke Crkve, zajedno s nekim pravnim rješenjima. Tema je to koja je vrlo opsežna i odmah na početku potrebno se ograditi da je vrlo teško na par kartica teksta svesti sve ono što Crkva naučava i donose pozitivni pravni propisi. Ipak, pravo na život, kao temeljno ljudsko pravo, zajedničko je i Crkvenom učiteljstvu kao i pravnim sustavima mnogih država i mnogih međunarodnih dokumenata koji pravo na život stavljaju kao prvo i osnovno, jer ako nema života onda je nemoguće ostvariti ostala prava, kao što su pravo na zdravstvenu zaštitu, pravo na rad, pravo na slobodu misli, pravo na slobodu vjeroispovijesti, pravo na slobodu kretanja i udruživanja, pravo na državljanstvo i pravnu zaštitu, pravo na brak i zasnivanje obitelji i potomstvo, pravo na izbor zaposlenja i stupanja u javnu službu, pravo na imovinu, pravo na životni standard, pravo na odmor, pravo na školovanje i kulturni život, pravo na socijalnu pomoć i tako dalje.

Upravo zato Crkva stavlja sebe u zaštitu onih kojima je ona najpotrebnija, a to su najslabiji u društvu. Također, Crkva se stavlja u obranu i zaštitu ljudskoga dostojanstva. Drugačije niti ne može progovarati, to joj je zadaća jer na taj način svjedoči Boga koji sam za sebe govori da je onaj „koji daje rađanje“ (Iz 66, 9), koji je „začetnik života“ (Dj 3, 15).

1. Čovjek kao osoba

1.1. Antropološko pitanje čovjeka kao ljudske osobe

Postavljamo si s pravom pitanje: Tko je čovjek? Na čemu se temelji čovjekovo dostojanstvo i pravo? Je li taj temelj u mnoštvu pravnih propisa koji bi trebali jamčiti pravo i jednakost svih? Može li malo crne tinte na bijelom papiru učiniti nekoga više ili manje jednakim, „jednakijim“? Može li tinta meni kao osobi dati toliko željeno dostojanstvo? Mi, kršćani, vjerujemo da naše ljudsko dostojanstvo prvenstveno izvire iz svojega počela, a to je sam Bog kao Stvaratelj na kojega smo upućeni i s kojim smo povezani. Čovjeka kao osobu, kao cjelinu ne čine samo razum, sloboda, tijelo, ili pak duša, naprotiv; čovjek je cjelina. Biće koje je upućeno na Boga, a Biblija nam potvrđuje taj izravan odnos čovjeka s Bogom. U pogledu antropološkog poimanja osobe, imamo vid Božjeg stvaranja i otkupljenja čovjeka. Upravo zato postavljamo si pitanje: „Tko sam ja?“, a ne: „Što sam ja?“[5] Bog kao darivatelj života daje nam odgovor na to pitanje. Čovjek svoje postojanje ne duguje niti jednoj izvanjskoj sili,

5 Usp. Tonči MATULIĆ, *Bioetika*, Zagreb, 2001., 237.

već upravo Bogu koji postaje njegov temelj. Ovdje dolazimo do temeljnoga pitanja, a to je pitanje *osobe*. „Boetije je prvi pisac iz zapadnoga intelektualnoga kruga koji je pojam „osoba" postavio na razinu definicije koja se provukla nealterirana do naših dana."[6] „Za Tomu Akvinskog „osoba znači ono što je najsavršenije u cijeloj prirodi – a to je supsistentni pojedinac razumske naravi". Ova savršenost osobe ne temelji se na tome kako osoba djeluje u ovom našem svijetu nego na onome što je ona u sebi, što je ona promatrana s metafizičkog aspekta. Klasična je definicija osobe ona koju zastupa Boetie i koju kasnije prihvaća i dorađuje Toma Akvinski. Boetie kaže da je osoba: „*Naturae rationalis individuasubstantia* (individualna supstancija racionalne naravi)"."[7] Osoba je, dakle, individua te kao takva ne može biti podijeljena, no ipak je od svega ostalog itekako odijeljena, to jest u svojoj biti različita. Iz toga proizlazi da su sva bića supstancije s razlikom na princip individualizacije.[8] Danas se pojam osobe u mnogome želi relativizirati i svesti na vrednovanje prema kojemu ga se svrstava prema klasama ili ideologijama.[9]

1.2. Čovjek stvoren na sliku Božju

Ono po čemu se čovjek razlikuje od ostalih stvorenja jest njegova sposobnost za rad, za razvitak, slobodno djelovanje i ostvarivanje svoje osobnosti u potpunoj slobodi i zajedništvu s drugima. U tom smislu čovjek kao pojedinac ne može biti žrtvovan u neke druge svrhe, čak ni ako se radi o smislu nekog vrlo velikog dobra.[10]

Međunarodna teološka komisija izdala je dokument *Zajedništvo i upravljanje, Ljudske osobe stvorene na sliku Božju*, unutar kojega u drugom poglavlju, broj 28, razrađuje pitanje stvorenosti na sliku Božju i govori o tijelu i duši:

> „Stav da je tjelesnost bitna za osobni identitet temeljan je, čak iako ne posve izričito tematiziran, u svjedočanstvu kršćanske objave. Biblijska antropologija isključuje dualizam duh - tijelo i o čovjeku govori u njegovoj cjelovitosti. Među osnovnim hebrejskim pojmovima za čovjeka korištenih u Starom Zavjetu, *nèfès* označava život konkretne, živuće osobe (Post 9,4; Lev 24,17-18; Izr 8,35). No čovjek nema *nèfès*, on jest *nèfès* (Post 2,7; Lev 17,10). *Basar* označava tijela životinja i ljudi, a katkad i čitavo tijelo (Lev 4,11; 26,29). I opet, čovjek nema

6 *Isto,* 248.

7 Borislav KNEŽIĆ, Ivana DADIĆ, Metafizička istraživanja o osobi, u: *Riječki teološki časopis*, 17 (2009.) 2, 554.

8 Usp. Luka TOMAŠEVIĆ, Ontološko i funkcionalističko shvaćanje osobe: Bioetička rasprava, u: *Crkva u svijetu*, 2 (2011.) 46., 147–148.

9 Usp. V. POZAIĆ, Život prije rođenja, FTI, Zagreb, 1990., str. 80-81.

10 Usp. Michele ARAMINI, *Uvod u bioetiku*, Zagreb, 2009., 89.

> *basar*, nego on jest *basar*. Novozavjetnim pojmom *sarx* (put) može se označavati materijalna tjelesnost čovjeka (2 Kor 12,7), ali i čitava osoba (Rim 8,6). Još jedan grčki pojam, *soma* (tijelo) upućuje na čitavog čovjeka s naglaskom na njegovo izvanjsko očitovanje. I ovdje čovjek ne posjeduje svoje tijelo, nego jest svoje tijelo. Biblijska antropologija jasno pretpostavlja jedinstvo čovjeka i tjelesnost smatra temeljnim za identitet osobe."[11]

„Ljudska je osoba radikalno društvena veličina. Ona je prije svega subjekt odnosa. Po svojoj naravi bitno je upućena na drugoga. Ona izriče čovjeka u totalitetu, tj. u njegovu tjelesnom (biološkom) i duhovnom (psihološkom) integritetu."12 Čovjek je osoba (personalna dimenzija čovjeka kao subjekta), ali je i društveno biće (socijalna dimenzija ljudske osobe), predodređeno za život u zajedništvu.[13] Svaka osoba je neponovljiva, cjelina koja postoji u određenom tijeku vremena i ne može se ponoviti, isto kao što se ni proteklo vrijeme ne može ponoviti. Bog kao stvoritelj neponovljivo djeluje u svojim stvorenjima, stoga je Bog prvotni uzrok koji djeluje u svom stvorenju i po njemu. Ta činjenica stvorenosti na sliku Božju, u teologiji *imago Dei*, daje još veće dostojanstvo ljudskoj osobi.[14]

Promatrana u tom vidu, osoba, njezin integritet, posebnost i postojanje ne može biti dovedena u pitanje postojanja. Pred nas se stavlja peta Božja zapovijed (ne ubij), koja je u većini pravnih i moralnih sustava ozakonjena i tim činom život je stavljen pod posebnu zaštitu pravnog sustava koji prijeti sankcijama u slučaju kršenja te zapovijedi. No, tu zapovijed možemo staviti pod upitnik tako da stavimo pasivno „djelovanje" čineći distinkciju između „ubiti" i „pustiti umrijeti".

> „Razlikovanje aktivnog zahvata i pasivnog držanja, te »učiniti« i »pustiti da se dogodi«, služi u graničnim zonama između života i smrti (kraj i početak života), da bi se odredila granica uzajamne odgovornosti s kojom se ljudi mogu suočiti. Npr., u slučaju početka života treba priznati da samo vid zaštite dječjeg prava na život (pravo da dijete ne bude ubijeno) može zahtijevati apsolutnu valjanost, dok njegov pozitivni zahtjev za mjerama usmjerenima na održanje na životu ide samo do točke do koje država opravdava vrijeme postojećim medicinskim resursima i vodeći računa o drugim ciljevima zdravstvene politike (npr. vodeći računa o

11 Međunarodna teološka KOMISIJA, Vatican (2004.), u: http://www.vatican.va/roman_curia/congregations/cfaith/cti_documents/rc_con_cfaith_doc_20040723_communi on-stewardship_en.html (5. 10. 2016.).

12 Tonči MATULIĆ, *Bioetika*, Zagreb, 2001., 392.

13 Usp. Đ. HRANIĆ, Čovjek – slika *Božja. Teološka antropologija Ivana Pavla II*, u: *Diacovensia* 1 (Đakovo, 1993.), str. 33.

14 Usp. Hrvatska biskupska KONFERENCIJA, *Katekizam Katoličke Crkve*, Zagreb, 1994., 308.

> tromjesečnom fetusu u utrobi majke koja je cerebralno mrtva). No i ovomu razlikovanju moguće je prigovoriti. U čemu se točno sastoji razlika? Lakše je zanijekati razliku nego reći u čemu se ona sastoji. Leži li razlika u jasnoj distinkciji između djelovanja i nedjelovanja, u našim nakanama, ili u tome da se prepustimo sudbini, Bogu, prirodi? Isto tako, leži li razlika na temelju umjetnih ili prirodnih uzroka smrti?
>
> Na temelju teleološke etike teško je opravdati neku razliku, jer je posljedica uvijek ista, tj. smrt ljudske osobe. Naprotiv, prema etici uzajamnog poštovanja, koja priznaje suvereno pravo svakoga čovjeka na život, kao samostojni temelj naših uzajamnih odnosa, čak je i pravo na vlastitu smrt, koju ne smijemo preuraniti, sastavni dio ljudskog dostojanstva koje trebamo poštivati.“[15]

U razmišljanjima o kriterijima definicije osobe polazi se od pitanja o stupnju zaštite nekih ljudskih bića (embriji, duševno poremećeni, hendikepirani). U tom slučaju pojam »osoba« koji je duboko povezan s pojmom »dostojanstvo«, upućuje uglavnom samo na pojedinca koji je glavni subjekt prava koja se pripisuju ljudskom biću. Kroz pojam »osoba« pojedinac postaje nositelj prava, a posebice subjekt prava na život. U suvremenim etičkim razmišljanjima pitanje *Je li ljudsko biće osoba ili nije?* svodi se na pitanje *Treba li to ljudsko biće poštovati i zaštititi kao i svako ljudsko biće?*[16] Odgovor na ova i slična pitanja vrlo je jasan i leži u petoj Božjoj zapovijedi koja kaže: “Ne ubij!” te na taj način poštovati prirodni ciklus od začeća do smrti.

2. Dostojanstvo ljudskog života

> “Prije nego što te oblikovah u majčinoj utrobi, ja te znadoh; prije nego što iz krila majčina izađe, ja te posvetih.“ Jr 1, 5

2.1. Dostojanstvo ljudskog života kod prvih kršćana

2.1.1. Iz Poslanice Diognetu

Danas, kada s vremenskim odmakom promatramo živote prvih kršćana, svjesni smo da su oni živjeli pri „samom izvoru“, bili su svjedoci Objave, svjedoci Božjeg spasenjskog djelovanja; i upravo nam oni daju pravo svjedočenje života koji su učili bez posrednika od samoga Gospodina. Sami apostoli svjedoče da su s njime „zajedno jeli i pili“ (Dj 10, 41) Naše istraživanje prvotne zamisli treba nas uvijek vraćati k životu prvih kršćana, svjedocima njihova načina života.

15 Michele ARAMINI, *Uvod u bioetiku*, Zagreb, 2009., 94-95.

16 A. GAVRIĆ, *Osoba*, u: *Glas Koncila*, 43 (Uskrs, 2004.), br. 15, str. 14.

> „Kršćani se ne razlikuju od ostalih ljudi ni područjem gdje stanuju, ni jezikom, ni načinom života. Ne žive u svojim vlastitim gradovima, ne služe se nekim neobičnim jezikom, ne provode neki osobiti život. Nisu pronašli taj način života nekim domišljanjem i nastojanjem radoznalih ljudi. Nisu zaštićeni ni ljudskim zakonom kao neki drugi. Nastavajući grčke i barbarske gradove, gdje je koga sudbina postavila, prihvaćajući svagdje domaće običaje u odijevanju, hrani i uopće načinu života, oni žive i time predlažu izvanredan i po jednodušnom mišljenju svih nevjerojatan način života. Žive u vlastitoj domovini, ali kao došljaci. Kao građani s ostalima imaju sve zajedničko, a sve trpe kao tuđinci. Svaka im je tuđa pokrajina domovina, a svaka domovina tuđina. Žene se kao i ostali i rađaju djecu, ali ne odbacuju još nerođene djece. Imaju zajednički stol, ali ne i postelju. U tijelu su, ali ne žive po tijelu. Provode život na zemlji, ali na nebu imaju domovinu. Pokoravaju se izglasanim zakonima, a načinom svoga života nadvisuju zakone.“[17]

Vidimo da su se i prvi kršćani razlikovali od ostalih naroda s kojima su živjeli, upravo po svojim visokim moralnim načelima koja su živjeli i koja su drugi primjećivali. Između ostaloga „nisu odbacivali još nerođenu djecu“, dakle, poštovali su ljudski život od samoga početka. Ljudski je život vrednovan od samoga začeća, te je kao takav smatran darom.

3. Vrednovanje života u učenju Katoličke Crkve

Gledati na život očima otvorenim za mogućnost, očima koje ne vide tijelo kao nakupinu stanica, već tijelo kao biološko-duhovnu cjelinu koja je neodvojiva i neponovljiva ljudska jedinka, cjelina za sebe i dar života. Dar je to koji nam je darovan u vremenu i prostoru u kojem možemo promatrati čovjeka kao pripadnika velikog organizma prirode i na taj način postavljamo kozmološko pitanje koje nas upućuje na pitanje čovjekova položaja u svemiru, a s druge pak strane ono antropološko pitanje koje za sobom vuče već spomenutu cjelinu u smislu duša – tijelo.[18] Poruku o pitanju čovjeka kao osobi, kao daru, nečemu neponovljivom izrekli su i pape. Tako je papa Ivan XXIII. rekao: „Svaki je čovjek osoba, to jest da je narav obdarena razumom i slobodnom voljom. Ona sama po sebi ima prava i dužnosti što izravno o skupa izviru iz same njegove naravi. Budući da su oni općeniti i nepovredivi, ne mogu se ni na koji način otuđiti. Promatramo li pak dostojanstvo ljudske osove prema istinama objavljenim od Boga, tada ne možemo a da ga daleko više ne cijenimo;

17 *Poslanica Diognetu (Br. 5-6: Funk 1, 317-321)*, u: *Časoslov rimskoga obreda*, Zagreb, 2012., 613.

18 Usp. Michele ARAMINI, *Uvod u bioetiku*, Zagreb, 2009., 76.

ta ljudi su otkupljeni krvlju Isusa Krista, po višnjoj milosti postali su Božja djeca i prijatelji postavljeni za baštinike vječne slave".[19] Papa Ivan Pavao II. kaže: „U svojoj neponovljivoj posebnosti svaka ljudska osoba sastoji se ne samo od duha nego i od tijela, tako da se u tijelu i preko tijela ostvaruje sama osoba u svojoj konkretnoj stvarnosti. Prema tome, poštovati ljudsko dostojanstvo znači uvažavati taj čovjekov identitet kojim je on dušom i tijelom jedan (*corpore et anima unus).*"[20] U tom smislu progovara nam i *Donum vitae*[21]: „Dar života što ga je Bog Stvoritelj i Otac povjerio čovjeku, od njega zahtijeva da bude svjestan njegove neprocjenjive vrijednosti i da za nj preuzme odgovornost."[22]

Upravo iz razloga koje nam svjedoči izvještaj o stvaranju čovjeka u prvom poglavlju same Knjige Postanka u 27. retku, a to je stvorenost na sliku Stvoriteljevu, Crkveno učiteljstvo u dokumentu Drugog Vatikanskog Sabora progovara sljedećim riječima: „Čovjek – slika Božja. Prema gotovo jednodušnom uvjerenju vjernika i nevjernika, sve na zemlji treba biti usmjereno prema čovjeku kao svojem središtu i vrhuncu."[23] Stoga, u samom temelju ljudskog stvaranja stoji Bog i, kao takav, Bog je osnova i temelj dostojanstva i svetosti ljudskog života, ljudske osobe. Upravo stoga čovjek nije predodređen ni za kakvo drugo stvorenje, nego samo za Boga u zajedništvu s drugim ljudima. Stoga je ljudski život jedinstven, neponovljiv i neprocjenjiv. U dokumentu *Gaudium et spes* progovara nam Crkva o osobnom dostojanstvu čovjeka općenito i tu ne ulazi u pitanje osobnog dostojanstva samog djeteta koje se ima roditi, ali sljedeći tekst smjera upravo na dostojanstvo djeteta u majčinoj utrobi: „Budući da su svi ljudi – oduhovljeni razumnom dušom i stvoreni na sliku Božju – imaju istu narav i isti iskon te jer svi, od Krista otkupljeni, uživaju isti poziv i isto božansko određenje, sve se više mora priznavati temeljna jednakost među svima."[24]

19 IVAN XXIII, *Pacem in terris* (1963.), br. 9-10, u: *Sto godina katoličkoga socijalnog nauka*, uredio Marijan Valković, Zagreb, 1991., 165.

20 Zbor za nauk VJERE, *Donum vitae - Dar života, Naputak o poštivanju ljudskog života u nastanku i o dostojanstvu rađanja*, Zagreb, 2012., 12., (dalje: DV).

21 *Donum vitae – Dar života*, naputak kongregacije za nauk vjere o poštivanju ljudskog života u nastanku i o dostojanstvu rađanja

22 DV., 7.

23 DRUGI VATIKANSKI KONCIL, *Gaudium et spes - Radost i nada. Pastoralna konstitucija o Crkvi u suvremenom svijetu. (7. XII. 1965.)*, u: *Dokumenti*, Zagreb, 2008., 12., (dalje: GS).

24 GS, 29.

4. Pravni sustavi

4.1. Pravni sustav kao izvor norme za vrednovanje života

Pravo, kao normativni izričaj duha civilizacije nastaje, živi i razvija se unutar društva kao njegov neodvojivi dio. Promatrano kroz povijesne okolnosti najprije se javlja kao običajno pravo određene zajednice te s vremenom poprima pisani oblik. No, u kojem god obliku pravna norma bila, uvijek odražava volju zajednice. Na neki način ocrtava upravo duh kojim ta zajednica živi. Dakako da je nemoguće da pravo kao bitan, rekao bih *konstitutivan* element društva, regulira društvo do u svaku i najmanju pojedinost, ta to je *njemačka bolest*, kako je naziva Hegel kada kaže:

> „Za javni zakonik valja, s jedne strane, zahtijevati jednostavna opća određenja a, s druge, priroda konačne građe vodi ka beskonačnim daljim određenjima. Opseg zakona treba da je, s jedne strane, gotova zatvorena cjelina, a s druge, on je neprekinuta potreba novih zakonskih određenja. Kako ova antinomija, međutim, pripada u specijaliziranje općih načela, što čvrsto dalje traju, zato time ostaje neokrnjeno pravo na gotov zakonik, kao na to da su ta opća jedinstvena načela za sebe, različita od svog specijaliziranja, razumljiva i postavljiva. Zahtijevati od zakonika savršenost, da on treba da bude gotov, nesposoban za neko dalje određivanje - zahtjev koji je naročito njemačka bolest - te s razloga što nije mogao postati tako savršen, ne dopustiti da dođe do nečega takozvanoga nesavršenoga, tj. do zbiljnosti - osniva se na nepoznavanju prirode konačnih predmeta, kao što je privatno pravo.“[25]

4.2. Zaštita života u rimskom pravu

Vratimo se li na izvorište europskog pravnog naslijeđa, a to je rimsko pravo, tada u njemu jasno vidimo načelo prava na rođenje iz kojeg slijedi i vrijednost ljudskog života i prije samoga rođenja. „Začeto dijete u neku se ruku smatra kao da je već rođeno. – Conceptus quidammodo in rerum natura esse existimatur.“[26]

4.3. Zaštita života u Tori

Dobro nam je poznata revnost Židova u vršenju svih zapovijedi što ih im je Gospodin dao preko Mojsija. Strogost Tore (Zakona), s vremenskim i geografskim odmakom

25 Georg Wilhelm Friedrich HEGEL, *Osnovne crte filozofije prava: s Hegelovim vlastoručnim marginama u njegovu priručnom primjerku filozofije prava*, Sarajevo, 1989., §216.

26 ULPIJAN, *Digesta, 38, 19, 7*, u: Ante ROMAC, *Izvori rimskog prava*, Zagreb, 1973., 140-141.

od onog vremena često nam se čini odviše rigorozna, a posebice što se tiče Subote. No, u Starome zavjetu, nakon velikog potopa, Bog Noi i njegovim sinovima upućuje značajne riječi: „Tko prolije krv čovjekovu, njegovu će krv čovjek proliti! Jer na sliku Božju stvoren je čovjek!" (Post 9, 6)

Taj redak komentira se u Babilonskome Talmudu (Sanhedrin 57b) riječima: „Tko prolijeva krv čovjeka u čovjeku, krv će mu se proliti. Tko je čovjek u čovjeku? To je zametak u majčinoj utrobi." Spašavanje nerođenoga života za vrijeme cijele trudnoće potiskuje zabrane Tore, pa je tako, primjerice, dopušteno kršiti subotu kako bi se spasilo dijete (sav posao nužan za porođaj djeteta može se obaviti subotom – Talmud, Mišna Moed, Šabat 18, 3), da bi u budućnosti ono moglo držati mnoge subote."[27]

4.4. Zaštita života u pozitivnom pravu

4.4.1. Konvencija o pravima djeteta

Život kao pravno dobro zaštićen je u mnogim dokumentima, tako i Deklaracija o pravima djeteta[28] govori u četvrtom načelu sljedeće: „Dijete mora uživati sve pogodnosti socijalne zaštite. Mora imati pravo na život i razvoj u zdravoj okolini i stoga je i njemu i njegovoj majci potrebno pružiti posebnu njegu i zaštitu, kao i skrb prije poroda. Dijete ima pravo na odgovarajuću prehranu, smještaj, razonodu i zdravstvene usluge."[29] Konvencija o pravima djeteta[30] kasnije nam u svom članku šestom potvrđuje i izričito govori o prirođenom pravu na život, te se državama potpisnicama nalaže da osiguraju u najvećoj mogućoj mjeri opstanak i razvoj djeteta.[31]

4.4.2. Primjer pravnih propisa Njemačke

Visoki stupanj doprinosa u zaštiti još nerođenoga ljudskog bića daje njemački Ustavni sud kada tumači odredbu njemačkoga Temeljnog zakona, odnosno Ustava. Svojim tumačenjem Ustavni sud daje nedvojbeno mišljenje o zaštiti života i prije negoli je rođen. Na taj je način otklonjena svaka sumnja u pitanju zaštite, ali i dostojanstva ljudskog bića, bića koje se ima roditi i kao takvo nosi već određena prava u samom

27 Stanko LASIĆ, *Pravo na rođenje u učenju Crkve*, Zagreb, 2009., 60.

28 *Deklaracija o pravima djeteta* iz 1959. godine, a usvojena na Općoj skupštini Ujedinjenih naroda 20. studenoga 1959. u rezoluciji br. 1386/XIV.

29 *Deklaracija o pravima djeteta iz 1959.*, u: Dobriša SKOK (ur.), *Ljudska prava, Osnovni međunarodni dokumenti*, Zagreb, 1990., 129.

30 *Konvencija o pravu djeteta*; donesena 20. studenoga 1989. na 44. zasjedanju Generalne skupštine Ujedinjenih naroda u New Yorku.

31 Usp. *Konvencija o pravu djeteta*, u: Juraj HRŽENJAK, *Međunarodni i evropski dokumenti o ljudskim pravima: Čovjek i njegove slobode u pravnoj državi*, Zagreb, 1992., 186.

pravnom sustavu. Tu vidimo analogiju sa starim rimskim pravom koje je također davalo visoki stupanj priznanja činjenice života i prije samoga rođenja. „Članak 2. stavak 2. *Temeljnog zakona* (Ustava) *SR Njemačke* od 8. svibnja 1949. određuje „Svatko ima pravo na život", a tumačeći tu odredbu njemački Ustavni sud u odluci od 25. veljače 1975. godine kaže: „pravo na život jamči se svakome tko živi; između pojedinih dijelova života u razvoju, prije rođenja ili između rođenoga i onoga koji se ima roditi ne postoji nikakva razlika. Svatko, u smislu čl. 2. st. 2. podstavka 1. Temeljnoga zakona, jest *svaki živi čovjek*; drugim riječima; svaki ljudski individuum koji posjeduje život; *svatko* zato znači i još nerođeno ljudsko biće."[32]

4.4.3. Primjer pravnih propisa Hrvatske

Hrvatski pravni sustav također ima regulirano pitanje zaštite života u samome Ustavu. Na taj način progovara i štiti život u svim okolnostima, pa čak i u slučaju ratnoga stanja život ima prednost zaštite u službi obrane života i ljudskog dostojanstva. „Članak 21. stavak 1. *Ustava Republike Hrvatske* od 22. prosinca 1990.: „Svako ljudsko biće ima pravo na život." (Narodne novine br. 56/90). U skladu s člankom 14. stavkom 1. istoga *Ustava*, to pravo postoji neovisno o rođenju. Članak 17. stavak 3. istoga *Ustava* dodatno određuje: „Niti u slučaju neposredne opasnosti za opstanak države ne može se ograničiti primjena odredbi ovoga Ustava o pravu na život."[33]

Zaključak

Temeljno polazište pitanja ljudskog dostojanstva i ljudskih prava jest pitanje *osobe* i njezine slobode. Potrebno je staviti naglasak na osobu kao neponovljivu individuu koju tako promatraju i pravni sustavi, a napose Katolička Crkva, s obzirom na stvorenost na sliku Božju, kojoj je zadaća naviještati, širiti i tumačiti primljenu Objavu koja svoju puninu ostvaruje u osobi Isusa Krista.

Upravo rođenje djeteta, rođenje nove osobe, individue, povlači za sobom veliku radost. Svjedoči nam o tome i Lukino evanđelje donoseći radosnu vijest o rođenju: „Evo, javljam vam blagovijest, veliku radost za sav narod! Danas vam se u gradu Davidovu rodio Spasitelj Krist, Gospodin." (Lk 2, 10-11) U samome Uvodu spomenut je Bog kao „davatelj života", to je i središte Isusovog djelovanja koje je proegzistentno,

32 Stanko LASIĆ, *Pravo na rođenje u učenju Crkve*, Zagreb, 2009., 46.

33 *Isto.*

usmjereno na čovjeka pojedinca kojeg ozdravlja i kojem vraća njegovo dostojanstvo, a sam progovara: „Ja dođoh da život imaju, u izobilju da ga imaju." (Iv 10, 10)[34]

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34 Usp. Ivan Pavao II, *Evangelium vitae - evanđelje života. Enciklika o vrijednosti i nepovredivosti ljudskog* života., (25. III. 1995.), Zagreb, 2003., br. 1.

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Bioethics, Human Dignity and Human Rights

ABSTRACT

Today's modern society offers us the resolutions to many contradictions of the social image that is present today. Only a bit stronger engagement is needed to open the wider horizons of the real socio-political situation of society. An integral part of human society is both right and law, at first as a custom (common law) and later codified law. In history, we can observe the image of society through the legal norms of different legal systems, and what kind of regards to life, the right to life, and ultimately to human dignity had a certain civilization. As a postulate of this work, the purpose is to portray human rights, human dignity and a view on life, especially through the Teachings of the Catholic Church, with a brief focus on Jewishlearning in the Torah, on Roman law, and of course, on positive law and legal practices along the development of speech about dignity and the right to the human person's life starting with the general view on speech about human life, through reflection on early Christian times, tothe speech about the dignity, and man created in the image of God.

Talking about human rights and the dignity of a human person is not a grateful topic at all. Throughout history, human rights and the dignity of the human being have always been a stumbling block. In the cases of such a disruption, we might even say gross violations of human dignity and human rights; Evangelical doctrine, as a revelation that the Catholic Church inherits, is the key to defending and protecting the weakest ones.

Key words: person, human dignity, life, right, human image of God.

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The Importance of the Assessment of Quality of Life in Glaucoma Patients

ABSTRACT

Glaucoma is a chronic, progressive eye disorder that can lead to visual impairment and blindness. The projection of glaucoma prevalence in the world suggests that in 2020, 79,6 million of people will have glaucoma, 11,2 million of them will be bilaterally blind. The chronic disease, such as glaucoma, affects the different roles of a patient in everyday life and his/her well-being. Quality of Life (QoL) helps to define the inability of performing specific task that is most important to patient. Patients' perspective on their visual impairment and well-being are essential in the planning of management of glaucoma. The assessment of QoL should be standard procedure in the management of glaucoma patients. In clinical practice it should represent a gold standard in the care of chronic patients and a proof of fulfilling the patients' rights. The assessments of QoL should serve as a tool for good clinical practice, for respecting the patients' rights, and respect for the value of human life in general.

Keywords: Quality of life, glaucoma, patients' perspective, rights of the patients.

Introduction

Glaucoma is a chronic, progressive eye disorder that can lead to visual impairment and blindness (1,2). In the early stage glaucoma is often asymptomatic, therefore undiagnosed chronic disease with irreversible consequences on the vision, physical, psychical and social life of the patients. It is assumed that only half of glaucoma patients in developed countries are aware of their disease (3), in comparison

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to 90% of unaware glaucoma patients in the developing countries. Glaucoma is important public health issue of 21st century (4,5,6,7). The projection of glaucoma prevalence in the world suggests that in 2020, 79,6 million of people will have glaucoma and 11,2 million of them will be bilaterally blind (6,8). As Bourne (2,9,6) suggested, many papers started with the sentence that "Glaucoma is the second leading cause of vision loss in the world" that actually could represent awareness of researchers worldwide regarding the seriousness of glaucoma's consequences. The ophthalmologists worldwide are focused more on how to maintain the intraocular pressure (IOP) within the normal values or how to preserve the visual function of their patients, while the patients are focused on their ability to fulfill everyday's tasks and roles in everyday's lives (family, business or social roles). The chronic disease, such glaucoma is, effects the different roles of patients and well-being of the patients too. Perspectives of ophthalmologist and perspectives of glaucoma patients regarding the different important issues in management of glaucoma sometimes do not coincide (10). Ophthalmologists should be aware of the importance of well-being for the glaucoma patients, and should estimate it through their work. Measuring the quality of life (QoL) related to the health and vision can assess the well-being of patients. One of the most important aims of the glaucoma management is preservation of QoL of glaucoma patients.

Glaucoma

Glaucoma is a chronic neurodegenerative disorder that could lead to irreversible changes of retinal ganglion cells and loss of optic nerve cells (7). If not treated properly and timely, it could cause severe vision impairment and blindness. Generally, glaucoma mostly affects people over 40 years of age. Visual impairments are the highest in older population (11) with an effect on visual function and general well-being. The demographic characteristics in the world suggest that along with the population ageing there is a higher prevalence of glaucoma (1,12,13,14). On the other hand, the worldwide trend is an increasing age of working active population. It is assumed that there will be a great number of working active population suffering from glaucoma and its' consequences on working ability and everyday functioning. The review of literature suggests that advanced glaucoma degrades the patient's general health, Quality of life (QoL), and vision related to quality of life (2,10,15). The chronic disease has negative impact on patients' physical, emotional and social aspects of life (11,16).

Quality of life

One of the most important aims of the glaucoma management is preservation of glaucoma patients' QoL (16,17,18,19,20,21). The goal of the ophthalmologist is prevention of the loss of health related quality of life (HRQOL).

QoL could be defined as person's own estimation of physical, psychological or social well-being (17,19). It is important to assess the multidimensional characteristics of QoL such as physical parameters (sign of illness and therapy), functional (ability to move and mobility), social (interpersonal contact and relationships) or psychological (mental health and stability) (22,23,24).

The instruments used to assess QoL identify presence or absence or severity and frequency of different types of symptoms (16). But they are not useful for the identification of the priority of particular symptoms, which mostly disturbs the patient. The ability to work, drive the car, do the sports, to be active in social life are indirect signs of successful glaucoma therapy. These elements contribute to preservation of good QoL.

QoL is not a constant value, it differs in one patient over time (19) or depending on the situation (25). QoL of two persons suffering from the same diagnosis is different. Various factors can contribute to QoL, such as culture, social environment, or the patients' expectations in life.

The researcher's goal is to choose an instrument to measure QoL (26). Mainly, those instruments are self-reported or interview administered questionnaires (19). Health related questionnaires, which are used in glaucoma patients for assessing QoL, could be divided in general health questionnaires and disease related questionnaires (17,19,22).

In this paper we will put an emphasis on disease related questionnaires or vision-specific QoL questionnaires in glaucoma patients.

Instruments for assessing the QoL in glaucoma patients

The Activities of Daily Scale (ADVS) originally was addressed to cataract patients. ADVS is made of 22 questions divided in 5 subgroups (near vision, distant vision, glare disability, daytime driving and night driving) (19).

The Visual Function Index (VF-14) originally was designed to assess functional impairment in patients with cataract (19).

The Visual Activities Questionnaire (VAQ) is made of 33 questions divided in 10 subgroups. The aim of VAQ is to assess the difficulties in everyday's visual problem in older glaucoma patients (19).

The Impact of Vision Impairment (IVI) consists of 32 questions regarding the impact of visual impairment on everyday life experience (19).

The National Eye Institute Visual Function Questionnaire (NEI-VFQ) consists of 25 questions regarding the impact of different ocular problems on everyday vision functioning (17,19).

The Glaucoma Symptoms Scale (GSS) is constructed to assess 10 symptoms that glaucoma patients experience (visual and non-visual symptoms) (19).

The Viswanathan Questionnaire is constructed of 10 questions with yes or no responses regarding the ability to find a lost object, or climb up the stairs, or bump into the objects (19).

The Glaucoma Quality of Life (GQL-15) is composed of 15 questions for the purpose of assessing the stage of functional disability (17,19).

Glaucoma Symptom Identifier (GSI) is constructed to identify various glaucoma symptoms with their impact on QoL (17).

Independent Mobility Questionnaire (IMQ) is constructed for measurement of patients' ability for independent mobility (17).

Comparison of Ophthalmic Medications for Tolerability (COMTOL) is constructed for use in clinical trials in order to compare the side effects of medication therapy and impact on QoL (17).

Treatment Satisfaction Survey-Intraocular Pressure (TSS-IOP) is designed for assessment of patient's satisfaction regarding the different aspects of topical antiglaucoma medication.

In general, patient-reported outcomes can be divided in three categories: those which address functional status regarding the vision; those which assess QoL in general, and the third one which detect other issues connected to the disease and treatment (17).

Until today there are no ideal questionnaires for assessing QoL in glaucoma patients.

Glaucoma Patients' perspectives on the QoL

Difficulty and inability to perform daily activities often bring the patient to the ophthalmologist's office before the patient actually knew that he has glaucoma.

Irreversible changes of optic nerve axon and retinal ganglion cells result in inability to perform many visual demanding tasks (27), such as difficulties while reading, writing, dressing, traveling in glaucoma patients (24). Functional loss, anxiety due to diagnosis, the costs of treatment, or inconveniences might also have negative impact on QoL (28). Patients usually report bumping into the things, difficulties in climbing stairs, etc.

QoL helps to define the inability of performing specific task that is most important to patient. This is very important moment in planning the management of glaucoma. Because of that, the assessing of QoL in clinical practice is important for allocation of limited resources and for therapy planning of particular patient (16).

Even a moderate visual impairment leads to deterioration of patient's QoL (2,29) regardless of the primary ocular diagnosis. Moderate visual impairment can lead to deterioration of visual impairment, and can have a negative impact on emotional well, increased functional disabilities. These findings were collected from the patients' perspectives, because of their negative impact on patients' well-being. They suggest that even the patients with moderate visual impairment should undergo further evaluation of their vision health status. Without exploring the patients' perspective regarding the moderate visual impairment, ophthalmologist might postpone further evaluation of vision that could lead to more serious deterioration of visual impairment with the consequences on emotional status, family, business, or social functioning.

Why QoL instruments should be assessed in clinical practice regarding glaucoma patients?

The assessment of QoL in glaucoma patients, regardless of the type of QoL questionnaires, has multiple benefits on glaucoma patients' well-being. It reminds ophthalmologist that his/her perspective on success of glaucoma treatment might differ from patients' perspectives. It reminds patients of glaucoma consequences on everyday tasks that he/her is not able to perform anymore. It recalls that adherence to the lifelong therapy is important for patient functioning and fulfilling life tasks in family, business or social environment.

There are wide possibilities available to assess the QoL in glaucoma patients (7,19) but it seems that these possibilities are mostly reserved for the researches' purposes and not for the clinical practice. On the other hand, the perception of patients suggests the necessity of including the assessment of QoL in daily work of ophthalmologists. As Waisbourd suggests, every ophthalmologist should ask him/herself how he/she can preserve or even improve the health and well-being of their patients (7). The ophthalmologists' interest should not focus only on the value of intraocular pressure

or on visual field loss, it should also focus on the possibilities of patients to perform different daily activities. The patients' reports regarding difficulties in daily activities could have an impact on clinical decision making and antiglaucoma therapy planning. If these elements are not taken into account, the right of the patients to proper care could be disturbed.

On the other hand, assessing QoL (health related or vision related) instruments in undiagnosed glaucoma patients could serve as a diagnostic tool. McKean-Cowdin et all (2) performed study in which they assessed health related QoL instrument among the participants who were not aware of their glaucoma diagnosis at that time. Among the 6357 participants, 291 were identified with open angle glaucoma (OAG), 75% of them were diagnosed glaucoma for the first time. Those diagnosed glaucoma for the first time had modest levels of vision loss, but lower health related QoL. It could be assumed that assessing HRQoL instruments in settings such as general medicine office or in general ophthalmological office might serve as a screening tool for glaucoma in the patients who have lower HRQoL.

Bioethical approach regarding QoL

If QoL is determined by well-being, which is a more subjective factor, then it is difficult to accurately define QoL (30). There are several values that are gained by assessing QoL:

a. The progression of illness and success of therapy could be measured
b. Analyzing the database of the previously obtained QoL data, physician can choose the best appropriate therapy for the present patient
c. The databases can provide the information regarding side effects of specific treatment
d. Assessment of the cost effectiveness of certain therapy

The assessment of QoL has a dangerous side, as is the case where somebody's subjective perception of QoL is low, this could lead to value QoL as the quality of human person with consequent discussion of whether this person should receive medical treatment or is it worth living (30).

Addressing the participants of the Study Congress of the Pontifical Academy for Life "Quality of life and ethics of health", Pope John Paul II said that theme „…is of the greatest ethical and cultural importance for both developed and developing societies" (31). He emphasizes the danger of understanding the QoL through the health economics, consumerism, physical beauty and pleasure, while forgetting the essence of QoL, such as interpersonal, spiritual, and religious existence.

The utilitarian perspectives

Pragmatic utilitarian perspectives evaluate QoL as minimizing the pain and the economic costs (32). Utilitarian perspectives are based on the ethic of consequentiality. There are human lives worth living and those which are not worth living. There are different measurements, such as minimum intellectual capacity self-awareness, self-control, orientation in time and spaces, capacity to relate to others, interest for others, capacity to communicate. Other measure can be hedonistic perspectives.

The utility theory, developed in 1940 and implemented in health care by the 1970s, associate QoL with health care. Utility analysis enabled objective evaluation of QoL in health care, especially associated with visual field loss (10,33,34). A utility value of 1.0 correlates with good health, while a value of 0.0 correlates with death. The higher the utility value, the better the QoL is. Regarding the ophthalmology, utility values decrease in correlation with visual loss (10).

As we represent, there are possibilities of different perspectives of patients and ophthalmologists regarding the glaucoma patients' well-being. An appropriate approach to glaucoma patient necessary includes patient's perception of his/her well-being and subjective self-reported measures together with the clinical measures, and performed based measures (7). A holistic, complete approach to a patient, in this case to a glaucoma patient, needs time. Because of the shortage of time, health care policies, unclear regulation, or lack of the regulation regarding implementation of the health care, the glaucoma patient often does not receive holistic approach from his/her ophthalmologist. In the bioethical sense, the plan for assessment of glaucoma patients should include all above mentioned elements. Many authors agree that consideration of patients' perspectives and preferences should be gold standard in establishing the impairment caused by a health state and eventual improvement in QoL (10,35).

The health care decisions often have to be individualized. Two patients might have the similar score in Qol measurements but with different perceptions of one's own well-being or the patients' and physicians' perspectives on the same results could have opposite perception of patients' health status and well-being. As well, the choices between possible outcomes may be viewed differently by different patients (35) or physicians.

Conclusion

Awareness of the importance of QoL and its' assessment in glaucoma patients goes beyond the research and statistics. The assessment of QoL of glaucoma patients should

be the standard procedure in clinical practice, the base for future therapy planning. The QoL assessment is a way to incorporate patients' perspectives on their well-being into the future therapy planning. It is the guarantee to incorporate patients' rights in everyday practice. To prevent a global pandemic of glaucoma patients, the assessment of health and vision related QoL should be considered as a diagnostic tool for glaucoma patients. The QoL assessment is generally of great value to patients but could be interpreted from an unethical perspective and unethical reasons.

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Važnost ispitivanja kvalitete života kod pacijenata oboljelih od glaukoma

SAŽETAK

Glaukom je kronična, progresivna očna bolest koja može dovesti do oštećenja vida i sljepoće. Projekcije prevalencije glaukoma u svijetu sugeriraju kako će 2020. godine 79,6 milijuna ljudi imati glaukom, dok će 11,2 milijuna biti obostrano slijepo. Kronična bolest, kao što je glaukom, utječe na različite životne uloge oboljelog i njegovu dobrobit. Određivanje kvalitete života (QoL) pomaže odrediti koje svakodnevne zadatke pacijent ne može izvršiti, a za njega su najvažniji. Pacijentova perspektiva na oštećenje vida i njegovu dobrobit esencijalni je element u planiranju liječenja. Ispitivanje kvalitete života trebalo bi biti standardni postupak u skrbi o pacijentu s glaukomom. Ispitivanje QoL-a u kliničkoj praksi trebalo bi predstavljati *zlatni standard* u skrbi o kroničnom pacijentu i poštovanju njegovih prava. Ispitivanje QoL-a trebalo bi služiti kao sredstvo dobre kliničke prakse i poštovanja prava pacijenata, kao i poštovanja ljudskog života općenito.

Ključne riječi: kvaliteta života, glaukom, perspektiva pacijenta, prava pacijenata.

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Uvod u holistički environmentalizam

SAŽETAK

Holistički environmentalizam jest cjelovito sagledavanje materijalnog (priroda) i duhovnog (svijet) okoliša, a njegova bit jest promicanje dobrohotnosti u odnosima čovjeka prema drugim bićima. Istraživački prostor holističkog environmentalizma nalazi se unutar integrativne bioetike. Cjelovit pristup okolišu, karakterističan za holistički environmentalizam, istražuje mogućnosti i postavlja modele dobrohotnog suživota bića na Zemlji. Holistički environmentalizam ne bavi se samo zaštitom okoliša već razumijevanjem okoliša. Razumijevanje materijalnog i duhovnog okoliša daleko nadilazi ono što se pogrešno naziva zaštitom okoliša. Razumjeti materijalni okoliš znači ne uništavati staništa, ne narušavati kvalitetu zraka, vode i tla, ne posezati za nepopravljivim razaranjem, ne bahatiti se inteligencijom, ne polomiti i preoblikovati sve što smo sposobni polomiti i preoblikovati. Razumjeti duhovni okoliš znači biti dobrohotan, znači shvatiti jednakost, bratstvo, slobodu, jedinstvo i pravednost kao model smislenog i stvaralačkog življenja.

Ključne riječi: holistički environmentalizam, materijalni okoliš, duhovni okoliš, dobrohotnost, razumijevanje okoliša.

Uvod

Okoliš je apsolutno sve što postoji *oko* nas, sve što nije u nama kao ljudskom biću, u našem tijelu i u našoj duši. U svakom trenutku, tijekom cijelog ljudskog života, prema pojavama i bićima u našem okolišu zauzimamo određene stavove, a u našem neposrednom okolišu i djelujemo.

U materijalnom okolišu, u prirodi, mi se rađamo, živimo i umiremo. U duhovnom okolišu, u svijetu, egzistiramo kao duhovna bića. Kao što su tijelo i duša tijekom

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ljudskog života međusobno neodvojivi, isto su tako u nedjeljivom jedinstvu materijalni i duhovni okoliš.

Prema Hrvatskom enciklopedijskom rječniku okoliš jest ukupnost materijalnog i živoga svijeta kojeg je čovjek biološki dio1. Holistički environmentalizam jest cjelovito sagledavanje materijalnog (priroda) i duhovnog (svijet) okoliša. Holistički environmentalizam promiče cjelovit pristup okolišu, a cjelovit pristup okolišu po definiciji je iznalaženje mogućnosti i postavljanje modela dobrohotnog suživota bića na Zemlji.

Istraživački prostor holističkog environmentalizma nalazi se unutar integrativne bioetike. Pojam integrativne bioetike zorno pojašnjava Hrvoje Jurić:

"No, bioetika se ne bi smjela zadovoljiti pukim mehanički okupljanjem različitih perspektiva, različitih disciplinarnih i svjetonazorskih pogleda, nego bi trebala težiti *zbiljskoj integraciji*, izradi jedinstvene platforme za raspravu o etičkim problemima vezanim uz život – u cjelini i u svim kontekstualno odredivim nijansama. *Integrativnost* bi stoga trebala označavati zadaću (odnosno sposobnost) bioetike da sve različitosti o kojima je bilo riječi okupi u jedinstveni *bioetički pogled*, radije negoli u disciplinarni i disciplinirani znanstveni okvir. Prije se, dakle radi o promoviranju bioetičkog pogleda u različitim disciplinama i pristupima, negoli o utjerivanju različitih partikularnih pogleda u jedan, bioetički disciplinarni kalup. *Integrativnu bioetiku* bi se, u tom smislu, moglo pojmiti kao čvrsto tijelo u određenom prostoru, čija je uloga da permanentno upija energiju, te da je isijava prema drugim tijelima u prostoru, koja su za tu energiju prijemčiva."[2]

Bioetički pogled moguć je i u tehničkim znanostima, pa time i u metalurgiji koja je moja matična struka. Bez proizvodnja i prerade metala teško je zamisliti modernu tehničku civilizaciju i sve materijalne udobnosti koje svima nama ona pruža. No, ako se neće uvažavati bioetička perspektiva, rezultati znanstvenih istraživanja na području tehničkih i prirodnih znanosti mogu donijeti čovječanstvu u cjelini daleko više štete no koristi. Klimatske promjene ozbiljna su posljedica neobuzdanog tehnološkog razvoja.

Tehnološki napredak uglavnom donosi i opasnost od daljnjeg socijalnog raslojavanja unutar kapitalističkog društva jer povećava profit vlasnicima sredstava za proizvodnju, a istovremeno smanjuje potrebu za radnom snagom. Ako ne postoji adekvatna porezna politika unutar demokratske i socijalne države koja bi financijski profit od

1 Hrvatski enciklopedijski rječnik, Novi Liber, Zagreb, 2002., str. 866.

2 H. Jurić, Etika odgovornosti Hansa Jonasa, Pergamena, Zagreb, 2010., str. 241.

tehnološkog napretka pravedno distribuirala, tada znanstveni napredak znači ujedno i etički nazadak. I tu je važna uloga bioetike da ukaže na problem.

Trajanje ili postojanje

Svaki ljudski život može se pojednostavljeno sagledati kao postojanje ili kao trajanje. Naravno, postoji i bezbroj nijansi između te dvije krajnosti što jasno očituje ljudska povijest. Hoće li naš život biti u većoj mjeri postojanje ili trajanje ovisi o tome kako se određujemo prema materijalnom i duhovnom okolišu. Postojanje je po sebi funkcija vječnosti i nadilazi život između fizičkog rođenja tijela i smrti tog istog tijela, dok je trajanje funkcija vremena i oštro je omeđeno između trenutaka rađanja i smrti.

Postojanje zahtijeva bar minimalno razumijevanje materijalnog i duhovnog okoliša. No, čak i ljudska bića, ne samo životinje i biljke, mogu trajati bez da pokušaju razumjeti temeljna pitanja egzistencije u materijalnom i duhovnom okolišu.

Nažalost, u suvremenoj civilizaciji jačaju tendencije nasilnog ograničavanja postojanja i svođenje drugih ljudi na trajanje tako da je sve više ljudi gurnuto u materijalnu oskudicu, pa i materijalnu bijedu, te im je u toj poziciji onemogućeno razvijanje vlastitih intelektualnih i fizičkih potencijala.

Kada netko nema pristup obrazovnom procesu tijekom kojeg može razotkriti vlastite talente i realizirati vlastite intelektualne potencijale, kada netko nema pristup zdravstvenoj zaštiti u mjeri da mu vlastito zdravlje nije ugroženo zbog socijalnog statusa, kada netko nema pristup radnom procesu zbog po ljudsko dostojanstvo neprihvatljivih uvjeta rada i/ili cinično niske nadnice, kada netko nema pristup stanovanju koje zadovoljava barem najosnovnije kriterije privatnosti i udobnosti – tada je prisiljen na trajanje. Tada život klizi u životarenje, u bezbojno i bezlično trajanje.

Trajanje može biti i odabir slobodne volje pojedinca u smislu potpune nezainteresiranosti za pročišćavanje vlastitog materijalnog i duhovnog okoliša. U suvremenom svijetu postoje i mnogi ljudi koji imaju sve preduvjete kako bi razvili vlastite potencijale, no radije se odlučuju na pragmatični egoizam i sagledavanja okoliša po kriteriju utilitarnosti.

Takve pojedince ne zanimaju problemi drugih koji nisu s njima u neposrednoj interakciji. Savjest tretiraju kao slijepo crijevo – nešto bez čega se može živjeti, štoviše, kao nešto bez čega je i jednostavnije živjeti. Ne postavljaju si pitanja, niti ih zanimaju odgovori. Njihov cilj je trajanje u zadovoljstvu, a ne postojanje u sreći.

Za postojanje nužno je imati mogućnosti i želje razviti vlastitu osobnost, moći se izraziti kao pojedinac sa svojim identitetom, kao neponovljiva jedinka koja osjeća jedinstvo s prirodom i kojoj je dano sudjelovati u oblikovanju i uljepšanju svijeta.

Cilj holističkog environmentalizma jest da svi ljudi, svaka jedinka unutar čovječanstva ima mogućnost postojanja u najdubljem smislu te riječi te da trajanje ili postojanje bude stvar slobodnog izbora svakog pojedinca. Naravno, holistički environmentalisti zalagat će se i boriti da oni koji odabiru trajanje nemaju sredstva prisile kojima bi druge, one koji žele postojati, primoravali na trajanje.

Čovjek kao tijelo izražava se u materijalnom okolišu, a čovjek kao duhovno biće izražava se u duhovnom okolišu. Materijalni okoliš sačinjava materija, priroda u svoj svojoj raznolikosti i smislenoj ljepoti. Klasična zaštita okoliša bavi se isključivo materijalnim okolišem, a dijeli se na zaštitu tla, vode i zraka. Duhovni okoliš, svijet oko nas, tvori ustrojstvo međuljudskih odnosa u privatnoj i javnoj sferi ljudskog djelovanja, kao i odnos čovjeka prema drugim bićima na Zemlji.

Bit holističkog environmentalizma jest promicati da taj odnos čovjeka prema drugom čovjeku, prema životinjama, prema svijetu u cjelini i svakom segmentu prirode bude dobrohotan. Holistički environmentalizam zbog toga treba istraživati mogućnosti i postavljati modele dobrohotnog suživota bića na Zemlji. Na ovome mjestu vrlo je bitno sagledati razliku između dobronamjeran i dobrohotan.

Dobronamjernost nije dovoljna, barem ne više na današnjoj razini destrukcije materijalnog i duhovnog okoliša. Destrukciju materijalnog i duhovnog okoliša neodgovorno provode razulareni, pa i podivljali egoisti, često u uštogljenim i perfidnim formama i strukturama, tako što ubrzano gomilaju materijalno bogatstvo ne obazirući se ni na druge ljude, a još manje na životinje, biljke i prirodu u cjelini.

Dobronamjernost u sebi ne uključuje djelatnu akciju, britku odlučnost za poboljšanje kvalitete materijalnog i duhovnog okoliša. Dobronamjernost ne uključuje suprotstavljanje i borbu sa zlom i zlikovcima, a bez te borbe, naravno nenasilne, nema realnih promjena ni na lokalnom, a kamoli na globalnom nivou.

Policajac neće uspjeti zaustaviti pljačku tako što će pljačkaša lijepo zamoliti da odloži novac na mjesto s kojeg je novac uzeo. Isto tako dobronamjerni ljudi neće zaustaviti onečišćenje pojedine rijeke tako što će pisati peticiju vlasniku tvornice koja rijeku onečišćuje pozivajući ga da prestane zagađivati rijeku i da obuzda pohlepu za vlastitim profitom time što će dosljedno poštovati zakone o zaštiti okoliša i brinuti o zdravlju stanovnika uzduž rijeke.

Dobrohotnost u sebi uključuje dobronamjernost, no i nadilazi je. Dobronamjeran je onaj koji ima dobre namjere, koji želi dobro. Prema Hrvatskom enciklopedijskom

rječniku dobrohotan je onaj koji čini ili želi činiti dobro.[3] Bit jest u *činjenju*. Holistički environmentalizam zahtijeva činjenje i svaki znanstvenik bez obzira kojem polju znanosti matično pripada, a koji sebe želi nazivati holističkim environmentalistom, treba aktivno činiti dobro.

Nisu uvijek nužni ni mogući spektakularni rezultati činjenja, a vrlo često rezultati nisu ni vidljivi istog trenutka ili barem nisu vidljivi u punom obimu, no to ne znači da oni ne postoje. Nekada se pomaci mjere u kilometrima, a nekada u mikrometrima; bit je u tome da pravac djelovanja bude u smjeru povećane čistoće materijalnog i duhovnog okoliša.

Holistički environmentalizam nije monopol znanstvenika, svaki čovjek bez obzira na razinu obrazovanja, dob ili koju drugu odrednicu identiteta, može dati svoj doprinos u čišćenju materijalnog i/ili duhovnog okoliša, pa se po svom činjenju može smatrati holističkim environmentalistom.

Materijalni i duhovni okoliš

U holističkom environmentalizmu se pod materijalnim okolišem prvenstveno podrazumijeva priroda koja nas neposredno okružuje, no tu se materijalni okoliš ne iscrpljuje. Za holističke environmentaliste materijalni okoliš jest materijalni svemir. Naravno, žarište u sagledavanju materijalnog okoliša jest naš planet Zemlja sa svim dobrima kojima raspolaže i kojima se mi kao ljudska vrsta često neodgovorno služimo. Kao čovječanstvo u cjelini mi već dugo haračimo po Zemlji te tako ugrožavamo i sebe i druga živa bića s kojima dijelimo planet. To haračenje nužno mora vrlo brzo prestati ili ćemo ostati i bez nužnih uvjeta za opstanak!

Kratkoročno ugrožen je život mnogih biljnih i životinjskih vrsta kao direktna posljedica ljudske pohlepe i neodgovornosti, a dugoročno ugrožen je i opstanak većine čovječanstva ako se iživljavanje bogate, inteligentne i beskrupulozne manjine ne obuzda na ovaj ili onaj način.

Često korištena sintagma *zaštita okoliša* po mom sudu poprilično je arogantna u svojoj drskoj antropocentričnosti jer materijalni okoliš modernog čovjeka nisu ugrozili strašni meteori iz svemirskih dubina ni razorne sile što djeluju u Zemljinoj unutrašnjosti, a ponajmanje su materijalni okoliš modernog čovjeka ugrozile životinje ili biljke.

3 Hrvatski enciklopedijski rječnik, Novi Liber, Zagreb, 2002., str. 257.

Materijalni okoliš ugrozili su neodgovorni, tupi i zli izdanci čovječanstva i zbog toga kao ljudska vrsta nemamo nikakvo pravo često jadne pokušaje popravljanja štete koju smo sami prouzročili sebi i drugim bićima na Zemlji nazivati zaštitom. To je poprilično lažljivo i duboko cinično.

Bilo bi daleko prikladnije i bliže istini ono što čini sadržaj *zaštite okoliša* nazivati *sanacijom materijalnog okoliša* jer riječ je samo o pokušaju i nastojanju zbrinjavanja posljedica kolektivnog nesavjesnog djelovanja. Primjerice, kada pijani vozač osobnog automobila na pješačkom prijelazu obori staricu i slomi joj nogu, a potom je ipak ne ostavi ležati na cesti već je odveze u bolnicu - to se ne naziva zaštitom starice! Kada bi se vozač u bolnici pokušao predstaviti kao zaštitnik starice to bi naišlo na jednoglasnu i oštru osudu.

Pa onda bismo i mi morali opreznije govoriti o takozvanoj zaštiti okoliša. Naravno, slijedeći usporedbu, bolje rješenje je da je vozač odvezao staricu u bolnicu no da ju je ostavio na pješačkom prijelazu te pokušao pobjeći i ostati nekažnjen. Isto tako bolje je i „štititi" okoliš nego ga unutar koncepta neoliberalnog kapitalizma iskorištavati bez ikakvih skrupula i odgovornosti prema budućim pokoljenjima, a pritom svaki istinski pokušaj stvarne zaštite okoliša karakterizirati kao lelujavi utopijski idealizam i ismijavati uz pomoć pojedinih otupjelih ili korumpiranih medija.

Pritom moramo ipak priznati mnogim pojedincima koji su utkali svoje znanje, energiju i odlučnost u nastojanje da materijalni okoliš bude što čistiji i što pogodniji za miran i sretan život, kako oni najčešće nisu direktni uzročnici onečišćenja koje pokušavaju otkloniti.

Kolektivna krivica definitivno je na čovječanstvu, no pojedinačna odgovornost za onečišćenje materijalnog okoliša vrlo je nejednoliko raspoređena. Mnogo ljudi uistinu posvećuje se predanom radu na stvarnoj zaštiti okoliša i svoje sugrađane upozoravaju na činjenice o nepopravljivim štetama koje se nanose prirodi.

Pri onečišćenju materijalnog okoliša trebamo jasno razlikovati neposredno i posredno onečišćenje. Neposredno onečišćenje je direktno ispuštanje polutanata u materijalni okoliš bilo tijekom određenog industrijskog procesa, bilo tijekom aktivnosti svakodnevnog života. U suvremenoj civilizaciji nemoguća je apsolutna nevinost u odnosu na krivicu neposrednog onečišćenja materijalnog okoliša. Svaki čovjek tijekom svakog dana zagađuje materijalni okoliš, no ključna je pritom razina zagađivanja i opravdanost zagađivanja za kojim posežemo.

Trebali bismo si uvijek postavljati pitanja imamo li pravo na onečišćenje zraka, tla i vode u mjeri u kojoj onečišćujemo? Je li nam to nužno za održavanje kvalitete dostojanstvenog življenja? Hoćemo li svojom udobnošću ugroziti udobnost ili

čak i opstanak budućih naraštaja? Pojednostavljeno – je li naše djelovanje etički prihvatljivo?

Ljudi koji traju takva si pitanja neće postavljati sve dok ih zakonodavstvo na to ne prisili. Sve dok ne budu zapriječene kazne, za ljude koji traju pitanja zaštite okoliša bit će potpuno sporedna u odnosu na pitanja omogućavanja vlastitih zadovoljstava. Za ljude koji su skloniji postojanju takva pitanja se nameću sama po sebi i na njih nije uvijek moguće jednoznačno i odlučno odgovoriti.

Posredno onečišćenje materijalnog okoliša posljedica je onečišćenja duhovnog okoliša i često ne nastupa istog trenutka kada je došlo do onečišćenja duhovnog okoliša. Pohlepa često dovodi do nebrige o posljedicama određenih tehnoloških operacija, a bezobzirnost do izbjegavanja saniranja prouzročene štete.

Posljedice se nekada ukazuju tek desetljećima ili stoljećima nakon počinjenja prvih uzroka koji su doveli do onečišćenja. Klasičan primjer odgođenog ukazivanja posljedica je globalno zatopljenje s kojime se susrećemo sada na početku 21. stoljeća, a prvi uzroci su stvarani početkom industrijske revolucije.

U budućnosti se nadam da će pitanja posrednog onečišćenja materijalnog okoliša kroz zagađivanje duhovnog okoliša sve više dolaziti do izražaja u javnim diskusijama i pri donošenju političkih odluka, te da će dobrohotni stručnjaci moći sa sigurnošću ukazati na etički ispravan smjer razvoja moderne civilizacije.

Kao inteligentna bića mi bismo trebali nastojati *razumjeti* okoliš. Holistički environmentalizam se ne bavi zaštitom okoliša već razumijevanjem okoliša. Razumijevanje okoliša, materijalnog i duhovnog, daleko nadilazi ono što se pogrešno naziva zaštitom. Razumjeti materijalni okoliš znači ne uništavati staništa, ne narušavati kvalitetu zraka, vode i tla, ne posezati za nepopravljivim razaranjem, ne bahatiti se inteligencijom, ne polomiti i preoblikovati sve što smo sposobni polomiti i preoblikovati.

Razumjeti materijalni okoliš znači proizvoditi samo dobra koja ljudi uistinu trebaju za dostojanstven i ugodan život te proizvoditi u dostatnim količinama, a ne viškove. To znači ne sagledavati prirodu kao sirovinsku bazu u koju se može zadirati bez ograničenja i mjere. Zemlja nam je dana kao zajednički dom s drugim ljudima, životinjama i biljkama te bismo je tako trebali i tretirati. Planet zaslužuje zahvalnost i poštovanje.

Razumjeti duhovni okoliš znači biti dobrohotan, znači shvatiti jednakost, bratstvo, slobodu, jedinstvo i pravednost kao model smislenog i stvaralačkog življenja. Svaki oblik dominacije čovjeka nad čovjekom izraz je nerazumijevanja duhovnog okoliša, a svaki oblik zlouporabe razuma i pretvaranja inteligencije u sredstvo za podjarmljivanje

i zlostavljanje ljudi i životinja izraz je nerazumijevanja položaja i uloge čovjeka na Zemlji. Trenutno je na planetu u tom smislu stanje izrazito konfuzno.

Napredak tehnologije, nažalost, nije donio prvenstveno oslobođenje ljudi od iscrpljujućeg rada i obilje slobodnog vremena koje bi se koristilo u oplemenjivanju vlastitog postojanja, već je u mnogima donio užurbanost, otuđenje i strah od neizvjesne budućnosti.

Savjest čovjeku daje orijentaciju u duhovnom okolišu. Savjest je moguće ignorirati i pritom očuvati trajanje života, no ignoriranjem savjesti gubi se sadržajnost, dobrohotnost i smislenost življenja, pri čemu se ljudsko biće svodi na stroj za proizvodnju vlastitih užitaka. Svaki mehanički stroj određuje njegova učinkovitost, a svakog čovjeka njegova savjesnost. Bez savjesnog osmišljavanja duhovnog okoliša čovjek neminovno gubi svjesno postojanje.

Nažalost, kada se skupi kritična masa ljudi koji gramzljivo akumuliraju ekonomsku i političku moć i hedonistički traju, a da pritom ne osjećaju nikakvu potrebu za postojanjem – civilizacija biva ugrožena. U toj situaciji se sada nalazimo. Ako uzduž i poprijeko planeta hijerarhijski ustrojeni i tradicijski ostrašćeni trajući ljudi istovremeno ogreznu u beskrupuloznom i agresivnom osobnom, porodičnom, klasnom ili nacionalnom egoizmu, a početkom 21. stoljeća i raspolažu najsuvremenijim znanstveno-tehnološkim dostignućima, tada je propast takve civilizacije gotovo neminovna.

Potrebno je hitno otriježnjenje od moći, pohlepe i oholosti. Taj trokut daje mračnu sinergiju i zastrašujuće ubrzava destrukciju materijalnog i duhovnog okoliša. Moćni i zli nas uvjeravaju da je njihova moć neupitna, a zlo neminovno. Traže posvemašnje pokoravanje kako bi mogli razulareno trajati u obijesnom izobilju vlastitog materijalnog bogatstva. Oni ne dopuštaju propitkivanje utemeljenja njihovih privilegija i opravdanost njihove dominacije, žele nastavljati svoj mahniti pir bez obzira na to koliko materijalnog i duhovnog okoliša zatrovali i kakve posljedice njihov užitak donio po veliku većinu obespravljenih bića uzduž planeta. Tržište definiraju kao neprikosnoveni Mamon kome bi se svi morali klanjati. Od solidarnosti su učinili milostinju i tako ozakonili prezir.

Holistički ili redukcionistički environmentalizam

Pitanje kvalitete življenja budućih pokoljenja, pa i nas koji trenutno boravimo na Zemlji, svodi se na dvojbu hoćemo li krenuti putem radikalne promjene društvenih odnosa u smjeru razumijevanja prirode i socijalne pravednosti među ljudima ili ćemo nastaviti putem mlakog mirenja s raspojasanom eksploatacijom drugih ljudskih bića

i prirode kao cjeline od strane krvavo moćnih i perfidno licemjernih pojedinaca koji bez straha ili srama otimaju i prisvajaju sebi viškove vrijednosti. Pritom se ne obaziru na patnje drugih ljudi, a još manje na užase koje trpe mnoge životinje.

Put radikalnih promjena društvenih odnosa u smjeru dobrohotnog suživota nasuprot nesmiljenoj konkurentnosti može voditi u materijalno i duhovno blagostanje u kojem još uvijek na planetu ima dovoljno resursa za dostojanstven i ugodan život svakog ljudskog bića. Posljedica intenzivnije suosjećajnosti i veće uviđavnosti u međuljudskim odnosima može dovesti do univerzalnog jedinstva, poštovanja različitosti i nesebičnog pomaganja.

To se iz sadašnje perspektive neoliberalnog kapitalizma i tržišnog fundamentalizma ne nazire ni u obrisima, no to nije utopijska iluzija već preduvjet opstanka i jedina realna mogućnost koja može jamčiti dostojanstvenu budućnost čovječanstvu. Taj smjer je smjer holističkog environmentalizma.

Bioetički imperativ Fritza Jahra, po mnogima utemeljitelja bioetike, objavljen 1934. godine u časopisu Ethik: Sexual- und Gesellschaftsetnik ovdje prenosim iz knjige „Fritz Jahr i rađanje europske bioetike“ autora Ive Rinčić i Amira Muzura[4]:

„U svemu tome ukazuje se univerzalno područje valjanosti Pete zapovijedi, koja zahtijeva da bude primijenjena u odnosu na sav život. Kao parafraza Pete zapovjedi nudi se bio-etički imperativ: „Poštuj svako živo biće u načelu kao svrhu u sebi i po mogućnosti postupaj s njim kao takvim!“„

Kada bismo se uspjeli dosljedno držati bioetičkog imperativa u svakodnevnom životu mogli bismo sa sigurnošću ustvrditi da naša egzistencija čini svijet boljim i ljepšim. Nadahnut Jahrom, a promišljajući zbilju iz pozicija holističkog environmentalizma, postavio sam „okolišni imperativ“: *„Djeluj dobrohotno i smisleno prema okolišu i unosi u njega ljubav i mudrost.“* Okolišni imperativ vrijedi i za materijalni i za duhovni okoliš.

Mlako mirenje s razularenom i zastirućom eksploatacijom drugih ljudskih bića, kao i prirode kao cjeline, za veliku većinu ljudi vodi u grčevitu, iscrpljujuću i otuđujuću borbu za materijalni opstanak. Ta borba deprivilegiranoj većini donosit će sve više straha, neizvjesnosti, otupljenosti i bola. Za privilegiranu manjinu taj put vodi u obijesno iživljavanje svakojakih prohtjeva i nagonsko trajanje. Takva egzistencija je neprirodna, izopačena i u konačnici nužno vodi ubrzanoj propasti kako pojedinca tako i civilizacije u kojoj ta privilegirana manjina živi.

4 I. Rinčić, A. Muzur, Fritz Jahr i rađanje europske bioetike, Pergamena, Zagreb, 2012., str. 254.

To je smjer partikularnog pristupa okolišu ili redukcionističkog environmentalizma. Ragan Sutterfield redukcionistički environmentalizam naziva industrijskim environmentalizmom[5].

Integralnost i interdisciplinarnost holističkog environmentalizma jest u tome da se preklapa s pojedinim poljima prirodnih (geologija, kemija, biologija), tehničkih (metalurgija, strojarstvo...), društvenih (ekonomija, politologija...) i humanističkih (filozofija, teologija...) znanosti. Holistički environmentalizam nije znanost o okolišu (grana interdisciplinarnih prirodnih znanosti) ni inženjerstvo okoliša (grana interdisciplinarnih tehničkih znanosti), ni politička teorija/povijest političkih ideja (grana politologije), on je dio integrativne bioetike (polje interdisciplinarnog područja znanosti). Ključni pojam holističkog environmentalizma jest dobrohotnost. Prema već spomenutom Hrvatskom enciklopedijskom rječniku dobrohotnost jest osobina onoga koji je dobrohotan, a dobrohotan je onaj koji čini ili želi činiti dobro.

Svaki postupak svakog čovjeka holistički environmentalizam sagledava u odnosu na dobrohotan suživot bića na Zemlji. Ako djelovanje pridonosi dobrohotnom suživotu, ono se tretira kao pozitivno i poželjno, a ako narušava dobrohotni suživot bića ono se tretira kao negativno i nepoželjno. Jasno je pritom da svako djelovanje koje narušava bioetički imperativ ili okolišni imperativ smatramo nepoželjnim.

Isto tako poželjan je svaki proizvodni proces čiji produkti dovode do poboljšanja kvalitete življenja, a da pritom značajno ili nepovratno ne onečišćuje materijalni okoliš. Primjerice, proizvodnja genetski modificirane hrane ili proizvodnja oružja nepoželjne su djelatnosti dok je proizvodnja i uporaba obnovljivih izvora energije poželjna.

Svaki oblik svjesnog nanošenja bola drugom biću je neprihvatljiv, dok je svaki izraz nesebične skrbi o drugom biću poželjan. Nanošenje bola izraz je potpunog nerazumijevanja duhovnog okoliša i vodi do obostrane destrukcije, kako onog koji bol trpi tako i onog koji bol nanosi.

Budući da holistički environmentalizam sagledava jedinstvo okoliša u njegovoj dvojakoj prirodi kao materijalni okoliš i duhovni okoliš, razina čistoće materijalnog okoliša uvjetovana je razinom čistoće duhovnog okoliša, a čistoća duhovnog okoliša presudno utječe na čistoću materijalnog okoliša. Također vrijedi i obrat, čišćenje materijalnog okoliša katalizira čišćenje duhovnog okoliša i bez tog katalizatora proces čišćenja duhovnog okoliša mogao bi trajati nepodnošljivo dugo.

Za razliku od redukcionističkog environmentalizma koji se bavi sanacijom posljedica, holistički environmentalizam razotkriva i uklanja uzroke destrukcije materijalnog i

5 http://www.mnn.com/earth-matters/wilderness-resources/stories/industrial-environmentalism-vs-holistic-environmentalism

duhovnog okoliša. Za redukcionistički environmentalizam temelj i mjera svega je korisnost, dok je za holistički environmentalizam dobrohotnost. Redukcionisti žele stabilnost unutar održive nepravde pri čemu brane vlastite pozicije privilegiranih slojeva društva. Za njih je korisno onemogućiti što većem dijelu stanovništva kvalitetno obrazovanje i sigurnost zdravstvene zaštite jer time stvaraju o sebi ovisne ljude koje neće biti sposobni dovesti u pitanje uspostavljeni poredak dominacije.

Redukcionisti nikada neće tvrditi da su nepravda, ponižavanje i u konačnice nasilje dobri, najoštrije će te devijacije osuditi (čak neki od njih i priznati da su devijacije), no istovremeno će konstatirati da ih se ne može iskorijeniti, pa bi ih trebalo ublažiti. To ublažavanje najčešće ima krajnje sarkastičan i duboko neetički karakter.

U ljudskoj povijesti jedan od slikovitijih primjera redukcionizma bio je kada su zagovornici ropstva na američkom jugu tvrdili da ropstvo doduše nije idealni odnos, no bez ropstva urušila bi se kompletna ekonomija i nastao bi kaos koji ne bi bio dobar ni za same robove. Klasičan primjer redukcionizma je kada u moderno doba vlasnik neke tvornice plaća mizernu nadnicu od koje nije moguće dostojanstveno živjeti i zadovoljavati elementarne ljudske potrebe, a pritom njegova gospođa dijeli besplatno iznošenu odjeću suprugama radnika.

Daljnji primjeri su kada tvornica zagađuje rijeku do mjere da se više ne može u njoj kupati, ali istovremeno financira tečaj plivanja u bazenu. Kada država školarinama onemogućuje visoko obrazovanje dijelu svojih mladih građana i time im drastično smanjuje izglede za osobni razvoj, no istovremeno dijeli stipendije zanemarivo malom broju onih koje je ugrozila. U svakom redukcionističkom environmentalizmu ogleda se cinizam. Svaki pokušaj realnog suprotstavljanja zlu (primjerice *Greenpeacea*) proglasit će redukcionisti neodgovornim anarhizmom, utopijskim romantizmom ili čak industrijskim terorizmom.

Holisti žele jedinstvo, slobodu, pravednost, bratstvo/sestrinstvo i jednakost. Holistički environmentalisti žele da svijet bude ugodno mjesto za življenje svakom biću koje diše. To nije više utopijska tlapnja no što je svojevremeno bilo ukidanja kmetstva, omogućavanje prava glasa ženama ili letenja pomoću ljudskih tvorevina. Prirodna bogatstva Zemlje trebala bi se sa zahvalnošću i mjerom koristiti na opće dobro, a ne da prirodu prezirno pljačkamo i sagledavamo kao puku sirovinsku bazu.

U skladu s holističkim environmentalizmom znanstvenici prirodnih i tehničkih znanosti trebali bi ukazivati kako je u razigranoj lucidnosti ljudskom uma moguće oblikovati udobnost čovječanstva u suradnji s prirodom koja se dariva, od koje se zahvalno prima. Znanstvenici društvenih i humanističkih znanosti trebali bi ukazivati na to kako je u prožimanju racionalnosti i dobrohotnosti moguće organizirati ljudsko društvo u kojem patnja ima jasnu tendenciju pada, a blagostanje rasta.

Smislenost i sreću kako pojedinca, tako i čovječanstva u cjelini, moguće je doseći samo intenzivnom i predanom suradnjom svih koji su spremni solidarno dijeliti ovaj planet. Udružujući potencijale, objedinjavajući znanje i sposobnosti moguće je zaustaviti kataklizmu koja se nadvila nad modernim društvom. Holistički environmentalisti želi tome dati skroman doprinos.

Srednjeg (trećeg) puta između redukcionističkog i holističkog environmentalizma nema! Između dobrohotnosti i egoizma ne postoji pragmatična taktičnost uvjetovana objektivnim okolnostima, ni racionalno prihvaćanje tradicijskih okvira, ni nemogućnost suprotstavljanju moralu vremena u kojem živimo, ni ublažavanje problema kroz djelomičnu sanaciju posljedica. Sve su to samo sofističke smicalice. Pragmatičnost u modernom svijetu najčešće je, ne nužno i ne uvijek, najvulgarnije besramlje i samim time esencijalno zlo.

Svakodnevno ljudsko djelovanje nije etički obojeno isključivo crno ili bijelo. Svako svjesno ljudsko biće ostavlja sivi trag u vremenu, no hoće li to biti svjetlo ili tamnosivi trag to pojedinac sam odlučuje svojom slobodnom voljom i ton te sive boje ne može se relativizirati. Ako ne možemo dosegnuti savršenu dosljednost u dobroti ne znači da joj ne treba težiti.

Srednji put je perfidna laž kojom se koriste uzurpatori planeta kako bi katalizirali socijalno raslojavanje i ekonomsku neizvjesnost te cementirajući krizu dokinuli već dosegnutu razinu socijalne pravednosti. Ta razina, barem iz europske perspektive, uključuje neotuđivo i neprenosivo pravo na čist materijalni i duhovni okoliš. Okoliš se može sagledavati partikularno ili cjelovito. Međuprostora nema, koliko god redukcionisti nastojali stvoriti iluziju njegovog postojanja.

Mlakost, kalkulantstvo, pragmatika, popustljivost, plašljivost, lijenost, bezvoljnost i u konačnici besmisao vode u već doglednu katastrofu. Dio beskrupuloznih, bahatih i agresivnih moćnika postaje sve bezdušniji, njihove prijetnje miru i blagostanju sve su izraženije.

Više nije riječ o tome da će se stanje u kojem se svijet nalazi pogoršavati, već o tome da će mnoge od udobnosti života koje još danas većina ljudi uživa, barem u Europi, jednostavno nestati. Najučinkovitiji mehanizmi porobljavanju su istovremeno osiromašenje i zaglupljivanje. Na svakom je od nas koji još nismo porobljeni egzistencijalnom neizvjesnošću da se suprotstavimo materijalnom i duhovnom nasilju te da osmislimo koncept savjesnog ponašanja u materijalnom i duhovnom okolišu.

Sloboda ili jest ili nije, pravednost ili jest ili nije, dobrohotnost ili jest ili nije! Unutar nekog društva postoji samo cjelovita sloboda, cjelovita pravednost i cjelovita solidarnost, svaka partikularnost ujedno je i negacija. Razumljivo je da može i treba

postojati razumno sagledavanje dosega djelovanja i taktičnost u biranju slijeda postupaka, no pritom se ne bi smjelo prekoračiti okvir dobrohotnosti. Biti dobar jest najviše što čovjek može dosegnuti u egzistenciji unutar prostora i vremena. Bez dobrohotnosti istinska sreća ne postoji, samo prolazno zadovoljstvo.

Zaključak

Ovo je tek uvodno promišljanje o holističkom environmentalizmu, početak izazovnih istraživanja na području cjelovitog sagledavanja materijalnog i duhovnog okoliša. Daleko nadilazi moje sposobnosti prosudbe ustvrditi koje će sve plodove ta istraživanja donijeti u budućnosti i kojim će sve pravcima krenuti. Uvjeren sam da će holistički environmentalizam dati određeni doprinos osmišljavanju dobrohotnog suživota bića na Zemlji, a prije svega izgradnji pravednijeg, slobodnijeg i dobrohotnijeg društva. Svatko tko aktivno promiče dobrohotan i odgovoran odnos prema materijalnom i duhovnom okolišu može se smatrati holističkim environmentalistom.

Ovim uvodom u holistički environmentalizam nastojim potaknuti kolegice i kolege iz društvenih, humanističkih, prirodnih i tehničkih područja znanosti kojima je dobrohotnost pri srcu da se uključe u profiliranje i produbljivanje holističkog environmentalizma, jer toliko toga bi trebalo istražiti, osmisliti, predložiti, realizirati. Koristeći znanstvene metode istraživanja i povezujući spoznaje s različitih polja znanosti moguće je lakše i točnije sagledati i razumjeti zbilju.

Uvjeren sam da holistički environmentalizam može i treba pomoći u osmišljavanju izlaza iz krize u koju je moderna civilizacija zapala, krize koja u približno jednakoj mjeri nagriza materijalni i duhovni okoliš te koja prijeti kataklizmičkim razmjerima.

Holistički environmentalizam ne nastaje ni iz čega, bez temelja i prethodnika. Tijekom ljudske povijesti mnogi su znanstvenici materijalni i duhovni okoliš sagledavali kao jedinstven. Mnogi filozofi, teolozi, kemičari, metalurzi, strojari, ekonomisti, politolozi, znani i neznani, predlagali su holističko environmentalistička rješenja za probleme svog vremena. Sve njih, između ostalog, možemo smatrati i holističkim environmentalistima. Jedan od njih svakako je i Fritz Jahr te nije slučajno da je ovaj rad kao uvod u holistički environmentalizam poslan upravo u časopis koji nosi njegovo ime.

Budućnost je još uvijek u našim rukama i mi moramo preuzeti odgovornost. Dobrohotno je djelovanje u smjeru građenja i razumijevanja, dok je zlohotno djelovanje u smjeru razaranja i ubijanja. Holistički environmentalizam jedan je od sićušnih oslonaca ljudskom razumu da ne bude nerazuman.

Introduction to Holistic Environmentalism

ABSTRACT

Holistic environmentalism is a holistic consideration of the material (nature) and spiritual (world) environment. Its essence is to promote amicability in human relations to other beings. Research area of holistic environmentalism is located within integrative bioethics. A holistic approach to the environment, typical of the holistic environmentalism, explores the opportunities and sets the models of the amicable coexistence of the beings on Earth. It does not deal only with environmental protection, but also with an understanding of the environment. Understanding of the material and the spiritual environment goes far beyond of what is wrongly called environmental protection. To understand the material environment means not destroying habitats, not impairing the quality of air, water, and soil, not reaching out for the irreversible destruction, not showing off with intelligence, not breaking and reshaping everything we are capable of breaking and reshaping. To understand the spiritual environment means to be benevolent, to realize equality, fraternity, liberty, unity, and justice as a model of meaningful and creative living.

Keywords: holistic environmentalism, material environment, spiritual environment, amicability, understanding of the environment.

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Book Review

Marta Dajana Carti

L'approcio di Benedetto XVI alla bioetica nel contesto d'altri modelli attuali

Rim: Ateneo Pontificio Regina Apostolorum, 2016; 334 str.

Danas međunarodnu scenu bioetičkih publikacija okupiraju djela konzekvencijalističkog usmjerenja ignorirajući i zapostavljajući antropološku dimenziju u aktualnim bioetičkim raspravama. Razlog toga zapostavljanja antropološke dimenzije može biti i u obrisima naše današnje kulture i mentaliteta, koji na neki način zazire od metafizike i svega onoga što je povezano s njome. No, uzevši u ruke djelo Marte Dajane Carti *L'approcio di Benedetto XVI alla bioetica nel contesto d'altri modelli attuali* (Pristup Benedikta XVI. bioetici u kontekstu drugih modela) zamjećujemo kako se ono razlikuje od ostalih, bazirajući se na direktnom/indirektnom pristupu Josepha Ratzingera, kasnije Benedikta XVI., određenim bioetičkim problematikama. Samo djelo plod je dugogodišnjeg rada i istraživanja tijekom doktorskog studija dr. Carti. Sastoji se od pet poglavlja koja su tematski podijeljena na tri dijela: prvi dio A odnosi se na učenje Benedikta XVI., drugi dio B odnosi se na postojeće modele bioetike te treći dio C - finalna sinteza u kojoj se verificira konzistentnost ovog novog pristupa. U vezi sa samom strukturom djela primjećuje se kako se dr. Carti odlučuje za induktivnu metodu, pri tome analizirajući različita djela i govore Josepha Ratzingera i Benedikta XVI. koja se dotiču bioetičke problematike. Prvo poglavlje posvećeno je toj analizi, iz čega proizlaze određeni krucijalni koncepti, koji se prožimaju u svim njegovim djelima kao što su, primjerice: osoba, istina, sloboda, integralni razvoj čovjeka, interdisciplinarni dijalog i transcendentalna nada.

Joseph Ratzinger, s obzirom na svoju istaknutost teološke misli, prvenstveno impostira svoj pristup bioetici u *Teologiji i metafizici*. Na prvu ruku mnogi će pomisliti kako Ratzingerov pristup nema za ponuditi ništa novo, doli ono isto što se već nalazi u službenim dokumentima Katoličke Crkve koji se osvrću na određene

bioetičke probleme. No, kao rezultat već spomenute induktivne metode dobije se *zlatni presjek*, koji krasi pristup Benedikta XVI. bioetici, u obliku relacijske antropologije. Relacijska antropologija počiva na Ratzingerovu shvaćanju osobe, koje nadilazi esencijalističko Boetieovo poimanje iznalazeći svoje izvorište u hebrejskoj riječi pānîm (lice), odnoseći se više na egzistencijalnu dimenziju ljudskog bića, a ne esencijalnu (str. 87.). Drugim riječima, biti čovjekom znači preko svoje tjelesnosti biti u neprestanom dijalogu s drugima, tj. osoba nije subzistentna sama za sebe, već je u stalnoj relaciji. Nadasve, bitnost definiranja samog pojma osoba te njegov prikaz kroz povijest ogledaju se u posvećenosti većeg dijela drugog poglavlja samo toj problematici. Kristalizacija samog pojma pridonijela je jasnom definiranju onoga na čemu zapravo počiva relacijska antropologija, njenih prednosti i slabosti. Upravo do određene jasnoće dovodi nas dr. Carti ukazujući na tri bitne dimenzije osobe, „biti od", „biti za" i „biti s", a rezultat su odraza *imago Dei* u čovjekovoj osobi (str. 96.). No, to je samo polazišna točka za dr. Carti jer tu postavlja pitanje zbog kojeg je i djelo nastalo. Je li ta relacijska antropologija nov model u bioetici, koji bi nadomjestio nedostatke već postojećih i rasprostranjenih modela u svijetu? Stoga se drugi dio knjige, počevši trećim poglavljem, upravo posvećuje tome, tj. predstavljanju rasprostranjenih i najraširenijih bioetičkih modela. Među predstavljenim modelima ističu se i određene slabosti kojima su popraćeni, tako modeli koji se zasnivaju na biocentrizmu nemaju ispravno etičko utemeljenje bez antropologije, jer jedino čovjek može prepoznati i savjesno i odgovorno prihvatiti moralne norme. Štoviše, dr. Carti ne zauzima samo kritičan stav prema tzv. „laičkim modelima", već i prema onima katoličkog nadahnuća, ukazujući na njihovu nedostatnost jer se oslanjaju na esencijalistički koncept osobe. Četvrto poglavlje na prvi pogled daje međunarodnom čitatelju određeni dojam kako se ne uklapa u cjelinu i prvotnu ideju samoga djela, no ono se zapravo nadovezuje na treće poglavlje. Za nas je ono od bitne važnosti jer nam po prvi put daje kritički prikaz i analizu aktualne bioetičke situacije u Hrvatskoj. Opisujući trenutačnu situaciju autorica ukazuje na nekonzistentnost ustaljenog rascjepa na tzv. „laičku" i „katoličku" bioetiku, koja se zasniva na predrasudama prema religiji i svjetonazoru. Određena kritika ne samo da je upućena zastupnicima „laičke" bioetike, kao što je Ante Čović sa svojom integrativnom bioetikom,[1] već i prema zastupnicima „katoličke"[2] bioetike, kao što su Ivan Fuček i Tonči Matulić.

Treći dio knjige, tj. finalna sinteza, predstavlja rezultat usporedbe između Ratzingerova pristupa u obliku relacijske antropologije i već postojećih modela. Testiranje

1 Dr. Carti zaključuje kako je integrativna bioetika disciplina koja nije u stanju pružiti određeni normativ, već samo određenu usmjerenost. Zasnivajući se na biocentrizmu ne pruža valjanu osnovu za bioetiku.

2 Dr. Carti se osvrće na tzv. „katoličke" pristupe bioetici, ukazujući na činjenicu kako pružaju valjanu osnovu za bioetiku, no problem predstavlja ne pridavanje dovoljne pažnje relacionalnosti zbog toga što se oslanjaju na Boetieovo poimanje osobe.

primjenjivosti i normativnosti ovog novog pristupa i njegovu efikasnost dr. Carti nastoji demonstrirati na bioetičkim problemima pobačaja i eutanazije. U slučaju pobačaja upravo ta relacijska dimenzija čovjekove osobe dolazi do izražaja jer „… 'biti za' drugoga kod majke ne ograničava njenu osobu i slobodu, već upotpunjuje njezinu individualnost ukoliko ona ostaje otvorena za drugoga za život nerođenog (…) Zatvoriti se za drugoga, konkretnije za nerođeno, u izboru pobačaja, ranjava osobu u svojoj konstitutivnoj relacionalnosti" (str. 281.). Peto poglavlje ujedno daje i odgovor na pitanje koje postavlja dr. Carti - je li relacijska antropologija još jedan novi model? U njemu zaključuje kako „…pristup Benedikta XVI ne formira jedan potpuno novi bioetički model u usporedbi sa ostalim bioetičkim modelima s katoličkim nadahnućem…" (str. 296.). Stoga, pristup Benedikta XVI. bioetici u vidu relacionalne antropologije više predstavlja „jednu novost" koja „…može biti korisna bioetici, zato što, u usporedbi s drugim katoličkim pristupima (pristup Pellegrina-Tomasme i Sgreccinog), snažno ističe relacijski aspekt pri donošenju bioetičkih odluka, u kojima prije svega trebaju biti uzete u obzir nepovredivo dostojanstvo osobe i njena relacijska dimenzija, koje prema Benediktu XVI./Josephu Ratzingeru su prava bit osobe" (str. 297.). Znanstveni doprinos ovoga djela odlikuje se u tome da već postojećim modelima, koji se zasnivaju na antropologiji i metafizici, pruža nadopunu i ekstenziju u vidu relacijske antropologije. Na kraju krajeva, iz ovoga djela vidimo nesavršenost postojećih bioetičkih modela, no i spremnost pojedinih zagovornika da preispitaju slabosti i pronađu epistemološka poboljšanja. Knjigu dr. Carti toplo preporučujem svima koji su zainteresirani više saznati o bioetici s uporištem u metafizici i relacijskoj antropologiji.

Anto Čartolovni

Book Review

Stjepka Popović (ur.)

Zaštita prava djece i mladih na seksualno zdravlje

Zbornik radova s interdisciplinarnog znanstveno-stručnog skupa
Rijeka, 2016.

Stjepka Popović, Jasminka Zloković (ur.)

Djeca i mladi u alternativnoj skrbi: zaštita prava na zdravlje

Zbornik radova s interdisciplinarnog znanstveno-stručnog skupa
Zaštita prava na zdravlje djece i mladih u alternativnoj skrbi
Rijeka, 2017.

U povodu Međunarodnog dana djeteta, 21. studenoga 2014. na Medicinskom fakultetu Sveučilišta u Rijeci održan je interdisciplinarni znanstveno-stručni skup *Zaštita prava djece i mladih na seksualno zdravlje* u organizaciji dviju katedri ovoga fakulteta (Katedra za društvene i humanističke znanosti u medicini i Katedra za socijalnu medicinu i epidemiologiju) te Ureda za znanost Studentskog zbora Sveučilišta u Rijeci. Skup se održao u sklopu *Aktualnog trenutka hrvatskog zdravstva V*. Prošle je godine angažmanom organizatorice skupa, a sada urednice Stjepke Popović objavljen ovaj Zbornik. Kako je u Uvodu istakla urednica, inače doktorandica na doktorskom studiju Socijalni rad i socijalna politika pri Pravnom fakultetu Sveučilišta u Zagrebu i asistentica na Katedri za društvene i humanističke znanosti u medicini Medicinskog fakulteta i Katedri za javno zdravstvo Fakulteta zdravstvenih studija, *tema seksualnog zdravlja djece u Hrvatskoj još je uvijek tabu-tema, a većina roditelja ne razgovara s*

djecom o seksualnim pitanjima, što omogućava medijima i vršnjacima da oblikuju dječje razumijevanje seksualnih odnosa; s druge strane *medijska reprezentacija seksualnosti i vršnjačka iskustva nisu uvijek točna i zdrava*.

Izdavač zbornika je Katedra za društvene i humanističke znanosti u medicini Medicinskog fakulteta Sveučilišta u Rijeci, a suizdavači Veleučilište u Karlovcu, Fakultet zdravstvenih studija Sveučilišta u Rijeci te Pravobraniteljica za djecu.

Zbornik sadrži 10 radova i to jednak broj stručnih i preglednih članaka podijeljenih unutar triju tematskih blokova. Prvi je naslovljen *Dječji razvoj i pravo na seksualno zdravlje*, slijede blokovi *Dobra praksa u zaštiti prava djece i mladih na seksualno zdravlje* te *Mediji i pravo djece na seksualno zdravlje*.

Prvi tematski blok otvara rad *Pravo djeteta na spolno zdravlje – gdje smo nakon 10 godina?*

U radu pravobraniteljice za djecu Republike Hrvatske Ivane Milas Klarić, njene zamjenice Maje Gabelice Šupljike i savjetnice Davorke Osmak Franjić prikazano je što se događalo u posljednjih 10-ak godina u odnosu na uvođenje spolnog odgoja u škole u Hrvatskoj, što djeca kažu o spolnom odgoju te stajalište pravobraniteljice za djecu. U zaključku stoji da se zdravstveni odgoj u Hrvatskoj još uvijek ne provodi sustavno, ili se uopće ne provodi, nije dostupan svima, ne provode ga educirani stručnjaci ili ga provode dijelom nemotivirani nastavnici ili oni koji se ne smatraju kompetentnima, a sadržaj često ne odgovara stvarnim rizicima i potrebama djece.

U prilogu Gorana Arbanasa iz Karlovačke Opće bolnice naslovljenom *Razvoj rodnog identiteta i seksualne orijentacije* autor pojašnjava razliku između termina *spol*, *rod* i *seksualna orijentacija*. Prema njemu, ovi se termini često brkaju, a postoji također i očekivanje da bi sva tri termina trebala biti komplementarna. U nastavku autor razmatra pitanje kapaciteta za formiranje dijadnih odnosa, jer je upravo zreli razvoj rodnog identiteta i seksualne orijentacije spregnut s razvojem sposobnosti za ulaženje u bliske veze te emocijama zaljubljenosti i ljubavi.

Kaznenopravna zaštita djece od seksualnog zlostavljanja u Republici Hrvatskoj – potreba za daljnjom reformom? naslov je rada Dalide Rittosse s Pravnog fakulteta Sveučilišta u Rijeci. Rad tematizira najvažnije promjene unutar Kaznenog zakona, Zakona o kaznenom postupku i Zakona o sudovima za mladež vezanih uz sprječavanje seksualne viktimizacije djece i daje kritički osvrt na nova zakonodavna rješenja. Na temelju prikazane teorijske i praktične analize ponuđene su smjernice za daljnje osnaženje prava djece na zaštitu od seksualnog zlostavljanja unutar zakonodavstva.

Prvi prilog sljedećeg tematskog bloka je *Suradnja stručnjaka u zaštiti djece i mladih od seksualnog zlostavljanja i nasilja – primjer dobre prakse*. Autorice Gordana Buljan Flander, Tea Brezinšćak i Ana Marija Španić iz Poliklinike za zaštitu djece grada

Zagreba predstavljaju iskustva međuinstitucijske suradnje ove Poliklinike. U zaštiti djece od seksualnog nasilja stručnjaci Poliklinike uz interdisciplinarnu suradnju potiču suce na provedbu forenzičkog intervjua od strane educiranih stručnjaka u prostorima Poliklinike.

I sljedeći rad donosi iskustva pri tretmanu maloljetnih počinitelja seksualnog nasilja i to kroz prikaz rada u Dječjem domu *Tić* u Rijeci. Naime, autorice Ljiljana Bubnić i Nataša Makarun ističu da su, prema istraživanjima, u najmanje 20 % slučajeva počinitelji spolnog zlostavljanja nad maloljetnim osobama adolescenti. U radu su prikazale karakteristike maloljetnog počinitelja spolnog zlostavljanja, smjernice za tretman i na kraju prikaz rada Dječjeg doma *Tić* Rijeka u tretmanu maloljetnih počinitelja.

Posebno je osjetljivo područje *Prevencija seksualnog zlostavljanja djece s intelektualnim teškoćama.* To je ujedno i naslov priloga autorica Martine Šendula-Pavelić s Fakulteta zdravstvenih studija Sveučilišta u Rijeci i Nataše Tomljanović iz Centra za odgoj i obrazovanje Rijeka. Djeca i odrasle osobe s intelektualnim teškoćama češće su žrtve seksualnog nasilja u odnosu na ostalu populaciju, pa time potreba za sustavnim i organiziranim radom na prevenciji postaje prioritet.

Dječji doma *Tić* afilijacija je autorica sljedećih dvaju priloga. *Seksualno zlostavljanje djece: pravovremena intervencija i stručni tretman* naslov je priloga autorice Tamare Žakule Desnice. O iskustvu zlostavljanja djeca najčešće nerado govore, a cilj tretmana za dijete nije zaboraviti zlostavljanje, nego traumatski događaj ugraditi u svoje životno iskustvo.

Sljedeći prilog autorica Ljiljana Bubnić i Nataše Makarun *Kako razgovarati sa žrtvom spolnog zlostavljanja* donosi preporuke za stručnjake koji se mogu naći u situaciji da im dijete razotkriva svoje iskustvo spolnog zlostavljanja.

Posljednji blok zbornika posvećen je odnosu medija prema temi zlostavljanja djece i sadrži dva priloga. Rad *Uloga medija u povredi prava djece i mladih na seksualno zdravlje* potpisuje Gordana Vilović s Fakulteta političkih znanosti Sveučilišta u Zagrebu. Autorica analizira tri slučaja seksualnog zlostavljanja djece koji su uznemirili širu javnost.

Posljednji rad u zborniku prilog je urednice Zbornika Stjepke Popović, naslovljen *Istraživanja medijske prezentacije seksualnog zlostavljanja djece*. Popović ističe pozitivne i negativne učinke medijskog izvještavanja o seksualnom zlostavljanju djece te donosi sustavan pregled 20 relevantnih istraživanja medijskog sadržaja o seksualnom zlostavljanju djece na engleskom jeziku u dva desetljeća (1995.-2015.) koji su zadovoljili kriterije pretrage u više znanstvenih baza.

Nastavljajući praksu od prethodne godine, u povodu Međunarodnog dana djeteta pod pokroviteljstvom Ureda pravobraniteljice za djecu u studenome 2015. na Medicinskom fakultetu Rijeci održan je interdisciplinarni znanstveno-stručni skup *Zaštita prava na zdravlje djece i mladih u alternativnoj skrbi*. Organizatori skupa bili su Medicinski fakultet u Rijeci, Fakultet zdravstvenih studija, Studentski zbor ovog Fakulteta, Filozofski fakultet u Rijeci te Udruga *Igra*, neprofitna organizacija za pružanje rehabilitacijsko edukacijske i psiho-socijalno-pedagoške pomoći djeci u skrbi. Skup je održan u sklopu *Aktualnog trenutka hrvatskog zdravstva VI*. Zbornik radova sa skupa naslovljen *Djeca i mladi u alternativnoj skrbi: zaštita prava na zdravlje* u ovome je trenutku dostupan u e-izdanju. Njegova je urednica, uz Stjepku Popović, Jasminka Zloković s Filozofskog fakulteta Sveučilišta u Rijeci. Zbornik broji šest priloga, od toga dva izvorna znanstvena rada, jedno prethodno priopćenje i tri stručna rada. Izdavači zbornika su Filozofski fakultet, Medicinski fakultet i Fakultet zdravstvenih studija riječkog sveučilišta.

Prvi prilog autorica Lidije Petrović iz ureda Pravobraniteljice za djecu te Maje Laklija s Pravnog fakulteta Sveučilišta u Zagrebu donosi pregled o procesu deinstitucionalizacije u Hrvatskoj. Analiziran je trend smještavanja djece za razdoblje od 2010. do 2014. godine s obzirom na njihova sociodemografska obilježja, postojanje psihičkih smetnji, teškoća u razvoju, problema u ponašanju te ostvarenih uvjeta za posvojenje na strani djeteta. U zaključku su dane smjernice za buduće razdoblje.

Sljedeći prilog bavi se problemom tranzicije u odraslo doba djece i mladih iz alternativne skrbi. Branka Sladović-Franz, također s Pravnog fakulteta Sveučilišta u Zagrebu, u ovome je radu predstavila rezultate kvalitativnog istraživanja s 23 studenta iz alternativne skrbi koje je provedeno kroz fokusne grupne diskusije u pet sveučilišnih gradova Hrvatske, a odnosi se na spremnost na otkrivanje iskustava iz skrbi, povezanost skrbi s identitetom, spremnost na traženje pomoći i preporuke za pripremu mladih u skrbi za izlazak i studiranje. Posebno je istaknuti i niz preporuka sudionika istraživanja mladima iz skrbi koji namjeravaju studirati, odgajateljima i drugim stručnjacima o tome kako pripremiti mlade za studiranje te općenito na pripremu mladih za izlazak iz skrbi i olakšavanje tranzicije u odraslo doba.

O perspektivi onih drugih uključenih u alternativnu skrb pišu Teodor Sabolić iz Kuće za smještaj djece bez odgovarajuće roditeljske skrbi *Kuća Trešnjevka* i Lucija Vejmelka s Pravnog fakulteta Sveučilišta u Zagrebu, donoseći preporuke udomitelja, odgajatelja i stručnjaka iz centara za socijalnu skrb. Tako njihove preporuke za unapređenje alternativne skrbi za djecu uključuju poboljšanje prostornih uvjeta, uvjeta rada, određene kadrovske promjene i veće zapošljavanje stručnjaka, poboljšanje kvalitete i opsega edukacija za udomitelje, odgajatelje i stručnjake, ali i snažniju suradnju svih dionika socijalne skrbi za djecu i mlade.

Kako bi se pridonijelo rasvjetljavanju problema bjegova mladih iz odgojnih ustanova, početkom 2015. godine provedeno je istraživanje koje je bilo usmjereno na stjecanje uvida u učestalost, obilježja bjegova i razloga za bjegove mladih iz odgojnih ustanova. O tome istraživanju izvješćuju Gabrijela Ratkajec Gašević i Ivana Maurović s Edukacijsko-rehabilitacijskog fakulteta Sveučilišta u Zagrebu i Tena Zalović iz Centra za nestalu i zlostavljanu djecu iz Osijeka. Rezultati ukazuju na to kako 45,8 % mladih izvještava o iskustvu bijega iz doma. Autorice donose uvid u brojne aspekte problematike bjegova mladih iz odgojnih ustanova. Na kraju rada nude tri smjera za intervencije.

Sandra Laleta s Pravnog fakulteta Sveučilišta u Rijeci i Karla Kotulovski analiziraju radnopravne i socijalnopravne aspekte profesionalizacije udomiteljstva u hrvatskom i usporednom pravu. Na temelju provedene usporednopravne analize ovog instituta autorice ocjenjuju da je moguće rješenje problema udomiteljstva u Hrvatskoj u njegovoj profesionalizaciji, ističući kao smjernice postojeću praksu u susjedstvu, u Sloveniji i Srbiji.

Posljednji prilog u zborniku odgovara na pitanje što organizacije civilnog društva mogu ponuditi djeci i mladima u alternativnoj skrbi. Na to su pitanje odgovor ponudile Ines Rezo, Hana Hrpka i Jelena Tomić, predstavljajući program *Zagrlimo s(v)e* udruge *Hrabri telefon* iz Zagreba, koja se bavi zaštitom djece kroz aktivnosti edukacije, informiranja i savjetovanja. Program *Zagrlimo s(v)e* ima svrhu osposobljavanja djeteta za funkcioniranje u društvu kroz poticaj i razvoj praktičnih vještina i znanja te socioemocionalne zrelosti.

Možemo zaključiti kako ova dva zbornika predstavljaju značajan doprinos osvješćivanju pitanja zaštite dječjih prava, osobito u domeni ovako osjetljive problematike, seksualnog zdravlja djece, ali i zaštite prava na zdravlje djece odgajanih u alternativnim oblicima skrbi, i ne manje važno, donose pregled aktualne situacije u Hrvatskoj ističući primjere dobre prakse i smjernica kako poboljšati postojeće programe odnosno zakonsku regulativu. Sve to daje prostora uvjerenju kako će upravo ovakvi skupovi i publikacije proizašle iz njih značajno utjecati da zaštita ovdje predstavljenih prava djece, ali i njihovih prava generalno, dosegnu u Hrvatskoj viši nivo.

Robert Doričić

16th Lošinj Days of Bioethics

The 16th international scientific and cultural event *Lošinj Days of Bioethics* was organized by the Croatian Philosophical Society, Croatian Bioethics Society and the City of Mali Lošinj, and co-organized by the Centre of Excellence for Integrative Bioethics. The manifestation was held from May 14th – May 17th, 2017 at "Aurora" and "Vespera" hotels in Mali Lošinj, Croatia. This year's *Student Bioethics Workshop*, specially focused on "Abortion: Political Topic, Bioethical Problem", was organized by the Students of Philosophy Association from the Faculty of Humanities and Social Sciences from the University of Zagreb, and the Department of Philosophy of the Faculty of Humanities and Social Sciences from the University of Zagreb. The patrons of the 16th Lošinj Days of Bioethics were the Ministry of Science and Education of the Republic of Croatia and the Primorje-Gorski Kotar County. The Organisation Committee of the *Lošinj Days of Bioethics* included the President Ante Čović (Zagreb), Chief Secretary Hrvoje Jurić (Zagreb), Administrative Secretary Mira Matijević (Zagreb), and 64 board members, and the Organisation Team of the *Student Bioethics Workshop* included Luka Janeš, Roni Rengel, Augustin Kvočić, Mihailo Stojanović, Kristian Peter, Ivana Kovačić, and Lidija Knorr.

The solemn opening of the 16th *Lošinj Days of Bioethics* was held on Monday, May 15th, and it was followed by a plenary lecture about the history, condition, and perspectives of bioethics in Latin America. It was held by renowned Brazilian bio-scientist José Roberto Goldim, the winner of the "Fritz Jahr" Award 2017 for the research and promotion of European bioethics, for the second time given by the Fritz Jahr Documentation Research Centre for European Bioethics at the University of Rijeka. Afterwards, the symposium was held in three parallel sections in Croatian and English language. In its formal tradition, symposium continued to manifest finest example of transdisciplinary approach to solving contemporary issues, and has proven so by a vast amount of discussions oriented around recent rise of troublesome practices. The 68 papers were presented: José Roberto Goldim (Brazil): Bioethics in Latin America; Azra Jaganjac (Bosnia and Herzegovina), Ruken Esra Demirdöğen (Turkey): Engineering Ethics; Igor Čatić (Croatia): Medicine Increasingly Surrounded by Technology; Eva Jurković (Croatia): Carebots – Robots as Care Aid for the Elderly

and the Disabled; Tara Beata Racz (Croatia): Voice Assistants – Will They Enter Our Homes and Raise Our Children?; Matija Mato Škerbić (Croatia): Bioethical Issues within the W. J. Morgan's Ethics of Sport; Mislav Kukoč (Croatia): Bioethics at the 24th World Congress of Philosophy; Michael George (Canada): Bioethics: Crisis Management or Moving towards a Comprehensive Ethics?; Georgios Boutlas (Greece): Bioethics as the "Third Culture", Integrating Science and Humanities, Preventing "Normative Violence" on Each Other; Roman Paškulin (Slovenia): Epigenetics and Polytheism; Luka Perušić (Croatia): Integrative Bioethics and the Approach to Handling Radically Opposed Perspectives; Igor Eterović, Martina Šendula-Pavelić (Croatia): In Search of the Bioethical Leadership Standards; Jadranka Božić (Serbia): Bioethical Problems in the Literary Context; Vladimir Jelkić, Jelena Lacković (Croatia): Thoreau's Walden as a Possible Paradigm of a Bioethical Education; Luka Janeš (Croatia): Aldo Leopold and the Metaphysics of Forest; Mirna Petak (Croatia): Cannabis in Architecture; Josip Gud (Croatia): The Contribution of Nikola Visković's Cultural Zoology and Botany to Integrative Bioethics; Željko Kaluđerović (Serbia): Pythagorean palingenesia; Saša Zavrtnik, Damir Žubčić (Croatia): Bioethical Principles in the Relationship Between Man and Environment – an Example of the Old Hebrews; Anto Čartolovni (Croatia): The Contribution of Christian Ethics to the Current Interpolation Between Environmentalism and Ecomodernism/Ecopragmatism in the New Anthropocene Era; Antun Japundžić, Ana Jeličić (Croatia): Ecological Issues in the Orthodox Theology; Karel Turza (Serbia): Knowledge in Bioethics, Especially within Medical Aspects of Bioethics; Leonard Volarić Horvat, Lovro Furjanić (Croatia): Pascal's Mugging and Artificial Intelligence; Vanja Borš (Croatia): Nietzsche: Perspectivist or Pluriperspectivist?; Elena Michalakou (Greece): Humans and Nonhuman Animals: Issues of Ethical Foundation of Rights and the Effective Defense of the Legally Incapable; Julija Erhardt (Croatia): Laboratory Animals Today: How Far Have We Come with Alternatives?; Ivana Čović (Austria): The Embodied Mind in the Context of Integrative Bioethics; Eva D. Bahovec (Slovenia): Women's Bodies between Biopolitics and Bioethics; Ivana Zagorac (Croatia): The Concept of Vulnerability in Influential Bioethics; Marija Selak (Croatia): Informed Consent as a Sign of the End of (Medical) Authority; Francesca Zaccaron (Italy): What is Healing for a Caregiver? The Developing Subject as a Dynamic Unity; Zoran Todorović, Dragana Protić (Serbia): Patient Autonomy in Drug Development and Pharmacotherapy; Josip Markotić (Croatia): Bioethical Aspects of Commodification of Human Body in the Context of Application of New Technologies in Human Reproduction; Danijela De Micheli Vitturi (Croatia): Fear of Giving Birth; Martin Ilić (Croatia): Human Reproductive Cloning: The Problem of Spiritual Soul; Marina Katinić (Croatia): An Ethical Analysis of the Judgement of the Constitutional Court of the Republic of

Croatia regarding Constitutionality of the Medical Treatment Law regarding Free Choice of Childbearing; Dragana Denić (Serbia): Euthanasia – a Crossroad or a Labyrinth?; Iva Šokičić (Croatia): Euthanasia – the Right to Life and Death as a Free Choice; Suzana Vuletić, Silvana Karačić, Gordana Pelčić (Croatia): Hetero/auto/nomy in the Context of (Self)Determinism of Biological Testaments; Samir Beglerović, Orhan Jašić (Bosnia and Herzegovina): Euthanasia and Its Understanding in the Tradition of Bosnian-Herzegovinian Muslim Religious Authors; Marija Brdarević, Ivna Kocijan (Croatia): Nurses' Bioethical Doubts about Voluntary Euthanasia; Ajnija Omanić (Bosnia and Herzegovina), Amer Ovčina (Bosnia and Herzegovina), Hajrunisa Čubro (United States of America): Sketches from Life and Ethical Code of Conduct of Health Workers at the Mayo Clinic, with Special Regard to Nursing at the Saint Mary's Hospital in Rochester; Sonja Kalauz, Marijana Neuberg (Croatia): Bioethical Dimension of Nursing Theories; Velimir Terzić, Marija Terzić (Croatia): Urinary Catheterisation – Dilemmas of Doctor and Patient; Srećko Gajović (Croatia), Anna Lydia Svalastog (Norway): Knowledge Landscapes – Linear and Non-Linear Knowledge Communication in the Digital Society; Anna Lydia Svalastog (Norway): Navigating Knowledge Landscapes and Ethics; Andrej Bogatinoski (Macedonia): Ethical Issues in the Internet of Things; Denis Kos, Lidija Knorr (Croatia): The Concept of Standpoints in Knowledge Organization; Toni Pustovrh (Slovenia): Scientific Collaboration with Self-Organised and Alternative Research Spaces: The Bioethics of Collaboration between DIY (Bio)Hackerspaces and Public Research Institutions; Chris Agee (United Kingdom): The Contemporary Relevance of Hubert Butler (1900–1991); Sabina V. Paneva (United States of America): Ethical Considerations at the Intersection of Collective Memory, Personal Trauma and Teaching History: Teaching and Learning about Genocide; Sven Hočevar-Potokar (Slovenia): Nobel Prize in Physiology or Medicine through Time and the Greatest Ethical Controversies; Ana Švogor Šipek, Siniša Opić, Tomislav Krznar (Croatia): The Presence of Bioethical Issues in Education Programmes for Teachers and Educators; Marina Katinić, Damir Velički, Tomislav Krznar (Croatia): Acquaintance with Bioethical Issues in the Population of Students in Teacher Education; Ana Maskalan, Silvia Rogošić (Croatia): Feminist Bioethics and Moral Disgust; Damir Žubčić (Croatia): Why We Need to Learn about the Treatment of Animals; Goran Sunajko (Croatia): Homo Economicus as a Bioethical Issue in the Analysis by Raj Patel; Marko Kos (Croatia): The Other – After the Truth; Nikolina Ćavar (Croatia): How to End Modern Slavery?; Anita Lunić (Croatia): What Bioethics Can Say about Refugees and Immigrants? Peter Singer's Argumentation and Critique; Mario Jašić, Senad Ćeman (Bosnia and Herzegovina): The Ban on Wearing Hijab in European Convention Law; Teodora Not (Croatia): Intersectoral Cooperation – the Standard of Connecting and Cooperating in Rehabilitation of

Children with Disabilities; Mario Bebek, Marija Brdarević (Croatia): Bioethics and Autonomy of Persons with Disabilities; Marko Marinić (Croatia): Sexuality and Persons with Disability – What Disability Has to Do with Sex?; Amer Ovčina, Sebija Izetbegović, Jasna Bajraktarević (Bosnia and Herzegovina): Organisation Changes in Healthcare System and Ethical Concerns; Robert Doričić (Croatia): Bioethical Standards in the Light of Public Health (Bio)ethics; Maja Miloš (Croatia): The Content and Implementation of Bioethical Standards – Attitudes of the Local Community Representatives (Mali Lošinj, Bakar, Kršan); Aleksandar Racz, Antonio Badurina (Croatia): Bioethischer, Ökologischer und Ökonomischer Ansatz im Hinblick auf Entwicklungsstrategien des Golftourismus in Kroatien am Beispiel der Projekte "Punta Križa" und "Baštijunski Brig".

The International Student Bioethics Workshop "Abortion: Political Theme, Bioethical Problem" was the 13th student bioethics workshop organized in the context of the programme of *Lošinj Days of Bioethics*. More than 50 students from various study groups from different scientific fields from the University of Zagreb, Rijeka, Split, Osijek, Koprivnica/Varaždin, Novi Sad, Niš, and Skopje participated in three study days. Except for the Students bioethics workshop, three more relevant events were organized within the manifestation, namely "Presentation of Recent Bioethical Publications", "Bioethical Café", and "Round Table". Traditional presentation of recent bioethical editions took place on Monday at Aurora's Grand Hall. Twenty-one new bioethical publications (nine books and twelve scientific and professional journals) based in Croatia, France, and Serbia were presented during this round of evening presentation. This year's Bioethical Café was held on Tuesday and was entitled "Life in Poetry: Death, Loss and Applause". The guest of the evening was Chris Agee, a poet, essayist, and the editor of the *Irish Literary*, a magazine based in Ireland. This year, the traditional "Round Table" held on the last day of manifestation dealt with the problem of "Animal lives and human laws". Presentations were held by Hrvoje Jurić (Faculty of Humanities and Social Sciences, University of Zagreb), Tatjana Zajec (The Shelter for Abandoned Animals of the City of Zagreb in Dumovec), and Julija Erhardt (Faculty of Science, University of Zagreb). They spoke about the ways in which these issues were legally regulated, including the principle of animal-animal relations, the animalistic theory and the practice in Croatia, and current changes to Croatian hunting and animal protection laws.

All things considered, 16th *Lošinj Days of Bioethics* once again showed its protruding relevancy with the width of the topics covered, and a discursive openness to solving problems of modern society through broad scientific assembly.

Lidija Knorr

19. riječki dani bioetike na Fakultetu zdravstvenih studija u Rijeci Bioetičke dileme u palijativnoj skrbi: od teorije do prakse

(Rijeka, 12. svibnja 2017.)

Nastavljajući tradiciju jednog od najstarijih bioetičkih znanstveno-stručnih događanja u regiji, ovogodišnji 19. riječki dani bioetike na temu „Bioetičke dileme u palijativnoj skrbi: od teorije do prakse" bili su usmjereni na pitanja i izazove u palijativnoj skrbi s kojima se zdravstveni radnici susreću u svakodnevnom radu s palijativnim pacijentima. S naglaskom na potrebi za interdisciplinarnim pristupom u radu s palijativnim pacijentima, cilj ovogodišnjih Riječkih dana bioetike bio je sjediniti izazove i dileme praktičnog rada kroz izlaganja zdravstvenih radnika te pokušati dati odgovore kroz teorijske postavke koje nam pruža akademska zajednica.

Organizatori ovogodišnjeg skupa bili su: Centar za palijativnu skrb Fakulteta zdravstvenih studija Sveučilišta u Rijeci, Katedra za društvene i humanističke znanosti u medicini i Katedra za socijalnu medicinu i epidemiologiju Medicinskog fakulteta Sveučilišta u Rijeci, Katedra za javno zdravstvo Fakulteta zdravstvenih studija Sveučilišta u Rijeci, Dokumentacijsko istraživački centar za europsku bioetiku Fritz Jahr Sveučilišta u Rijeci, Znanstveni centar izvrsnosti za integrativnu bioetiku te UNESCO-ova katedra za društvene i humanističke znanosti u medicini Sveučilišta u Rijeci. Skup financijski podržava Grad Rijeke, a partneri skupa bili su Medico i Jadran galenski laboratorij.

Prije početka skupa održana je dodjela godišnje Nagrade za istraživanje i promociju europske bioetike „Fritz Jahr" u Dokumentacijsko-istraživačkom centru za europsku bioetiku „Fritz Jahr" Sveučilišta u Rijeci. Ovogodišnji dobitnik nagrade je Jose Roberto Goldim, profesor bioetike na Medicinskom fakultetu pri Katoličkom sveučilištu Rio Grande do Sul te voditelj bioetičke službe pri Kliničkoj bolnici u Porto Alegreu.

Skup se sastojao od pet glavnih sekcija unutar kojih je održano ukupno 20 tematskih predavanja:

- Distanazija
- Autonomija pacijenta na kraju života
- Bioetika u pedijatrijskoj palijativi
- (Ne)informirani pristanak
- Bioetička i filozofska razmatranja u palijativnoj skrbi.

U prvoj sekciji na temu *Distanazija* sudionici su izložili izazove i dileme s kojima se susreću zdravstveni radnici kada je riječ o uzaludnim postupcima. Renata Marđetko iz Centra za koordinaciju palijativne skrbi u Gradu Zagrebu prikazala je vlastito iskustvo rada s palijativnim bolesnicima i njihovim obiteljima u njihovom domu, dok je Lidija Fumić Dunkić iz Kliničkog bolničkog centra Sestre Milosrdnice progovorila o iskustvu rada s palijativnim pacijentima u bolnici. Obje su, iz aspekta vlastitog dugogodišnjeg iskustva, naglasile potrebu za daljnjim razvitkom palijativne skrbi u Hrvatskoj kako bi se palijativnim pacijentima omogućilo održavanje kvalitete života uz maksimalno ublažavanje patnje i bola. Ranko Stevanović iz Hrvatskog zavoda za javno zdravstvo progovorio je o medicinskom, javnozdravstvenom, moralnom i humanitarnom aspektu distanazije s naglaskom na potrebi promicanja „humane pravovremene smrti" te dostojanstvu pacijenta do smrti. Gordana Štirjan Marković iz Odjela za palijativnu medicinu i palijativnu skrb Specijalne bolnice za plućne bolesti Zagreb istaknula je kako u hrvatskom zdravstvu još uvijek dominira distanazija i neuređen sustav palijativne skrbi. Kako bi se podigla kvaliteta palijativne skrbi, Štirjan Marković poziva na otvorenu komunikaciju, motiviranost i empatiju te naglašava važnost edukacije svih dionika.

Druga sekcija na temu *Autonomija pacijenta na kraju života* sastojala se od seta predavanja koja su naglašavala važnost poštovanja želje pacijenata u vezi sa zdravstvenim postupcima i dilemama s kojima se susreću zdravstveni radnici kada je riječ o donošenju odluka i poštovanju autonomije pacijenta. Karmen Lončarek iz Centra za palijativnu skrb Fakulteta zdravstvenih studija u Rijeci te Zavoda za palijativnu medicinu Kliničkog bolničkog centra u Rijeci prikazala je opći sadržaj biološkog testamenta te naglasila važnost izražavanja želja i donošenja vlastitih odluka kada je riječ o zdravstvenim postupcima pri kraju života. Biološkom testamentu nadovezala se Sandra Milić iz Klinike za internu medicinu Kliničkog bolničkog centra Rijeka njegovim prikazom u praksi u formi kliničkog narativa. Prikaze slučaja i etičke dileme kroz iskustvo vlastitog rada prikazale su Milana Topić iz Mobilnog palijativnog tima Doma zdravlja Primorsko-goranske županije te Azra Ribić-Mrkonja iz KJU Doma za socijalno i zdravstveno zbrinjavanje osoba s invaliditetom i drugih iz Sarajeva. Na kraju sekcije, Nataša Dumbović govorila je o važnosti uloge obitelji

u autonomiji pacijenta na kraju života s prikazom nekoliko pozitivnih primjera umiranja u kući i poštovanja volje umirućeg.

Izlagači treće sekcije pod nazivom *Bioetika u pedijatrijskoj palijativi* osvrnuli su se na dileme u jednoj od, kako ističu, najtežih područja palijative. Kristina Lah Tomulić iz Odjela intenzivnog liječenja djece Klinike za pedijatriju Kliničkog bolničkog centra Rijeka progovorila je o etičkim dilemama u pedijatrijskom intenzivnom liječenju te ostavila otvoreno pitanje o tome tko bi trebao donositi odluke kada je riječ o (uzaludnim) postupcima liječenja u pedijatrijskoj palijativi. Također, naglasila je prisutnost etičkih dilema u radu pedijatrijske jedinice intenzivnog liječenja i pitanja je li produljenje života i agresivno liječenje u interesu bolesnika. Gordana Šimunković s Katedre za socijalnu medicinu Medicinskog fakulteta u Rijeci nadovezala se izlaganjem na temu o prisutnosti etičkih dilema u pedijatrijskom palijativnom liječenju te istaknula kako nedostaju objektivni alati koji bi olakšali postupak donošenja tako važnih i teških odluka. Ublažavanje bola i dječjeg žalovanja može se ostvariti interdisciplinarnim pristupom i konstruktivnim smjernicama proizašlim iz razvojne psihologije i duhovnosti, istaknula je Suzana Vuletić s Katoličko-bogoslovnog fakulteta u Đakovu Sveučilišta Josipa Jurja Strossmayera u Osijeku. Također je naglasila potrebu za holističkom koncepcijom palijative u svrhu kvalitetne provedbe integralne pedijatrijske palijativne skrbi. Jasminka Stepan Giljević iz Zavoda za onkologiju i hematologiju Klinike za dječje bolesti upozorila je na prisutnost razvoja raznih alternativnih postupaka koji pridonose želji za odustajanjem od primjerenog palijativnog zbrinjavanja te zaključila kako je od iznimne važnosti kvalitetna komunikacija na svim razinama te uvažavanje individualne situacije svakog djeteta i njegove obitelji.

Četvrta sekcija na temu *(Ne)informirani pristanak* sastojala se od dva izlaganja: o informiranom pristanku u teoriji, o čemu je govorila Marta Dajana Carti te o informiranom pristanku u praksi, odnosno prikazu kliničkog slučaja o kojem je govorila Vesna Grubješić iz Odjela intenzivnog liječenja Klinike za anesteziologiju i intenzivno liječenje Kliničkog bolničkog centra Rijeka. U prikazu slučaja, Grubješić je obuhvatila razna pitanja i dileme s kojima se susreće u svakodnevnom radu: pitanje etičkih dilema u vezi s autonomijom pacijenta, informiranim pristankom, sposobnosti donošenja odluka kod mentalnih poremećaja, poštovanjem volje obitelji, zakonskim skrbništvom, distanazijom te uzaludnim postupcima. Marta Dajana Carti nadovezala se izlaganjem s teorijskim okvirom te istaknula kako informativni postupak treba biti shvaćen kao proces u kojemu se davanje informacija pacijentu ne svodi na administraciju, nego se u širenju informacija komunicira na pacijentu razumljiv i shvatljiv način. Također, naglasila je potrebu za individualiziranjem informiranog pristanka te interdisciplinarnim pristupom u procesu donošenja odluka kako bi se izbjegle etičke dileme koje su prisutne u procesu liječenja.

Peta i posljednja sekcija ovogodišnjeg skupa Riječkih dana bioetike pod nazivom *Bioetička i filozofska razmatranja u palijativnoj skrbi* obuhvatila je razna pitanja i etičke dileme koje su prisutne u svim segmentima palijativnog liječenja. Marin Golčić iz Zavoda za internističku onkologiju Kliničkog bolničkog centra Rijeka progovorio je o „deprescribingu" u palijativnih onkoloških bolesnika, odnosno o ukidanju lijekova iz trajne terapije u terminalnih bolesnika s ciljem povećavanja kvalitete života i smanjivanja nuspojava lijekova te prikazao analizu najčešće korištenih lijekova u Hospiciju Marija Krucifiksa Kozulić u Rijeci od 2013. do 2017. Mijo Grgić iz Odjela za palijativnu medicinu i palijativnu skrb Specijalne bolnice za plućne bolesti Zagreb govorio je o problemu distanazije te izložio prikaz jednog slučaja. Dubravka Šimunović sa Zdravstvenog veleučilišta Zagreb kroz dva izlaganja naglasila je važnost radne terapije i logoterapijskog sagledavanja autonomije palijativnog bolesnika. Istaknula je važnost prepoznavanja bolesnikovih unutarnjih vrijednosti, uz neizostavno poštovanje osobnih uvjerenja kako bi se umanjila patnja i povećala kvaliteta života. Zaključno, Orhan Jašić s Fakulteta islamskih nauka Univerziteta u Sarajevu govorio je o palijativnoj skrbi u tradiciji muslimana kroz teološko-filozofski pristup poimanja ljudskog bića, a posljedično i fenomena palijativne skrbi.

19. riječki dani bioetike, koji su ove godine bili posvećeni bioetičkim dilemama u palijativnoj skrbi, jedna je od niza ovogodišnjih inicijativa Centra za palijativnu skrb Fakulteta zdravstvenih studija te Katedre za društvene i humanističke znanosti u medicini i Katedre za socijalnu medicinu i epidemiologiju Medicinskog fakulteta Sveučilišta u Rijeci na temu smrti, umiranja i skrbi za teško oboljele i neizlječive pacijente. U sljedećem poglavlju bit će nešto više riječi o ciklusu tribina za javnost na temu umiranja i smrti.

Tribine za javnost: „Ona riječ na s…"

„Ona riječ na s..." naziv je ciklusa tribina koji je započeo s provedbom 6. travnja 2017. godine u organizaciji Katedre za društvene i humanističke znanosti u medicini, Katedre za socijalnu medicinu i epidemiologiju Medicinskog fakulteta Sveučilišta u Rijeci te Centra za palijativnu skrb Fakulteta zdravstvenih studija Sveučilišta u Rijeci. Cilj tribina je otvoriti u javnosti temu jednog djela ciklusa života, učestalo prihvaćenu kao tabu-temu smrti i pridonijeti izgradnji palijativne skrbi kao sveobuhvatne (zdravstvene, psihološke, socijalne i duhovne) skrbi kod bolesnika s neizlječivom bolešću koja značajno skraćuje životni vijek.

Ciklus od 6 tribina obuhvaća teme: smrt kao dio kulturnog života, biološki testament, volonteri u palijativnoj skrbi, pravo na smrt kao ljudsko pravo, duhovnost u palijativi te razmišljanja Ivana Ilicha u teoriji i praksi.

Prva tribina „Ona riječ na s... - smrt kao dio kulturnog života“ progovorila je o smrti kao dijelu kulturnog života. Prof. dr. sc. Amir Muzur s Katedre za društvene i humanističke znanosti u medicini govorio je o razlozima zašto je smrt tabu-tema iznijevši nekoliko perspektiva. Izdvojeno je da oni koji o smrti uopće ne razmišljaju mogu ispasti bliži istini od ostalih. Možemo vjerovati u nadinstanciju koja se pobrine da se sve završi baš kako treba. Instancija koja treba biti savršeno dobra, jer ako nije takva, tada nam ni ne treba. U tom slučaju nemamo se razloga brinuti ni za što. Sve što nam se čini lošim, čini nam se takvim jer možemo sagledati samo dio zbivanja. Smatra se da je smisao smrti upravo u njenoj nepoznatosti i možemo reći da je riječ o najvećoj tajni na svijetu.

Prof. dr. sc. Karmen Lončarek, voditeljica Centra za palijativnu skrb Fakulteta zdravstvenih studija Sveučilišta u Rijeci, problematizirala je o tome kako govoriti o nečemu o čemu najradije ne bismo govorili. Razgovor o smrti najvažniji je razgovor od svih razgovora koje nećemo obaviti. Radije koristimo eufemizme: izdahnuo je, preminuo je, sniva vječni san, otišao je u bolja spominjanja, napustio je ovaj svijet, skončao je, promijenio svijet, otišao Bogu na istinu itd. Razlog je strah od smrti, a taj je strah najiskonskiji i najsnažniji strah uopće. Govoriti o smrti znači prije svega govoriti o najdubljem strahu. Naučiti u vlastitoj kući razgovarati o umiranju smireno i na vrijeme, da se umirućega ne bojimo i da budemo uz njega u smrtnom času, jedan je od vrjednijih zaloga obiteljskog života.

Kulturno blago riječkih groblja predstavila je mr. sc. Daina Glavočić pozivajući na zajedničko očuvanje kulturne baštine.

Druga tribina u Ciklusu, pod nazivom „Biološki testament – neka bude volja moja“, održala se na Međunarodni dan obitelji, 15. svibnja 2017. godine, ukazujući na značaj izražavanja vlastite volje o postupcima kojima osoba želi ili ne želi biti podvrgnuta u slučaju teške bolesti ili iznenadne traume.

O biološkom testamentu govorila je dr. sc. Marta Carti, doktor znanosti za područje bioetike, a o njegovoj primjeni u praksi govorila je prof. dr. sc. Karmen Lončarek. O ovjeravanju obrasca za odbijanje medicinskih postupaka, kao predsjednik Zajedničkog javno bilježničkog zbora Primorsko-goranske županije i Ličko-senjske županije i kao predstavnik Hrvatske javnobilježničke komore, govorio je Stevan Pejnović, dipl. iur.

Zaključeno je kako elementi biološkog testamenta pokazuju da osim odluka o korištenju sofisticirane tehnologije kao što su respirator i umjetno hranjenje, postoje brojne druge odluke koje se neizbježno moraju donijeti na kraju života. Želje u vezi sa zdravstvenim postupcima, pitanja u vezi s krajem života te želje vezane uz ublažavanje bola, sukobe, sudjelovanje u istraživanjima, trudnoću, darivanje organa, darivanje

tijela, sahranjivanje tijela, obdukciju, religiju, duhovnost itd. skup su smjernica koje kraj života mogu učiniti mirnijima za sve uključene strane.

Treća tribina pod nazivom „Nema suvišnih ljudi – volonteri u palijativi" održana je 5. lipnja 2017. godine poslavši poruku kako je svaki član zajednice važan u izgradnji solidarnosti, uzajamnosti, povjerenja i pripadnosti.

Gordana Šimunković s Katedre za socijalnu medicinu i epidemiologiju Medicinskog fakulteta Sveučilišta u Rijeci predstavila je volontiranje u palijativnoj skrbi sukladno europskoj praksi kao dobrovoljno dano vrijeme pojedinaca, u okviru određene organizirane strukture, koja ne uključuje postojeće socijalne veze i obiteljsku povezanost, bez očekivanja materijalne dobiti, a s namjerom da se unaprijedi kvaliteta života odraslih i djece sa životno limitirajućim stanjima, kao i njima bliskim osobama. Kvalitetan volonterski program pridonijet će psihosocijalnoj dobrobiti i kvaliteti života palijativnih pacijenata i njihovih obitelji, pružajući socijalnu, emocionalnu i tehničku podršku. Aktivnosti u koje se mogu uključiti volonteri u rasponu su od direktnog kontakta s palijativnim pacijentom i njegovom obitelji (pomoć pružateljima njege, pomoć pri održavanju kućanstva, duhovna podrška, pružanje informacija i dr.) do indirektne uključenosti u skrb kroz aktivnosti pružanja podrške u organiziranju skrbi (priprema informativnih materijala, organizacija podrške za tugujuće, kopiranje dokumentacije i dr.).

O konkretnim načinima kako se može kroz volonterski rad pridonijeti kvaliteti života palijativnog pacijenta i njegove obitelji govorila je prof. dr. sc. Karmen Lončarek predstavivši volonterski rad pri izradi senzornih dekica za osobe s demencijom i „najmanjih bijelih haljinica", haljinica izrazito male veličine, nedostupnih na tržištu, za preminulu dojenčad.

Predstavnica Volonterskog centra Rijeka Marta Hauser pozvala je prisutne da se jave kako bi ih se povezalo s postojećim volonterskim programima. U svome izlaganju predstavila je osnovne korake za osiguranje kvalitete volonterskog programa: planiranje volonterskog programa, opis volonterske pozicije, pronalazak i odabir volontera, edukacija i uključivanje volontera, praćenje rada volontera te supervizija i evaluacija volonterskog programa. Koordinator volontera pri tome je ključna osoba.

U razdoblju koje slijedi očekuje se provedba preostalih triju tribina iz ciklusa:

"Kako umrijeti bez stresa - pravo na smrt kao ljudsko pravo"

- Pravo na smrt kao ljudsko pravo? (doc. dr. sc. Dalida Ritossa)
- Projekcija kratkog filma „Gospođa i Kosac" (prof. dr. sc. Karmen Lončarek, dr. med. – uvod u film)
- Kako umrijeti bez stresa (Vedrana Rudan, književnica)

"Prijatelj do smrti - Ivan Illich u teoriji i praksi"

- *Amicus mortis* (doc. dr. sc. Iva Rinčić, dipl. soc.)
- Liječnik kao prijatelj do smrti (prof. dr. sc. Sandra Milić, dr. med.)
- Medicinska sestra kao prijateljica do smrti (Barbara Škrobonja, mag. sestrinstva)

"Smrt kao učitelj - duhovnost u palijativi"

- Nereligiozna duhovnost (Maja Miloš, mag. soc.)
- Smrt kao učitelj (Nađa Berbić, novinarka)
- Zašto pisati o smrti (Slobodan Šnajder, književnik)

Kao trajni trag provedbe ciklusa tribina u zajednici bit će tzv. Death cafe, organizirani susreti u jednom od kafića u gradu Rijeci gdje će se nastaviti govoriti o tabu-temi - smrti.

Gordana Šimunković, Maja Miloš i Karmen Lončarek

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Prof. José Roberto Goldim (Brazil) – the winner of the 2nd Annual Fritz Jahr International Award for Research and Promotion of European Bioethics, 2017

Prof. José Roberto Goldim,
Photo by Vedran Karuza, (2017)

The winner of the 2nd Annual Fritz Jahr International Award for Research and Promotion of. European Bioethics, 2017 is Professor José Roberto Goldim from Brazil. The award is presented to scholar or institution, which portrays efforts, qualities and achievements in the research and promotion of European Bioethics. It is given by the Centre of Research Excellence for Integrative Bioethics at the Faculty of Humanities and Social Sciences, University of Zagreb and one of the Centre of Research Excellence for Integrative Bioethics' constituent units, The University of Rijeka Documentation and Research Centre for European Bioethics *Fritz Jahr*. The awarding ceremony took place on the 12th of May this year at the Faculty of Medicine and the Faculty of Health Studies of the University of Rijeka on the occasion of the *19th Rijeka Days of Bioethics Conference*. This year's award was delivered to the winner by Prof. Amir Muzur, Director of the *Fritz Jahr* Centre, in the presence of Prof. Tomislav Rukavina, Dean of the Faculty of Medicine, University of Rijeka.

José Roberto Goldim is a Professor of bioethics at the Faculty of Medicine at the Rio Grande do Sul Catholic University and Head of Research Ethics Committee at the Clinical Hospital in Porto Alegre. Before 1988/1989 his main interests were in pharmacology and cardiology. After establishing cooperation with Prof. Joaquim Clotet, who was the first to teach bioethics in Brazil in late 1980's, bioethics has been a particular focus of Prof. Goldim's attention. Prof. Goldim and Prof. Clotet founded the first two Brazilian Research Ethics Committees in Porto Alegre. José Roberto Goldim obtained his PhD after the public defence of his thesis about informed consent in 1999. He was the first researcher to divulge in the Fritz Jahr's paper published in *Kosmos* journal in 1927. In 2004 he published its Portuguese translation on his research group's web site dedicated to the bioethical issues. Prof. Goldim is the author of the concept of the *Complex Bioethics*. It implies a pragmatic approach to the bioethics. According to Prof. Goldim, this is the concept that can transmit bioethics to real world, a tool that allows the use of different ethical approaches to the decision-making process in healthcare, research and elsewhere, a concept similar to the integrative bioethics' approach. During awarding ceremony Prof. Goldim pointed out the importance of cooperation in the field of bioethics at the international level, because many problems are perceived differently in different countries, but human beings are the same everywhere. He also stressed that the Rijeka's and the Porto Algre's bioethical groups should realize joint projects in the future to evaluate how the intercultural issues have affected or have not affected the bioethical perspectives.

As a part of the award, Prof. Goldim and his wife, Márcia Santana Fernandes, PhD, a lawyer and researcher at the Research Laboratory for Bioethics and Ethics at the Clinical Hospital in Porto Alegre and Coordinator of the Association of Judges of the Federal Republic of Rio Grande do Sul, were guests of the *16th Lošinj Days of Bioethics* held in Mali Lošinj, Croatia from 14th to 17th of May this year. Prof. Goldim presented his plenary lecture *Bioethics in Latin America* there.

Robert Doričić

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Acknowledgement of Sources: proper acknowledgment of the work of others must always be given. Authors should cite publications that have been influential in determining the nature of the reported work.

Authorship of the Paper: authorship should be limited to those who have made a significant contribution to the conception, design, execution, or interpretation of the reported study. All those who have made significant contributions should be listed as co-authors. Where there are others who have participated in certain substantive aspects of the research project, they should be acknowledged or listed as contributors. The corresponding author should ensure that all appropriate co-authors and no inappropriate co-authors are included on the paper, and that all co-authors have seen and approved the final version of the paper and have agreed to its submission for publication.

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The appropriate statistical analyses should be determined at the start of the study and a data analysis plan for the prespecified outcomes should be prepared and followed. Secondary or *post hoc* analyses should be distinguished from primary analyses and those set out in the data analysis plan. Researchers should publish all meaningful research results that might contribute to understanding.

Authors should supply research protocols to journal editors if requested (e.g. for clinical trials) so that reviewers and editors can compare the research report to the protocol to check that it was carried out as planned and that no relevant details have been omitted. Researchers should follow relevant requirements for clinical

trial registration and should include the trial registration number in all publications arising from the trial.

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Fundamental errors in published works: when an author discovers a significant error or inaccuracy in his/her own published work, it is the author's obligation to promptly notify the journal editor or publisher and cooperate with the editor to retract or correct the paper.

Editor-in-Chief

EUROPEAN JOURNAL OF BIOETHICS JAHR **EUROPSKI ČASOPIS ZA BIOETIKU**

IZJAVA O ETICI OBJAVLJIVANJA I NESAVJESNIM POSTUPCIMA

U ovom dokumentu prikazani su standardi očekivanog etičnog ponašanja svih strana uključenih u objavljivanje u časopisu *Jahr – Europski časopis za bioetiku*: autora, urednika i uredništva časopisa, recenzenata i izdavača.

Ove smjernice zasnivaju se na postojećim politikama Elsevierovih i COPE-ovih smjernica najbolje prakse za urednike časopisa.

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Odlučivanje o objavljivanju: urednik časopisa *Jahr* odgovoran je za odluku o tome koji od članaka podastrijetih časopisu može biti objavljen. Urednik se rukovodi politikama uredništva časopisa i vezan je zakonskim okvirima koji se odnose na eventualnu klevetu, povredu intelektualnog vlasništva i plagiranje. Pri odlučivanju urednik se može savjetovati s uredništvom ili recenzentima.

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Dužnosti autora

Standardi izvješćivanja: autori koji izvješćuju o izvornom istraživanju moraju iznijeti točan prikaz provedenog rada, kao i objektivnu raspravu njegova značaja. Podaci na kojima se rad temelji moraju u članku biti precizno prikazani. Članak mora sadržavati dovoljno pojedinosti i referenci kako bi drugima omogućio ponavljanje postupka. Lažne ili svjesno neprecizne izjave predstavljaju neetično ponašanje i nisu prihvatljive.

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Odgovarajuće statističke analize moraju biti utvrđene na početku studije, nakon čega treba pripremiti i slijediti plan analize podataka za pretpostavljene rezultate. Sekundarne ili *post hoc* analize treba razlikovati od primarnih i onih najavljenih u planu analize podataka. Istraživači moraju objaviti sve značajne rezultate istraživanja koji bi mogli pridonijeti razumijevanju problematike koja se spominje.

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Glavni urednik

EUROPEAN JOURNAL OF BIOETHICS JAHR **EUROPSKI ČASOPIS ZA BIOETIKU**

INSTRUCTIONS FOR THE AUTHORS

JAHR – EUROPEAN JOURNAL OF BIOETHICS is a journal that deals with a wide range of bioethical topics. The aim of the Editorial Board is to publish articles related to bioethics in social sciences, humanities, biomedicine, but also in other sciences. The journal is published twice a year.

Types of articles and a way of assessing articles

The journal publishes reviewed articles as well as articles that are not subject to the reviewing procedure. The reviewed articles are accepted to be published after having received two anonymous positive reviews (exceptionally three). The decision on the publication of articles in the journal "Jahr" is made by the editorial board.

Reviewed articles are categorized as following:

- original scientific papers that contain new, previously unpublished results of scientific research (*Original Articles*, *Short Communications*, *Preliminary Communications*);
- scientific papers that contain original, concise and critical presentation of a particular field or its part, in which the author himself/herself has an active role (*Review Articles*); the author's direct contribution to the particular field in relation to already published papers needs to be emphasized, as well as the overview of the already published papers;
- papers that contain useful contributions from and for the profession, and they do not have to be based on original research (*Professional Articles*);
- other contributions (*Letters to the editor*, *Essays* etc.).

The journal also publishes uncategorized papers, i.e. overviews of bioethics and other relevant publications published in the past three years in and outside Croatia, as well as reports and announcements of upcoming bioethics events (public lectures, book reviews, scientific conferences, etc.). By giving their consent to be published, the

authors give the journal the right for the first publication of the paper both in its printed and electronic format.

Works published in the journal *Jahr* authors can also publish in other publications with citing the data about the articles' first publication.

Layout and manuscripts

Preferable document size is up to 20 pages (including notes, references, tables, graphs and summary), while reviews and overviews should consist of 4-8 pages. The text should be written in 12-point Times New Roman font type, 1.5 inches spacing, and tables and graphs should be included within the text. Pages are numbered in the lower right corner of each page (including pages with bibliography). Notes (footnotes) should be inserted at the bottom of the page, where the numerical code of the footnotes is.

Books and journals that are reviewed should not be older than three years, and the review should include name and surname of the author (of the work being reviewed), title of the work, name of the publisher, place of publication, year of publication, number of pages, and the name and surname of the reviewer at the end.

Manuscript, in layout, must contain following elements:

- name and surname of the author(s),
- name and address of affiliation,
- contact address of the author (if different from affiliation),
- e-mail address,
- full title of the article (and subtitle if necessary),
- structured abstract: objective, methods, results, conclusions of no more than 100-250 words and keywords (no more than 8), in English and Croatian.

If complete bibliographical information regarding cited works is not stated in footnotes, the author must provide a reference list at the end of the article, containing complete information on cited works.

Graphs, tables, and images are generally included within the text at the point where they need to be displayed. Graphs, tables, and images should be enlarged to the whole page and possess adequate resolution (preferably 300dpi). They should be properly numbered and titled. If the figures, tables, etc. are reproduced from another source, the original source must be properly cited. Due to monochrome printing, all figures, graphs, etc. should be monochrome or grayscale, have a white background

and be made in applications, such as MS Office. Letters used in figures should be Arial font.

The accustomed foreign expressions, including the names of documents and institutions in a foreign language should be written in italics – for example, *de facto*. All of highlighting in the text is done in **bold**. Underline characters are not used in the text.

Dates are listed as follows: 01 July 2014. Numbers at the beginning of sentences and approximate numbers are written in words – hundreds, thousands, millions, etc. Decimal is separated exclusively by commas (e.g. 621,57), and thousands with single space (1 532 or 10 589 163). Statistical expressions are written in the whole decimal numbers (e.g. p <0,05).

All abbreviations should be expanded at first mention in the text, and introduced by placing it in parentheses after the term. It is necessary to respect standard abbreviations and the rules of shortening.

Quotation taken directly from another author's text is placed in quotation marks, and if one part of a quoted text is omitted, it is marked [...].

Citation method and writing literature sources

The editorial board recommends using footnotes as a method of citation. When a work is cited for the first time (regardless of the language in which the work has been published), it should look as following:

[for book] Tristram H. Engelhardt, *The Foundations of Bioethics*, University Press, New York 1986, p. 72.

[for proceedings] Jacob D. Rendtorf and Peter Kemp (ed.), *Basic Ethical Principles in Bioethics and Biolaw*, *Vol. I. Autonomy, Dignity, Integrity and Vulnerability*, Centre for Ethics and Law, Institut Borja de Bioetica, Copenhagen, Barcelona 2000.

[for journal article] Roberto Andorno, »The Oviedo Convention: A European Legal Framework at the Intersection of Human Rights and Health Law«, *Journal of International Biotechnology Law*, 2 (4/2005), p. 135.

[for proceedings article or book chapter] Diego Gracia, »History of Medical Ethics«, in: Henk Ten Have and Bert Gordjin (ed.), *Bioethics in European Perspective*, Kluwer, Dordrecht 2001, p. 34.

[for electronic works of reference] http://www.legalhelpmate.com/health-caredirective- patient-act.aspx (16 June 2009)

[for institutional publications] The Croatian Bureau of Statistics (2006). *Statistical Yearbook 2006*, The Croatian Bureau of Statistics, Zagreb.

[for laws and regulations] Environmental Protection Act (2007). *Official Gazette*, 110/2007.

In the second and further citations, notes should contain only the initial of author's first name and surname of the author, title of the work (book or article) and a page number:

T. Engelhardt, *The Foundations of Bioethics*, p. 113.

R. Andorno, »The Oviedo Convention: A European Legal Framework at the Intersection

of Human Rights and Health Law«, p. 138.

When work is cited consecutively, the note should contain only the abbreviation Ibid and a page number: Ibid., p. 150.

The works in the bibliography are listed alphabetically. If two or more works written by the same author and published in the same year are listed, lower-case letters (a, b, c, etc.) are added immediately after the year within parentheses (1996a).

The editorial board, naturally, accepts other methods of citation as well, under the condition they are used consistently within a particular text.

Authors please comply with these rules, and respect and follow the norms of the standard Croatian language. The editorial board reserves the right to adjust the work to the editorial propositions and standards of the Croatian language.

Steps to check the manuscript before submitting:

1. 1. The submitted article has not been previously published and is not under consideration for publication elsewhere. If the article has already been published, it should be emphasized when submitting the article.
2. 2. The file is in Microsoft Word format.
3. 3. The text should be written in 12-point Times New Roman font type, 1.5 inches spacing, and tables and graphs should be included within the text.
4. 4. The article is prepared according to the guidelines provided in the instructions for authors.

The communication of the author and the editor-in-chief

Manuscripts are to be sent by mail in three copies to the editorial board:

Department of Social Sciences and Medical Humanities at
University of Rijeka – Faculty of Medicine
Braće Branchetta 20, HR-51000 Rijeka, Croatia
Tel: + 385-51-688-261
Fax:+ 385-51-651-219

or in an e-mail attachment to: **igor.eterovic@uniri.hr**.

The editorial board does not return manuscripts.

Please feel free to contact the editorial board with any further questions or concerns.

Editor-in-Chief

EUROPEAN JOURNAL OF BIOETHICS JAHR **EUROPSKI ČASOPIS ZA BIOETIKU**

UPUTE AUTORIMA

JAHR – EUROPEAN JOURNAL OF BIOETHICS je časopis koji tematizira širok raspon bioetičkih tema. Namjera Uredništva je objavljivati članke koji se tiču bioetike u društvenim, humanističkim, biomedicinskim, ali i u drugim znanostima. Časopis izlazi dva puta godišnje.

Vrste članaka i način procjene članka

Časopis objavljuje neobjavljene radove odnosno članke koji se recenziraju i one koji ne podliježu recenzijskom postupku. Članci koji se recenziraju prihvaćaju se za objavljivanje nakon provedenog recenzijskog postupka, na temelju dviju anonimnih pozitivnih recenzija (iznimno tri). Odluku o objavljivanju radova u časopisu *Jahr* donosi uredništvo.

Recenzirani članci kategoriziraju se na sljedeći način:

- znanstveni članci koji sadrže nove, još neobjavljene rezultate znanstvenih istraživanja (*Izvorni članci*, *Kratka priopćenja*, *Prethodna priopćenja*);
- znanstveni članci koji sadrže izvoran, sažet i kritički prikaz jednog područja ili njegovog dijela, u kojem autor i sam aktivno sudjeluje (*Pregledni članci*); mora biti naglašena uloga autorova izvornog doprinosa u tom području u odnosu na već objavljene radove, kao i pregled tih radova;
- članci koji sadrže korisne priloge iz struke i za struku, a ne moraju predstavljati izvorna istraživanja (*Stručni članci*);
- ostali radovi (*Pisma uredniku*, *Eseji* itd.).

Časopis objavljuje i nekategorizirane radove, odnosno recenzije i prikaze bioetičkih, ali i drugih relevantnih izdanja objavljenih u zadnje tri godine u Hrvatskoj i inozemstvu, te izvještaje i najave bioetičkih zbivanja (javna predavanja, predstavljanja knjiga, znanstveni skupovi i sl.).

Svojim pristankom na objavljivanje autori daju časopisu pravo prvog objavljivanja u tiskanom i elektroničkom formatu. Radove objavljene u časopisu *Jahr* autori mogu objaviti u drugim publikacijama uz navođenje podataka o njihovu prvom objavljivanju.

Oblikovanje teksta i grafička oprema

Poželjni opseg članaka je do 20 stranica (uključujući bilješke, literaturu, tablice, grafičke prikaze i sažetak), a recenzija i prikaza od 4 do 8 stranica. Tekst treba biti napisan Times New Roman fontom, veličina slova 12, prored 1,5, a tablice i grafikone treba smjestiti unutar teksta. Stranice se numeriraju u donjem desnom kutu na svakoj stranici (uključujući i stranicu/e s bibliografijom). Bilješke (fusnote) nalaze se na podnožju stranice gdje se nalazi brojčana oznaka fusnote.

Knjige i časopisi koji se prikazuju ne smiju biti stariji od tri godine, a prikaz treba uključivati ime i prezime autora čije se djelo prikazuje, naslov djela, naziv izdavača, mjesto izdavanja, godinu izdavanja, broj stranica te na kraju prikaza puno ime i prezime autora prikaza.

Rukopis, u opremi teksta, treba sadržavati sljedeće elemente:

- ime i prezime autora,
- naziv i adresu matične institucije autora,
- autorovu adresu za kontakt (ako se razlikuje od adrese matične institucije),
- *e-mail* adresu autora,
- puni naslov rada (eventualno i podnaslov),
- strukturirani sažetak članka: cilj, metode, rezultati, zaključak (kada je primjenjivo) - ne duži od 100 – 250 riječi i ključne riječi (ne više od 8), na engleskom i hrvatskom.

Ako potpuni bibliografski podaci o citiranim djelima nisu navedeni u bilješkama (fusnotama), autor je dužan na kraju teksta navesti popis citirane literature s potpunim podacima o navedenim djelima.

Grafikoni, tablice i slike u pravilu se prilažu unutar teksta na mjestu gdje trebaju biti prikazani. Unutar priloga trebaju biti povećani na čitavu stranicu i posjedovati adekvatnu razlučivost (poželjno 300dpi). Svaki grafikon, tablica i slika trebaju biti numerirani i imati naslov. Ukoliko su preuzeti, izvor mora biti naveden. S obzirom na jednobojni tisak, svi grafički prikazi trebaju biti monokromatski ili u nijansama

sive, imati bijelu podlogu i biti izrađeni u programu MS Office. Pismo korišteno u slikama i grafičkim prilozima treba biti Arial.

Uvriježeni strani izrazi, uključujući nazive dokumenata i institucija na stranom jeziku pišu se kurzivom – npr. *de facto*. Sva naglašavanja u tekstu vrše se **podebljanim slovima**. Podvlake se u tekstu ne koriste.

Datumi se navode na sljedeći način: 1. srpnja 2014. Brojevi kojima započinje rečenica i aproksimativni brojevi izražavaju se riječima – stotina, tisuću, milijun i sl. Decimalno mjesto odvaja se isključivo zarezom (npr. 621,57), a tisućice jednim razmakom (1 532 ili 10 589 163). Statistički izrazi pišu se cijelim decimalnim brojevima (npr. $p < 0,05$).

Prilikom prvog pojavljivanja izraza koji se krati, potrebno je navesti izraz u cijelosti, a kraticu definirati u zagradama. Potrebno je uvažavati standardne kratice i pravila skraćivanja.

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[za knjigu] Tristram H. Engelhardt, *The Foundations of Bioethics*, University Press, New York 1986., str. 72.

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[za članak iz časopisa] Roberto Andorno, »The Oviedo Convention: A European Legal Framework at the Intersection of Human Rights and Health Law«, *Journal of International Biotechnology Law*, 2 (4/2005.), str. 135.

[za članak iz zbornika ili poglavlje iz knjige] Diego Gracia, »History of medical ethics«, u: Henk Ten Have i Bert Gordjin (ed.), Bioethics in European Perspective, Kluwer, Dordrecht 2001., str. 34.

[za literaturu u elektroničkom obliku] http://www.legalhelpmate.com/health-care-directive-patient-act.aspx (16. lipnja 2009.)

[za institucijske publikacije] Državni zavod za statistiku (2006). *Statistički ljetopis 2006.*, Državni zavod za statistiku, Zagreb.

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