I.
Vulnerable groups

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The role of Patient Autonomy and Informed Consent for equal access to healthcare: A conceptual inquiry of contemporary bioethical debate

Abstract
In contemporary, increasingly interdisciplinary discourse, so-called »patient autonomy« has been emphasized as a moral as well as a legal right of any individual affected, commonly resulting in autonomy understood as a justified claim to make decisions on grounds of provided information within the encounter between physician and patient. The focus on the pragmatic implementation of such concepts through standardization – »best practice« – has contributed to the increasing relevance of terms like »patient choice« and »informed consent« in contemporary bioethics. In order to ensure their normative force in practice of public healthcare, these concepts have been strongly linked to juridical, political and sociological inquiry and measures. Based upon the assumption that the protection of patient autonomy cannot happen successfully and comprehensively without the awareness of their underlying roots, normative dimensions and limitations, these notions are re-assessed on a conceptual level, resulting in an alternative understanding of autonomy and minority groups.

1. Introduction

The rising significance of a notion of autonomy in the context of bioethical debate referred to as »patient autonomy« and its implementation as a well-entrenched ethical principle for so-called »best practice« in public healthcare are undeniable developments. Drawing back upon ideas to strengthen any individual's free choice in healthcare practice and research, seeking to protect patients against involuntary

treatment, this understanding of autonomy has become strongly linked to decision making procedures with an emphasis on »patient choice« and the idea of »informed consent« to ensure its realization in medical practice with the aid of legal authority. The increasing overlap of differing normative implications tied together in the same expression, namely »autonomy«, is a result of growing demands of a more complex and interdisciplinary environment and as such a phenomenon that was to be expected. However, problems arise as soon as conceptual roots and limitations disappear not only in pragmatic debate on the implementation of ethical principles, but go unnoticed even in scholarly debate on patient autonomy, aiming at improving issues of discrimination and injustice in public healthcare. Applying a concept like autonomy as *terminus technicus* in a highly specific or stipulative way only, linking it to other notions or even individual requirements, could result in inadvertent effects on the attempt to improve equal access to healthcare. Therefore, in this work, the problematic link between patient autonomy, patient choice and informed consent on the basis of abilities to process information and participate in rational decision making has been of particular interest. Besides, the tension between individual patient autonomy and requirements of public healthcare, often relying upon generalizable and standardized approaches, has been identified as another problem to be discussed. Lastly, the assumption that informed consent and patient autonomy in their current understanding as entrenched ethical and legal principles are always suitable means to protect every individual and ensure justice and equality in public healthcare is challenged by possible disadvantages they might bring about, resulting in an alternative definition of minority groups. Overall, this study aims to re-assess the conception of autonomy by exploring its various normative dimensions, the development of its usage up to the present day and possible links to other notions across several disciplines, countries and scientific inquiries. Emphasis has been laid upon the comparative evaluation of two main branches in medical ethics defending differing views on autonomy. In identifying and discussing these opponent perspectives, conceptual roots of the term are traced back to Kantian philosophy and a notion encountered less frequently in contemporary bioethical debate. Finally, underlying premises and implications of both stances are carefully examined with regard to possible effects on equality and access to healthcare, illustrated by means of selected examples.

For this purpose, an evaluation of international and interdisciplinary discourse on (in)equality in the context of healthcare, social diversity and minority groups has been conducted, whose procedural details will be explained in part 2 (Methods and Materials). Relevant research literature has been selected and analyzed based upon the following research questions, which will be re-addressed in part 3 (Results): (1) Which methods have been employed in order to survey (un)equal access to public healthcare, and which areas of expertise or subjects of examination have been central for conducting these inquiries? Is there a certain systematic order which could be identified? If so, how have concepts, definitions and terms been applied in the resulting categorization of research? (section 3.1.); (2) Based upon which criteria, e.g. certain features or traits of individuals, has contemporary research on social diversity and minority groups as well as discrimination in healthcare mainly been conducted? As one aim of this study is to accentuate the conceptual links of »patient autonomy« and »informed consent« with pivotal notions in research on minority health and social diversity, the understanding and application of these two concepts is examined against this backgroundand thus embedded into the broader topic of this book (section 3.2.); (3) If the conception of »patient autonomy« has been incorporated into research on social diversity and minority health, how has it been defined, which normative ideas are carried over – and what implications for individual and public healthcare could eventuate, especially with regard to (in)justice and equality? It will be demonstrated that there is a predominant understanding of patient autonomy stronlgy linked to the idea of informed consent in contemporary bioethical debate,mostly emanated from Anglo-American discourse in social sciences and related research areas (section 3.3.1.). This stance, which represents the results of a systematic and international literature review, is contrasted by a different notion, drawing back on conceptions of autonomy according to Kantian philosophy (section 3.3.2.), which is expanded to questions of medical care in the selected material. In the following part 4 (Discussion), the results of this contrastive evaluation are applied to the individual medical encounter between patient and physician first – it is illustrated how and in which way current understandings of patient autonomy could even contribute to inequality and exclusion in certain cases (section 4.1.), thus introducing a different definition of minority groups (section 4.2.). After extending the findings to systematic problems of injus-

tice and discrimination in public healthcare (section 4.3.) and a critical evaluation of the threats just as the undeniable importance of informed consent requirements (section 4.4.), possible limitations of this work and its methodology are provided to the reader in part 5. In the final part (Conclusion), the strong appeal to re-assess fundamental normative concepts like autonomy is reinforced by consolidating the main findings of this work in a condensed and concise summary.

2. Methods and Materials

Methods of this work include both systematic literature review in order to identify and present predominant stances in contemporary bioethical discourse and an additional non-systematic evaluation of several opponent perspectives in order to re-assess concepts, terms and definitions by means of a contrastive, comparative analysis.

2.1. Systematic literature review

In order to identify a corpus of textual material representing the predominant stances on the research questions formulated above, a systematic literature search was conducted in the electronic databases Pubmed, Embase, SpringerLink and Wiley Online Library in a two-step procedure, following the guidelines set forth by the Preferred Reporting Items for Systematic Reviews and Meta-analysis (PRISMA 2020). For this purpose, several key words in accordance with the subject of this work had been established, as detailed in Table 1. Based on the two core keywords and additional keywords strongly related to the thematic focal point of the book, here defined as »contextual keywords« or »contextual search strings – stage I«, a large corpus of central texts was identified in a first step. Following an initial reading phase and overview, the search scope was augmented by identifying further search strings as listed in »contextual search strings – stage II«, which appeared most frequently in the literature resulting from the primary search. This way, the usage of the core keywords within the context of social diversity and public healthcare could be examined more comprehensively. The key words were joined by either »AND« or »OR«.

Stage	Algorithm
Core keywords	*»autonomy« (Title/Abstract) AND/OR »informed consent« (Title/Abstract)*
Contextual search strings – stage I	*»minority group*" (Title/Abstract) AND/OR »social diversity« (Title/Abstract) AND/OR »public health care« (Title/Abstract) AND/OR »injustice« (Title/Abstract) AND/OR »justice« (Title/Abstract)*
Contextual search strings – stage II	*»minority health disparit*« (Title/Abstract) AND/OR »medical ethics« (Title/Abstract) AND/OR »ethical tool*« (Title/Abstract) AND/OR »decision making« (Title/Abstract AND/OR »beneficence« (Title/Abstract) AND/OR »paternalism« (Title/Abstract) AND/OR »patient choice« (Title/Abstract)*

Table 1: Search algorithms for the systematic literature search

For inclusion in the initial comprehensive literature review, articles needed to meet the following criteria: 1) abstract available in English or German language, 2) free full text available, 3) date of publication between 1970 and 2022, 4) at least one keyword in either title or text. Articles were excluded if they did not meet the stated inclusion criteria. Thus, a primary corpus of research literature was identified with a total of more than 8000 works, not limited to a specific area or country and therefore including American or English literature as well as works created in Germany or other EU countries, including both qualitative and quantitative research, ranging from the 1970s to having been published only recently in 2022. Research conducted within the last two decades was of particular interest. After a digital screening of the contents for a combination of certain keywords,

e.g. the combination of the keyword »autonomy« or »informed consent« with the keyword »minorities« in title or text, the resulting material could be further reduced in size. In total, 2266 texts available in the databases were identified this way. Based on an even more specific content screening for inclusion of additional keywords as presented in table 1 and after the elimination of a huge data redundancy caused by works appearing in multiple databases, a total of 234 full texts and linked bibliographical data were imported into MAXQDA 11 for textual analysis. Relevant text passages were labelled with coding that was generated deductively and inductively. Publications on patient autonomy or informed consent combined with an inquiry on social diversity and minority groups have been preferred in the final selection process in order to keep a strong thematic link to the topic of the book, i.e. social diversity and access to healthcare for minority groups. Finally, based on these criteria and various search procedures, a number of 89 works which appeared to be most significant and cover predominant stances without redundancy was selected to be examined and evaluated manually with due regard to the research questions formulated above, meant to represent the main contemporary understanding of autonomy and informed consent in the context of medical healthcare.

2.2. Non-systematic documentary evaluation

As this work not only aspires to provide an overview of predominant international perspectives on the research questions formulated in the introduction, accessible via systematic literature search in online databases, but constitutes a contrastive conceptual inquiry, not all positions cited in the following parts have been obtained via systematic literature review procedures. A non-systematic documentary evaluation was preferred as an additional methodological approach for representing perspectives rarely discussed in international bioethical discourse, not open to systematic review procedures due to the limitedamount of eligible material.. But not solely the notably small number of texts defending other stances did advise against an exclusively systematic literature review, suggesting this additional methodological approach. Instead, it was deemed necessary for the conduct of a conceptual inquiry and comparative evaluation

whose aim was to identify similar notions appearing in various contexts, likely to differ in terms, understanding and application. Relevant research material applying diverging terms whilst nonetheless referring to genuinely similar underlying notions might have gone unnoticed in a purely systematic search procedure. This applies specifically to the notion of autonomy according to Kantian philosophy, which could only be portrayed using a small sample of Continental research literature. The material evaluated for this purpose has been selected manually in order to contrast more common understandings of »patient autonomy« in the field of applied ethics (especially when linked to questions of social justice and equality). Material for this part of the literature evaluation has been selected according to the four criteria of documentary research suggested by John Scott,[1] with an emphasis on the criterion of representativeness and on the criterion of meaning (being understood as a comprehensive hermeneutical approach, allowing the researcher to draw conclusions as interpretation of both analysis of text/style and content). In total, 14 positions cited are not covered by the systematic literature analysis conducted in the databases. These works were chosen manually because they were either judged to constitute significant opposing stances in comparison with the results of the systematic literature analysis, or as they appeared to add new perspectives to the controversies discussed in part 4 (Discussion).

3. Results

3.1. Overview of research literature and categorical evaluation

As a result of the overall examination of the corpus of literature with regard tocore questions of inquiry, aims and methods employed, three different levels of research and their respective features of methodological approaches could be identified.

[1] John Scott: A matter of record: documentary sources in social research. Cambridge 1990.

3.1.1. Level one: implementation, concrete observation, evaluation

On this level, research is directed to evaluating the concrete benefits and/or issues of particular implementations and healthcare practices observable. In the context of social diversity and medical ethics, this inquiry could, for example, lead to examinations on whether so-called ethical consultants are able to improve healthcare by supporting encounters with the aid of ethical frameworks.[2] A large area of research on this level is committed to investigating how certain features of social diversity, e.g. gender/sex, are likely to influence treatment in a particular setting and according to well defined criteria.[3] Methods include both empirical approaches as well as qualitative methods, e.g. interviews. In this work, level one research comprises not only investigations into individual encounters between physician and patient, but also addresses institutional and governmental measures, e.g. so-called »organizational ethics«[4] or the evaluation of EU legislation in order to systematically improve equality and access to public healthcare,[5] such that the subject of examination is a concrete and particular question which is related to practice.

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[2] Chris Kaposy, Fern Brunger, Victor Maddalena, Richard Singleton: The use of ethics decision making frameworks by canadian ethics consultants: A qualitative study. In: Bioethics 30 (2016), pp. 636–642.

[3] Florence D. Mowlem, Mina A. Rosenqvist, Joanna Martin, Paul Lichtenstein, Philip Asherson, Henrik Larsson: Sex differences in predicting ADHD clinical diagnosis and pharmacological treatment. In: European Child and Adolescent Psychiatry 28 (2019), pp. 481–489.

[4] Christiane Burmeister, Robert Ranisch, Cordula Brand, Uta Müller: Organisationsethik in Einrichtungen des Gesundheitswesens. In: Ethik in der Medizin 33 (2021), pp. 153–158; Patrick Schuchter, Thomas Krobath, Andreas Heller, Thomas Schmidt: Organisationsethik: Impulse für die Weiterentwicklung der Ethik im Gesundheitssystem [Organizational ethics: Impulses for the further development of ethics in the healthcare system]. In: Ethik in der Medizin 33 (2021), pp. 243–256.

[5] Marcin Orzechowski, Marianne Nowak, Katarzyna Bielińska, Anna Chowaniec, Robert Doričić, Mojca Ramšak, Paweł Łuków, Amir Muzur, Zvonka Zupanič-Slavec, Florian Steger: Social Diversity and access to healthcare in Europe: how does European Union´s legislation prevent from discrimination in healthcare? In: BMC Public Health 20 (2020), https://doi.org/10.1186/s12889-020-09494-8.

3.1.2. *Level two: meta level – underlying mechanisms, dynamics, interactions*

Research conducted on this level is committed to questions, measures and subjects of study which presumably highly affect practical healthcare patterns and are linked to problematic dynamics, but are not directly measurable and accessible; e.g. studies examining patterns and elements of health communication[6] or studies on judgment and decision-making in the context of medical decision making,[7] supposed to bring about a better understanding of how certain mechanisms come to play, interact and actually affect the settings in which discrimination could occur. In recent works, the attempt to detach conceptions like discrimination from highly specialized fields of inquiry like e.g. gender health disparities is made by means an extension to more general concerns of health and equality in medical practice.[8] The conceptual level is of relevance for this type of research; however, concepts are appropriated according to the inquiry and its aims, such that, e.g., the examination of communication in the context of possible biases[9] is not touching the concept of communication and its dimensions, limitations and different understandings in general. On this level, research becomes increasingly interdisciplinary in both methods and materials, which can be regarded as a result of the demands of the subject of examination. This tendency is accompanied by major effects on the terminology as well as underlying conceptual dimensions of scientific works: concepts from one area are made use of in order to assess or even legitimize another. Methods tend to include empirical research, data evaluation or systematic analysis. So-called evidence-based approaches and quantifiable features are of major relevance in the first place, whilst conclusions on a more abstract

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[6] Neda Ratanawongsa, Benyam Hailu, Dean Schillinger: Health Communication as a Mediator of Health and Healthcare Disparities. In: Irene Dankwa-Mullan, Eliseo J. Pérez-Stable, Kevin L. Gardner, Xinzhi Zhang, Adelaida M. Rosario (Eds.): The Science of Health Disparities Research. First Edition. Hoboken 2021, pp. 339–358.

[7] Robert M. Hamm: Medical Decision Scripts: Combining Cognitive Scripts and Judgment Strategies to Account Fully for Medical Decision Making. In: David Hardman, Laura Macchi (Eds.): Thinking: Psychological Perspectives on Reasoning, Judgment and Decision Making. Hoboken 2003, pp. 315–345.

[8] Maximiliane Hädicke, Claudia Wiesemann: Was kann das Konzept der Diskriminierung für die Medizinethik leisten? [What can the concept of discrimination provide for medical ethics?]. In: Ethik in der Medizin 33 (2021), pp. 369–386.

[9] Ratanawongsa, Hailu, Schillinger: Health Communication (Note 6), here p. 346.

and conceptual level are rather inferences from the phenomenon observed. Otherwise, terms and definitions are made use of in a technical and pragmatic way in order to conduct the examination according to relevant determinants and salient features, c.f. the not otherwise specified notion of »trust« as a key element within the identification of relevant components of successful communication.[10]

3.1.3. Level three: conceptual level – re-assessing concepts, terms and definitions

Works in the context of social diversity and public healthcare which address the underlying terms, definitions and concepts applied within research conducted on level one and two could be categorized as »conceptual inquiry« of research. In contrast to the aforementioned types of research, concepts, definitions and terms, their contextual relations and their application in the sciences, methodologically as well as regarding their normative implications, are themselves subject of inquiry. Differently put, assumptions necessary to conduct research on level one or two are not taken as starting points for other, more specific inquiries, nor are they to be inferred after the collection of data – instead, they are re-assessed by means of an inverse analytic procedure. Not the question how a certain inquiry could be carried out in an effective manner and according to already established premises and goals of evaluation is central to the examination, but the question what underlying notions are subject to most inquiries, in which aspects they differ from one another, make use of same terms and which implications they thereby involve. Consequently, these works are highly sensitive to otherwise – necessarily so – neglected dimensions of concepts and terms applied, questioning their implicit semantic and genuinely normative content as well as possible effects on research conducted on level one or two. They thus serve as a potential corrective and reflexive means to complete, support and accompany other research. This article aims at conducting a level three examination of relevant notions, dimensions and implications of »autonomy« and »informed consent«, first as applied within the medical encounter, then with special regard to research on public healthcare and minority health disparities. For this purpose, selected literature which could be attributed to level three research will be

[10] Ratanawongsa, Hailu, Schillinger: Health Communication (Note 6), here p. 341.

discussed in the scope of the work, partly with the aid of evaluation of research work conducted on level one or two.

3.2. Research on Social Diversity and Minority Health: The relevance of Patient Autonomy and Informed Consent

Research on social diversity and minority health in the context of public healthcare primarily challenges questions of justice and equality regarding the distribution of access to medical care, its quality and possible disparities. On the basis of what has been defined as, for instance, »social diversity«, »minority groups« or »minority health«, these inquiries on possible inequalities grounded their most eminent determinants in individual, so-called socially salient features, which have been identified as socioeconomic status, geographic aspects, ethnicity or race in the past.[11] Similarly, in recent debates on health disparities, socially salient features like race and ethnicity, gender identity and sexual orientation and religion or belief are highlighted and examined with regard to their correlation with unequal access to public healthcare.[12] In order to investigate, measures on a national level, e.g. through the American National Institute on Minority Health and Health Disparities,[13] the European legislation[14] or institutional measures[15] have been subject to such examinations with the above mentioned terms and features serving as relevant criteria according to which a systematic analysis could be conducted. Research on these questions, aiming at bringing about a better understanding and detection of relevant features, patterns, and dynamics, could be

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11 Eliseo J. Pérez-Stable, Jennifer Alvidrez, Carl V. Hill: Definitions, Principles, and Concepts for Minority Health and Health Disparities Research. In: Irene Dankwa-Mullan, Eliseo J. Pérez-Stable, Kevin L. Gardner, Xinzhi Zhang, Adelaida M. Rosario (Eds.): The Science of Health Disparities Research. First Edition, Hoboken 2021, pp. 1–2.

12 Orzechowski, Nowak, Bielinska, et al.: Social Diversity (Note 5), here p. 1.

13 Pérez-Stable, Alvidrez, Hill: Definitions, Principles (Note 11), here p. 1.

14 Orzechowski, Nowak, Bielinska, et al.: Social Diversity (Note 5).

15 Robert Ranisch, Annette Riedel, Friedemann Bresch, Hiltrud Mayer, Klaus-Dieter Pape, Gerade Weise, Petra Renz: Das Tübinger Modell der »Ethikbeauftragten der Station«: Ein Pilotprojekt zum Aufbau dezentraler Strukturen der Ethikberatung an einem Universitätsklinikum [The Tübingen model of the »ethics delegate of the ward«: A pilot project to set up decentralized structures for ethics advice at a university hospital]. In: Ethik in der Medizin 33 (2021), pp. 257–274.

attributed to what has been referred to as level one or level two research, oftentimes making use of empirical evidence, qualitative interviews and systematic analysis. »Social minority groups«, as a first conclusion, have first and foremost been defined by sociologically salient features and, on the grounds of these, they are *eo ipso* regarded as threatened in maintaining their autonomy: in the context of healthcare by either other individuals, institutional or governmental restrictions, or the medical professional, who is portrayed as a potential source of paternalism by design and *ex professo*. With regard to medical ethics and healthcare, it is especially the concept of so-called »patient autonomy« which has received wide ranging attention from international and interdisciplinary discourses. »Patient autonomy«, in this context, is commonly defined as constrained power to exert influence within a treatment or decision making process; it is rarely subject to examinations itself, but serves as a component that shall be increased in order to enable access to proper healthcare, avoid unnecessary or inadequate treatment as well as discrimination by institutions or medical professionals. In their work, Moulton and King[16] are referring to the study once conducted by J. A. Glover,[17] which is identifying the »(...) current chief medical officer (...)«[18] of a certain public health region as »the only significant predictive facto[r]«[19] for healthcare disparities detected in the context of the study – aside from socioeconomic well-being. Additionally, evaluating another study on geographic disparities,[20] they summarize that »(...) physician recommendations (...) to the patient were major driving forces of these variations, rather than clinical need or patient preference.«.[21] Based on this, they proceed to claim that:

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16 Benjamin Moulton, Jaime S. King: Aligning Ethics with Medical Decision-Making: The Quest for Informed Patient Choice. In: The Effects of Health Information Technology on the Physician-Patient Relationship. In: Journal of Law, Medicine and Ethics 38 (2010), pp. 85–97.

17 J. Alison Glover: The Incidence of Tonsillectomy in School Children. In: Proceedings of the Royal Society of Medicine 31 (1938), reprinted in: International Journal of Epidemiology 37 (2008), pp. 9–19.

18 Moulton, King: Aligning Ethics (Note 16), here p. 85.

19 Moulton, King: Aligning Ethics (Note 16), here p. 85.

20 John E. Wennberg, Alan Gittelsohn: Small Area Variations in Health Care Delivery: A Population-Based Health Information System Can Guide Planning and Regulatory Decision Making. In: Science 182 (1973), pp. 1102–1108.

21 Moulton, King: Aligning Ethics (Note 16), here p. 85.

> As a result, over the last three decades, medical ethicists have shifted from guiding physicians to focus on beneficence and improving patient health (...) toward a more subjective and patient-centered' practice, which also prioritizes patient autonomy in medical decision making.[22]

In contemporary bioethical and sociological discourse, any patient's autonomy is widely regarded as a highly desirable and morally required, yet still unduly omitted basis of their right to be treated equally – in comparison to either other patients, or within a strongly hierarchical medical encounter.[23] Patient autonomy thus not only serves as a legitimate basis for claims to equal access but is also regarded as manifestation of an equal and just public healthcare system on an individual level: In such a system, patient autonomy could unfold without restrictions and limitations imposed on said autonomy, e.g. by systematic or individual discrimination. Furthermore, patient autonomy is frequently interpreted as individual freedom and independence within a community, finding expression in not only right to participation but even relative power in decision making, in particular within the medical encounter.[24] Patient autonomy is, moreover, discussed as an individual capability which needs to be proven, exercised and increased in order to improve equality and care for the individual affected – resulting in the vague yet complex notion of so-called »informed consent«,[25] which will be of major relevance for this work. Stavroula Tsinorema notes that: »The idea of ›informed consent‹ is well entrenched in medical care (...) and forms an outstanding feature of bioethical reasoning. It is taken to signify a paradigm shift from a discredited model of medical paternalism in medical ethics.«[26] This way, patient autonomy has mainly been captivated in its active and relative dimension in the context of decision-making procedures from the perspective of either patient or physician.

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22 Moulton, King: Aligning Ethics (Note 16), here p. 85.

23 Mark Sullivan: The New Subjective Medicine: Taking the Patient´s Point of View on Health Care and Health. In: Social Science and Medicine 56 (2003), pp. 1595–1604.

24 Moulton, King: Aligning Ethics (Note 16), here p. 86.

25 Moulton, King: Aligning Ethics (Note 16), here p. 86.

26 Stavroula Tsinorema: Consent and autonomy in contemporary Bioethics. In: Annuaire International Des Droits De L'Homme 8 (2016), pp. 229–244, here p. 233.

3.3. The concept of Patient Autonomy: Terms, definitions and normative claims

In the course of the literature analysis, differing notions of autonomy appearing in the specific context of healthcare as »patient autonomy« could be attributed to one of the two general conceptions elaborated below.

3.3.1. Autonomy as individual right to rational decision making: defying paternalism

As Stavroula Tsinorema is highlighting in her work committed to more recent understandings of autonomy in medical healthcare and their reliance upon other notions and concepts: »Overall, in international documents there has been a gradual shift toward specification of detailed processes of consent and a close link to right-based discourse coupled with appeal to the principle of individual autonomy.«[27] This observation fits the hypothesis arrived at in this work after an analysis of research on the topic. The distinction between legal and moral dimensions is blurred, legal passages make use of the word referring explicitly to moral dimensions when justifying a decision and vice versa. Within this broad notion, patient autonomy is generally portrayed as a moral as well as a legal right and a justified claim to make decisions voluntarily and rationally after having beenprovided with all relevant information through an act or procedure summarized as »informed consent«. For the physician and the institution of healthcare, the act of obtaining such informed consent from the person treated is a legal obligation, with only few exceptions, e.g. emergency treatment or the loss of consciousness – which can challenge the motivation of both physician and patient to interact in a more immediate, genuinely interpersonal process. Indeed, as Moulton and King rightly criticize, in many healthcare settings »(...) legal informed consent requirements have reduced (...) to obtaining a patient's signature on a written form, which is rarely read and even less frequently understood.«[28] If, within this branch of research literature, problematic aspects of concepts like autonomy are discussed, they especially

[27] Tsinorema: Consent and autonomy (Note 26), here p. 232.
[28] Moulton, King: Aligning Ethics (Note 16), here p. 90.

address the controversy about how much information should be revealed to the patient so they can act autonomously, and under which circumstances, or to which degree, the disclosure of information is desirable and hence morally justified: »Health services research (...) reveals a consistent pattern of inadequate information disclosure and low patient comprehension and retention.«[29] In other cases, the possibility that a patient´s cognitive capacities are impaired enough to question the integrity of personhood and autonomy are discussed;[30] here, the immediate link to the ability to grasp, being informed and making decisions rationally is most obviously accepted as an implicit premise. Possible limitations of any individual's autonomy and the problematic results for patients in suspicion of lack of such capacity are already addressed.[31] In the context of medical settings in international medical ethics discourse, autonomy has additionally been directly related to so-called patient centered decision making or patient choice and even the notion of general beneficence, as opposed to otherwise dominant paternalism of physicians and maleficence.[32] However, the link between patient autonomy and beneficence as opposed to physician authority, or paternalism, is not consistently portrayed in research literature. Moulton and King, for example, claim that an inadequate amount of patient autonomy could pose a threat toward so-called beneficence: »Whilst the shift toward autonomy is well represented in the literature and ethical guidelines (...), physicians have yet to strike the ideal balance between absolute patient autonomy and beneficence.«[33] Within their work, they argue that too much disclosure of information would ultimately coerce the patient

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29 Moulton, King: Aligning Ethics (Note 16), here p. 87.

30 Rebecca S. Dresser: Life, Death and Incompetent Patients: Conceptual Infirmities and Hidden Values in the Law. In: Arizona Law Review 28 (1986), pp. 373–405; Rebecca S. Dresser, John A. Robertson: Quality of Life and Non-Treatment Decisions for Incompetent Patients: A Critique of the Orthodox Approach. In: Law, Medicine and Health Care 17 (1989), pp. 234–244; Ronald Dworkin: Life's Dominion. New York 1993, pp. 218–237.

31 Katrina Hauschildt, Raymond De Vries: Reinforcing medical authority: clinical ethics consultation and the resolution of conflicts in treatment decisions. In: Sociology of Health and Illness 42 (2019), pp. 307–326, here p. 315 and 319.

32 Kunal Bailoor, Thomas Valley, Chithra Perumalswami, Andrew G. Shuman, Raymond DeVries, Darin B. Zahuranec: How acceptable is paternalism? A survey-based study of clinician and non-clinician opinions on paternalistic decision making. In: AJOB Empirical Bioethics 9 (2018), pp. 91–98.

33 Moulton, King: Aligning Ethics (Note 16), here p. 85.

into making a medical treatment decision without the support of the physician and medical expertise, in which cases »(...) the pendulum has swung too far. The unmitigated rise of autonomy can result in the decline of beneficence.«[34] The two notions of autonomy and beneficence have also been described as conflicting in many cases from the perspective of clinicians and so-called »best practice«.[35] The relative »authority« of patient or physician has become the epicenter of a lively debate in the context of clinical decision making: As Katrina Hauschildt and Raymond De Vries portray within their work,[36] the alleged rivalry between »Patient vs. physician autonomy«[37] is seen as a huge issue, with physician authority, often equaled with physician autonomy, contributing to injustice because it supposedly reduces the autonomy of the patient. It is argued that, even in cases where ethical consultants are involved in solving ethical conflicts, they still tend to seek the expertise of clinicians and thereby reinforce medical authority, albeit in a far subtler way, into the encounter.[38] Thus, the increase of patient autonomy is still regarded as an effective and desirable measure for a just medical environment within most bioethical and sociological research literature. In case this approach is rejected, objections refer to hierarchical encounters by design and necessity, emphasizing possible outcomes if the role of the medical professional and their expertise were neglected: the underestimation of medical expertise and guidance could lead to overwhelm of patients not prepared and skilled enough to understand medical treatment options to the degree necessary for decision making.[39] Additionally, it is considered preferable for medical ethics to train physicians who are in charge and enabled to perform decisions *ex professo* in being virtuous instead of trying to limit their influence.[40]

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34 Moulton, King: Aligning Ethics (Note16), here p. 85; Ruth R. Faden, Tom L. Beauchamp: A History and Theory of Informed Consent. Oxford, New York 1986.

35 Hauschildt, De Vries: Reinforcing medical (Note 31), here p. 319.

36 Hauschildt, De Vries: Reinforcing medical (Note 31), pp. 307–236.

37 Hauschildt, De Vries: Reinforcing medical (Note 31), here p. 319.

38 Hauschildt, De Vries: Reinforcing medical (Note 31), here p. 317.

39 Hauschildt, De Vries: Reinforcing medical (Note 31), here p. 319; Sharon R. Kaufmann: Ordinary Medicine: Extraordinary Treatments, Longer Lives, and Where to draw the Line. Durham 2015.

40 Hauschildt, De Vries: Reinforcing medical (Note 31), here p. 319; Howard Brody: The Healer's Power. New Haven 1992.

3.3.2. Kantian autonomy as an inherent status sui generis

Whilst the focus of most recent and international research on the topic has been laid upon structural and generalizable measures after evaluating collective data and general tendencies, which resulted in fields like »organizational ethics«[41] or tools like »ethical frameworks«[42] applicable to medical decision making as a standard procedure, only few scholars have offered an alternative yet non-arbitrary perspective on ethical decision making and justice in healthcare by drawing attention to more direct, immediate and genuinely interpersonal concepts of high relevance for any doctor-patient relationship. Aside from virtue ethics, which can be re-assessed e.g. by means of Aristotelian concepts in a fruitful way ,[43] those approaches are mostly based upon Kantian ethics. Here, the aforementioned definitions and especially the strong link or even interdependence with concepts like informed consent are not denied; meanwhile, in contrast to the notion of autonomy explained in Section 3.3.1., they are not adopted as a premise or a conclusion to arrive at but discussed as possibly problematic. With regard to its social as well as individual dimensions, autonomy has largely been portrayed as an expression or requirement of individual freedom in the sense of independence and self-empowerment, almost exclusively without referring to genuinely social aspects. Thomas Sören Hoffmann, for instance, notes that: »›Autonomy‹ is one of the keywords of modern ethics and its orientation on the realization of freedom (...)«, subsequently stating that »(...) misunderstandings appear as soon as the original sense of ´autonomy´ as the rational self-legislation of human action is confounded with mere formal self-determination or even mere arbitrariness.«[44] In his work on autonomy, the Kantian notion including the dimension of limitation of individual autonomy, resulting from its essentially interpersonal nature, are elucidated and then applied to relevant examples within medical healthcare practice. The crucial question for him seems to be the relationship between autonomy and what he refers to as

[41] Burmeister, Ranisch, Brand, Müller: Organisationsethik (Note 4); Schuchter, Krobath, Heller, Schmidt: Organisationsethik: Impulse (Note 4).
[42] Kaposy, Brunger, Maddalena, Singleton: The Use (Note 2).
[43] Marcus Knaup: Virtues: foundations for medical ethics? In: European Journal for Person Centered Healthcare. 3 (2015), pp. 108–112.
[44] Thomas S. Hoffmann: On the Relation of Autonomy, Self-Determination and Arbitrariness. In: Imago Hominis 23 (2016), pp. 189–198, here p. 189.

the German equivalent of »care« (»Fürsorge«),[45] which ideally seeks to form a complementary and not competing concept in medical healthcare – especially being aware that individuals tend to heavily rely upon others in situations, in which they are seeking medical help and need treatment. Indeed, the quest for autonomy cannot be extended to public healthcare without questioning this premise of mere self-determination, and similarly its connection with other alleged requirements in order to be considered an autonomous living being. In her work, Stavroula Tsinorema adverts to complex underlying premises and problematic links, criticizing that:

> (...) Only where this capacity [note: the capacity to have a distinctive character and act out of a sense of identity with one's values (individuality)] exists over a continuous period of time (...) does one have the required abilities so as to claim a right for autonomy.[46]

Aside from the stipulation of autonomy as a legal or moral right on the basis of certain abilities (implying a dependency of autonomy on said abilities as a prerequisite), it is the disconnection of this idea from social dimensions which seems highly debatable in comparison with her own notion of autonomy. She thus proceeds to clarify that:

> (...) Kantian autonomy is not a ›value‹ or a ›right‹. Autonomy is necessarily attributed to the will of each and every moral agent, qua member of the human community. (...) Put differently, autonomy means responding to moral reasons. It is not merely an individual right or a value, but a structural feature of moral agency and is, as such, presupposed by all rights and duties. Rights stem from (moral) autonomy. (...) Kant does not ground moral requirements on some prior value, or some valuable feature to be found in other human beings. Rather, he turns the relation the other way round: something has value because it is morally required.[47]

This means, amongst other things, that individual autonomy cannot be thought without autonomy of others, for it is constituted by a shared moral endeavor to respect other beings in their autonomy, famously formulated as the Categorical Imperative in Kantian phi-

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45 Hoffmann: On the Relation (Note 44), here p. 191.

46 Stavroula Tsinorema: The Principle of Autonomy and the Ethics of Advance Directives. In: Synthesis Philosophica 59 (2015), pp. 73–88, here p. 80.

47 Tsinorema: The Principle (Note 46), here p. 82.

losophy,[48] and thus forms individual autonomy in relation to all other human beings.[49] Although this relational aspect sets limits for individual autonomy, it is therefore a genuinely social and interpersonal, not at all separating idea.[50] Autonomy is nonetheless an absolute, not a relative, individual status and an inherent property or, in Latin, »proprium«,[51] independent from abilities and capacity for performance – instead, it results from higher moral and shared principles, and every human being is an autonomous being qua member of the moral community.[52] Assuming that autonomy is indeed, as Kant put it, the ground of the dignity of human nature and every rational nature,[53] it seems even more problematic to couple dignity to aspects of so-called competence, control and voluntary rational decision making, additionally relying upon alternatives open to the individual having to perform the choice within the medical healthcare setting. This stance is contrasted by more comprehensive notions; e.g. by Jan P. Beckmann, who is clarifying that, according to Kantian conceptions, the capacity to make decisions rationally and thus be an autonomous being is an inherent property[54] which can be violated, just like human dignity – but which cannot be taken away, get lost or be considered decreased, even in the case of significant impairment and loss of decision making abilities.[55] Therefore, any human being is autonomous sui generis, instead of in possession of, more or less, autonomy; the autonomous decision is a manifestation of inherent autonomy and ought not to be confused with a prerequisite or requirement.[56]

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48 Immanuel Kant: Grundlegung der Metaphysik der Sitten [Foundation of the metaphysics of morals]. In: Akademie der Wissenschaften (Hg.): Immanuel Kant: Gesammelte Schriften [Collected Writings], AA Bd. IV. Berlin, here p. 450.

49 Jan P. Beckmann: Autonomie: Aktuelle ethische Herausforderungen der Gesellschaft [Autonomy: Current ethical challenges of society]. Freiburg, München 2020, here pp. 21–23.

50 Beckmann: Autonomie (Note 49), here pp. 21–23.

51 Beckmann: Autonomie (Note 49), here pp. 21–23.

52 Tsinorema: The Principle (Note 46), here p. 82.

53 Kant: Grundlegung (Note 48), here p. 436.

54 Beckmann: Autonomie (Note 49), here p. 21.

55 Beckmann: Autonomie (Note 49), here pp. 21–22.

56 Beckmann: Autonomie (Note 49), here p. 22.

4. Discussion

4.1. Patient Autonomy and Informed Consent in individual medical encounters

Two notions of patient autonomy and their links to so-called informed consent have been discussed above. The way in which especially the reliance of the latter upon the quest for »rational decision making« and the actual cognitive ability to do so could affect public healthcare in such a way that it possibly results in less equal access shall be illustrated by means of selected examples in this section. In the context of dementia, so-called advance directives based upon what is coined »precedent autonomy«[57] in the form of legal instructions or designating someone on behalf, a proxy, are seen as legitimate solutions to ethical questions of treatment options under certain conditions. However, as a measure of so-called post-competence seemingly ensuring self-determination and control of one's own life before loss or decrease of the ability to make choices rationally could occur, notions like precedent autonomy likewise reveal some limitations of underlying normative and philosophical grounds, e.g. regarding the idea of personhood, which is sometimes taken to be discontinuous on the basis of cognitive changes. In her work, Stavroula Tsinorema challenges such views and contrasts them with the Kantian notion of autonomy; as a conclusion, she states:

> (...) when obvious harm to the contemporary patient's well-being will be a consequence of the application of the advance directive, those making the decision ought to scrutinize carefully whether and to what extent the author of the directive anticipated and considered the effects now occurring. As Onora O'Neill puts it, quoting Bernard Williams, ›we should not put too much weight on the fragile structure of the voluntary‹.[58]

Whilst Stavroula Tsinorema is highlighting the necessity to re-assess the current situation through the perspective of the »author of the directive«, i.e. the »previously competent patient«,[59] thereby putting

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[57] Ronald Dworkin: Autonomy and the Demented Self. In: The Milbank Quarterly 64 (1986), pp. 10–14.

[58] Tsinorema: The Principle (Note 46), here p. 86; Onora O'Neill: Questions of Life and Death. In: The Lancet 372 (2008), pp. 1291–1292.

[59] Tsinorema, The Principle (Note 46), here p. 86.

less emphasis on the voluntary, represented by the current will or agreement of the patient, this stance is debatable and highly objected in other contexts. In a qualitative study on informed consent and its effect on research in the context of dementia,[60] the authors conclude that their inquiry on research ethics raises the question:

> (...) whether the current prevailing emphasis on the cognitive aspect of autonomous decision making, i.e., comprehension, may be too one-sided, and to what extent the ›volitional‹ aspect in giving consent should be given greater consideration.[61]

At first glance, this conclusion appears to be in direct opposition to what Stavroula Tsinorema is arguing for in her work cited above. And indeed, the aspect of the so-called voluntary dimension of autonomous decision-making is where both works essentially differ from one another. Yet, this observation ought to be examined more carefully than initially suggested: In essence, it is not the rejection or promotion of the voluntary which is crucial for the authors´ critique. Instead, both works coincide with regard to one misunderstanding of current notions and approaches to implementation of patient autonomy: that is, the generalized assumption that being autonomous is reliant upon cognitive competence and maintained by the ability to consent on the basis of information. As Stavroula Tsinorema puts it in her work on advance directives: »Moral autonomy does not involve empirical abilities to function independently, or lack of dependence on continuous medical intervention, or freedom from physical or cognitive deterioration«.[62] They thus both challenge the value and unquestioned application of conceptions like informed consent and their link to autonomy, albeit in a different way and for different reasons. In their qualitative study on informed consent and dementia mentioned above, the authors come to conclude that, whilst both demented patients as well as caregivers did not comprehend the information provided to them, with the latter being unaware of their incomplete understanding, and the demented individuals

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60 Holger Schütz, Bert Heinrichs, Michael Fuchs, Andreas Bauer: Informierte Einwilligung in der Demenzforschung. Eine qualitative Studie zum Informationsverständnis von Probanden [Informed consent in dementia research. A qualitative study on the information comprehension of subjects]. In: Ethik in der Medizin 28 (2016), pp. 91–106.

61 Schütz, Heinrichs, Fuchs, Bauer: Informierte Einwilligung (Note 60), here p. 92.

62 Tsinorema, The Principle (Note 46), here p. 86.

partly being aware of their inability to comprehend,[63] it seemed to be of less relevance for the demented persons to fully grasp the consent documents, and participation served as a coping strategy for dealing with their diagnosis.[64] Finally, they do see a threat for demented patients and other groups not deemed »competent« in the situation assessed to be systematically and by necessity excluded from research, and hence from possible progress on questions regarding the underlying illness and treatment options, stating that: »This might result in exclusion of dementia patients from research, as capacity for understanding and decision making are often equated with the ability for rational decision making.«[65] Consequently, this work illustrates how the tension between respecting every individual´s autonomy and dignity in an attempt to avoid unequal outcomes ought not always to be as obvious as it is e.g. within organ donation or similar allocation issues in public healthcare systems. Instead, questions of (in)justice and equal access to healthcare already arise within the context of research itself.

4.2. Re-definition of Minority Groups in the light of the findings

On the basis of the critical revision of autonomy and its links to informed consent, an attempt to re-define so-called minority groups is made. When Onora O´Neill scrutinizes: »If some persons are more autonomous than others, will informed consent procedures be more important for them? Or will they, on the contrary, be more important for those with limited autonomy?«,[66] there are two key aspects worthy of being considered in identifying minority groups which are entailed within these questions. As already stated, the stance that individuals can be more or less autonomous than others is rejected in this work; however, they can be able to act autonomously and live in coherence with their autonomy to a greater or lesser extent, dependent on themselves as well as their environment. Assuming that the integrity of any patient's autonomy is indeed not only the legitimization, but the teleological foundation for any other measure, e.g. legal

[63] Schütz, Heinrichs, Fuchs, Bauer: Informierte Einwilligung (Note 60), here p. 92.
[64] Schütz, Heinrichs, Fuchs, Bauer: Informierte Einwilligung (Note 60), here p. 92.
[65] Schütz, Heinrichs, Fuchs, Bauer: Informierte Einwilligung (Note 60), here p. 92.
[66] Onora O'Neill: Informed consent and public health. In: Philosophical Transactions of the Royal Society 359 (2004), pp. 1133–1136.

or institutional implementations in healthcare practice, and those patients supported by informed consent requirements in protecting their autonomy are supposed to form the majority, all others would, by logical necessity as well as according to conventional stipulations of discrimination or disadvantage, form the minority group a conclusion arrived at through this so-called »qualitative approach«. If informed consent procedures are indeed more important – as in: relevant – for some compared to others, which group can be identified as suffering from disadvantage or even systematic exclusion according to current understandings of autonomy and the partly hidden, premises already outlined above; i.e.: links between autonomy and cognitive abilities in decision making scenarios? Most commonly, constellations in which informed consent requirements are considered to be problematic instead of protective are summarized as »hard cases« in scholarly discourse, implying a comparatively small number of individuals affected in comparison to all other, »normal« or »easy« cases. This implicit assumption is rarely addressed; however, Onora O'Neill is clarifying that:

> The hard cases are numerous and intractable. Many patients cannot consent to medical treatment because they are too young, too ill, too disabled or too demented to understand the information that they would have to grasp to make an informed choice.[67]

She has thereby already outlined four out of various possible features, in coherence with the concept of social diversity and socially salient features in the context of decision making, which could prevent informed consent requirements to unfold their supposedly beneficent effect – given the premise of the capability to understand relevant information is accepted, and leaving many other possible features aside. Likewise, Jan P. Beckmann is emphasizing that the misunderstanding of autonomy as a capacity to make decisions rationally and participate in decision making procedures could result in questioning the autonomy of large groups of citizens, like e.g. young children, very ill or disabled individuals,[68] thereby criticizing a statement of the German Ethics Council from 2016 which defined autonomy essentially as capability to discuss and deliberately make decisions

[67] O'Neill: Informed consent (Note 66), here p. 1133.
[68] Beckmann: Autonomie (Note 49), here p. 22.

in their medical treatment.[69] The traits or circumstances mentioned above as unfavorable in the context of autonomy and decision making are not only vague, but partly even constitute causal factors to seek treatment in public healthcare institutions, e.g. regarding patients considered »too ill« to consent. Consequently, calling these constellations »hard cases« would render most cases »hard cases« – and the number of patients possibly affected by this requirement in a way which is likely to unfold negative effects on their treatment unexpectedly high. In fact, this approach to identifying individuals who are suffering from disadvantages due to consent requirements could lead to a quantitatively large group which can, but must not, be part of more common definitions of minority groups according to socially salient features like ethnicity, gender or belief which already contribute to problems of injustice and exclusion. Likewise, this approach to identifying individuals suffering from disadvantages due to consent requirements could lead to a quantitatively large group, e.g. all cognitively impaired and demented patients, which can, but must not, be part of those commonly regarded as »privileged group« e.g. for being well educated, wealthy and natives, possessing no socially salient feature in accordance with predominant definitions of social minorities. On the basis of a concept of autonomy dependent on informed consent, the identification of minority groups in public healthcare would yield a completely different result which is extremely hard to grasp or quantify at all.

4.3. Expanding the results to systematic problems of access to public healthcare

But which relevance do the notions of autonomy and consent discussed above and the way in which they differ from one another unfold for concrete medical healthcare practice and questions on justice, equality and social diversity or minority groups? The question of access to healthcare, especially public healthcare, and comprehensive notions of autonomy reconcilable with collective and social needs has been of minor interest in most research evaluated. And yet, it is especially the quest for any individual's autonomy in the form of

[69] Deutscher Ethikrat: Patientenwohl als ethischer Maßstab für das Krankenhaus [Patient welfare as an ethical standard for the hospital]. Berlin 2016, here p. 38.

so-called informed consent which is potentially in conflict with public healthcare and guidelines, rules or other measures which need to be generalizable and applicable for all individuals possibly affected. Or, as Stavroula Tsinorema puts it: »A large area where informed consent procedures cannot be validly invoked is that of public health, where policies address groups or the whole of the population. (...) Public health is an area where consent requirements have limited application.«[70] It thus seems adequate and necessary to examine the definition and application of notions like the link of autonomy with patient or individual choice and informed consent especially in the context of public health and social diversity: Which challenges does public healthcare research face with regard to patient autonomy and eliciting consent? Which challenges could these notions impose in comparison to contexts like decision making settings? Onora O'Neill claims that:

> During the past 25 years, medical ethics has concentrated largely on (...) the treatment of individual patients. This focus permits a view of medical provision as a (quasi-) consumer good, whose distribution can be or should be contingent on individual choice. The approach cannot be extended to public health provision.[71]

She proceeds to open up a strict distinction between so-called individualist vs. public healthcare:

> Most uses of theories of justice in public healthcare have addressed distributive issues, such as the just distribution of clinical care. Discussions of healthcare allocation decisions (...) are discussions of the just distribution of a good that can be made contingent on individual choice.[72]

The assumption that the personal medical encounter is so very distinct from public healthcare and can be treated and examined just as differently and independently shall be questioned, being specifically aware of the relational and interactive components of both: Just as there would be no individual autonomy without others constituting it, there could be no individual treatment environment without other patients, physicians and public healthcare. More important, however, are the implications resulting from such a claim for social diversity

70 Tsinorema: Consent and autonomy (Note 26), here pp. 6–7.
71 O'Neill: Informed consent (Note 66).
72 O'Neill: Informed consent (Note 66), here p. 1133.

in the context of public healthcare: The emphasis put upon so-called patient choice relies upon more than the hidden assumption that the patient is able and willing to make a choice within an already given medical encounter. First, the discussion of patient choice requires that said patient has been able to access healthcare institutions – and ideally a suitable one, according to their individual needs and preferences. As access to certain healthcare procedures is not evenly and equally distributed, as many studies already cited suggest, the patient's dependence on influential factors like e.g. socioeconomic, geographical or other resources is thus ignored in most discussions evolving around patient autonomy and patient choice in medical encounters without incorporating public healthcare backgrounds. Moreover, the term »individual choice« implies that treatment alternatives are known and open to the patient. In this context, it seems worth mentioning that in more recent and systematic research on possible sources and patterns promoting injustice, inquiries have shifted towards including aspects of knowledge, drawing back to conceptions of Miranda Fricker[73] and subsequent developments of notions like epistemic injustice.[74] In the case of testimonial injustice, it becomes obvious how defining injustice as undue neglect of a person in their »role as a knower« and their »capacity to contribute to knowledge« can lead to problematic conclusions for persons not considered cognitively competent. By arguing about any justified, proportional amount of »credibility« which can be attributed to a person who has to defend their position by rational arguments, these theories draw back on formerly criticized definitions of autonomy, relying on capability or competence. Hermeneutical injustice, on the other hand, can be a result originating in different patterns, cultural habits, or language; consequently, some individuals may not be sufficiently included into contemporary research and healthcare measures because of a lack of possibilities to express their suffering adequately, or the treating medical person being unable to interpret them adequately for various reasons. Through the concept of epistemic injustice, albeit not ideal in itself, the gap between individual medical encounters, systematic

[73] Miranda Fricker: Epistemic injustice: Power and the ethics of knowing. Oxford 2007.

[74] José Medina: The relevance of credibility excess in a proportional view of epistemic injustice: Differential epistemic authority and the social imaginary. In: Social Epistemology 25 (2011), pp. 15–35.

issues of discrimination and public healthcare is bridged comprehensively.

4.4. The significance of Informed Consent for justice in public healthcare: a critical revision

Tracing the historical origins of the requirement for informed consent, its roots can be detected in the Nuremberg Code shortly after WWII in 1947, where it is explicitly mentioned as a requirement in the context of research in order to prevent abuse of individuals in the name of research, putting emphasis on the dimension of the voluntary and the cognitive abilities to agree.[75] Despite all the flaws discussed above, the concept of autonomy just as the implementation of informed consent as part of public healthcare procedures are not to be rejected as a whole, as this could open the door for a different form of arbitrariness – being legitimized and exerted not only by individuals within particular encounters, but instead by legislation and governmental measures themselves. It is undebatable that the implementation of informed consent procedures as such have contributed largely to secure individual rights – and protect individual autonomy. The issues lie deeper, when it comes to how informed consent procedures are implemented into medical practice and which other notions they rely upon. Even if individual autonomy is a notion often misunderstood, and individual patient choice can prove to be problematic, it is essential especially for public healthcare decisions to not neglect such principles of »best practice« completely by idealizing contemporary moral ideas and social imaginary. Conceptions form and guide our interactions according to our ideas about ourselves, others finally what we consider good and right – impacting how we approach issues of justice in public healthcare system and according to which criteria we attempt to identify exclusion and discrimination. More precisely, if it has been a generally accepted and unquestioned duty to worship life as such, every kind of assistance in suicide seems eo ipso morally despicable, and individuals affected are prone to undertake harmful suicide attempts instead of seeking medical advice; and if e.g. binary

[75] Paul Weindling: The Origins of Informed Consent: The International Scientific Commission on Medical War Crimes, and the Nuremberg Code. In: Bulletin of the History of Philosophy 75 (2001), pp. 37–71.

ideas of sex and gender have as of yet fundamentally shaped not only our own ideas of ourselves, but also those of our environment and of being a part of society as human being, this understanding could just as well serve as an obstacle to tackling pre-existing injustice in the form of prejudices. In the context of social diversity and equal access to public healthcare, it seems admittedly counterintuitive to question a standardized approach to largely systematic dynamics contributing to injustice. This stance is well portrayed with Onora O´Neill's claim:

> Because there are no obligations to do the impossible (›ought implies can‹), informed consent cannot be ethically required for the provision of public goods [note: public health included]. (...) For example, clinical care itself has to be provided to standards and formats that are also largely fixed and uniform (...). The public provision of healthcare can reflect democratic process, and thereby certain forms of collective choice; but its basic structures cannot be geared to individual choice.[76]

This statement poses a striking example of how the claim for standardized implementations and procedures could contribute to consolidating pre-existing ideas about values, behavior and justice. Kristie Dotson, on this note, elaborates so-called third order exclusion as follows: »Third-order epistemic exclusion proceeds from the outside of a set of epistemic resources to throw large portions of one's epistemological system into question as a result of the goals of a given inquiry.«[77] In literature on public healthcare, for instance, discussions are extended to the question whether informed consent ought to be invoked and considered ethically valuable or even necessary at all. This stance is expressed by Onora O'Neill when she claims that:

> An adequate ethics of public health needs to set aside debates about informed consent and to consider the permissible limits of just compulsion for various types of public good. It will therefore gain more from engaging with work in political philosophy than with individualistic work in ethics.[78]

Above, Onora O'Neill is even arguing that issues of public concern ought not to be tackled by means of ethical inquiry, but instead examined under the guidance of political philosophy. However, con-

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76 O'Neill: Informed consent (Note 66), here p. 1135.

77 Kristie Dotson: Conceptualizing Epistemic Oppression. In: Social Epistemology 28 (2014), pp. 115–138, here p. 129.

78 O'Neill: Informed consent (Note 66), here p. 1133.

cerns of public health are not a question of tracking down »the permissible limits«, as what is permissible is not, by principle, morally justified – nor are they to be treated according to the premise »ought implies can«, which paradoxically argues for the consolidation of established dynamics if no easily accessible solution is in sight. Instead of rejecting concepts like autonomy and informed consent in the context of public health concerns, or rather: throwing large portions of our epistemological system into question as a result of the inquiry, the underlying normative grounds must be re-assessed and separated from other intentions and influential factors – especially as research becomes increasingly interdisciplinary. Whether »(...) informed consent procedures [are] required because they provide a degree of assurance that patients are not deceived or coerced in the course of clinical practice«[79] in every case is, indeed, questionable at best. In most literature examined which portrayed autonomy in accordance with or even as synonym with patient choice and the right to be informed and consent, underlying legal, institutional and political motivation and dynamics affecting the rise of this tendency in international and interdisciplinary discourse as well as on institutional level, independently from whether in support or in objection to this principle, have failed to be addressed. The underlying premise that implementations like e.g. ethical councils or law are not impacted by e.g. political, economic, institutional, e.g. accreditation, or other incentives note genuinely resulting from the quest to protect the individuals affected is rarely discussed. Yet, this assumption needs to be scrutinized carefully for every particular claim in question: For institutional as well as governmental measures or healthcare policies are meant as a means to an end – justice – and not a means in themselves.

5. Limitations

In order to contribute to research on public healthcare, social diversity and minority groups in a fruitful way, a short remark on the scope and the limitations as well as the aim of this work is considered advisable. With regard to the chosen methods and the selection process of relevant material, which has been conducted systematically

[79] O'Neill: Informed consent (Note 66), here p. 1133.

as well as non-systematically, it is crucial to clarify that this work does not claim to provide an exhaustive or even representative overview of research in these areas or the application and understanding of concepts like autonomy and informed consent across disciplines. The relevancy of the literature that has been chosen manually in order to contrast other stances has been subject to specific selection criteria which were deemed suitable for this inquiry; consequently, these works should be regarded as indispensable for illustrative purposes but non-comprehensive. The specific examples chosen in »Discussion« seemed qualified in order to unveil potentially problematic dimensions of the notion of autonomy in actual medical practice – and yet, they should not be considered the only relevant or even the most relevant scenarios, as views on this selection will differ. Furthermore, the concept of autonomy and its links to informed consent represent only few of many ideas highly relevant for equality in public healthcare and worthy of being re-assessed according to what was termed level three research – conceptual inquiry. At this point, it seems necessary to highlight that this work does not promote the prioritization of either kind of inquiry, e.g. level three research, over other ones. Instead, any possible competitive understanding of this categorization, which was supposed to serve as a helpful methodological frame for carrying out this study, is rejected. Overall, this work aspires to provide an alternative approach to questions of (in)justice in the context of public healthcare, rather re-assessing underlying and implicit normative concepts and claims than examining more specific dynamics in healthcare practice. Resulting in a different approach to identifying minority groups on the basis of a qualitative rather than a quantitative understanding, it could help to amplify the scope of pre-existing, undeniably valuable inquiry. Similarly, whilst the question of actual access to public healthcare is addressed within this work and unfolds enormous relevance within the examination of autonomy and informed consent, the definition has been extended to »adequate access« and »access to (adequate) healthcare/treatment options/decision making process«.

6. Conclusion

Scholarly debate on equality and prevention of discrimination in public healthcare flourishes in various fields of science, leading to a more interdisciplinary and pragmatic approach to questions of (in)justice as well as possible measures to determine, quantify and combat existing discrimination issues. However, this generally approvable tendency likewise poses unanticipated conceptual challenges, which could result in a problematic influence of well entrenched normative principles like patient autonomy and informed consent on healthcare practice. By affecting certain individuals negatively and in an inadvertent manner, they are thus introducing a new definition of minority groups, as has been elaborated in this work. The underlying concepts and terms in question, most notably autonomy and dignity, can be traced back to genuinely philosophical grounds. In an attempt to implement such notions in medical practice, they nowadays find their resonance in corresponding moral claims and legal rights, with the latter originally supposed as a means to protect the former. However, as disciplines and terms increasingly overlap and are made use of in order to examine issues like discrimination, otherwise necessary methodological combination does affect those concepts in their core aspects and understandings – such that, for instance, the line between informed consent and patient choice as a an ethically desirable procedure vs. a legal measure to protect either patients´ rights or physician and institutions becomes blurred and teleological aspects disappear behind investigations targeting at increasing efficiency. So, why is re-assessing autonomy and its links to informed consent in the context of social diversity and public healthcare crucial for further inquiry? First, the unreflected usage of complex terms like autonomy shall not serve to falsely imply a thorough normative ground in order to justify problematic behavior or structural issues, thereby consolidating already established dynamics especially difficult for so-called minority groups. Secondly, because direct links to informed consent could possibly exclude or at least negatively affect many patients systematically from either access to healthcare, research on their underlying illness, or, in the case of individual medical encounters, adequate access to treatment options. Lastly, it is philosophical investigation which ought to accompany more pragmatic and empirical inquiries, e.g. in the field of applied

ethics, in order to prevent any misalliance or even abuse of moral notions and conceptions. Therefore, scientific endeavours ought to take these fundamental normative implications into consideration whilst continuing to conduct research on level one or two, e.g. empirically based research in line with the so-called evidence-based medicine (EBM) movement in general. These branches of research do not pose any rivalry for conceptual inquiry, but ideally seek to complement one another in a wholesome way. When John Worrall, with regard to the relevance of empirical research, is stating that: »In order to start to resolve this mess, we need to go ›back to the basics‹; and that means turning to the philosophy of science«,[80] the same conclusion is held to be pivotal for inquiries on social diversity and minority groups in the context of public healthcare.

[80] John Worrall: Evidence: philosophy of science meets medicine. In: Journal of Evaluation in Clinical Practice 16 (2010), pp. 356–362, here p. 356.