This section aims to go beyond day-to-day issues in research ethics by considering their background theories and assumptions. The starting point of contributions can be in real-life questions and answers to them, but the main objective is to explore their historical and theoretical bases. For ideas and submissions, contact Tuija Takala at tuija-maija.takala@aalto.fi

Research Ethics and Justice: The Case of Finland

TUIJA TAKALA and MATTI HÄYRY

Abstract: This paper explores how Finnish research ethics deals with matters of justice on the levels of practical regulation, political morality, and theoretical studies. The bioethical sets of principles introduced by Tom Beauchamp and James Childress in the United States and Jacob Dahl Rendtorff and Peter Kemp in Europe provide the conceptual background, together with a recently introduced conceptual map of theories of justice and their dimensions. The most striking finding is that the internationally recognized requirement of informed consent for research on humans can be ideologically tricky in a Scandinavian welfare state setting.

Keywords: justice; bioethics; research ethics; Finland; autonomy; nonmaleficence; beneficence; precaution; subsidiarity; solidarity; responsibility; dignity; integrity; vulnerability; consent; welfare state

Bioethics and Mid-Level Principles

Bioethics in all its forms relies heavily on principles, understood as authoritative statements with prescriptive power. Some forms of professional ethics—medical ethics, nursing ethics, social work ethics, and the like—emphasize, instead, character forming and virtue education, but rules and ideals are still needed for clarity and reflection. Some aspects of healthcare ethics—understood as good governance of health-related services—are dominated by political negotiations, but even these negotiations are ideally guided by moral standards, and they normally generate rules and instructions for practical work. Environmental ethics, species ethics, and life ethics in general may claim values—as opposed to rules—as their foundation, but they have also produced and utilized the principles of biodiversity, precaution, stewardship, and many others. And research ethics has its origins in the Nuremberg code, a set of ten rules;[1] and was taken further by the Declaration of Helsinki, currently a set of 37 guidelines;[2] and by the Belmont Report, the starting point of principlism in contemporary bioethics, with its three basic ethical principles.[3]

The authoritative statements with prescriptive power in bioethics and its affiliated fields come in many guises. Lofty ideals concerning human life and its value, the proper arrangement of social and political life, and humanity's relationship with other kinds of entities (animals and plants, ideologies and religions) always provide the background premises of bioethical considerations.

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The end results of legal and policy discussions are often presented as advice ("It would be wise for you to do X and to avoid Y."), orders ("Do X, or else!"), and prohibitions ("Don't do Y, or else!"); or permissions and licenses ("Exceptionally, *you* are allowed to do Z.") and regulations ("You are allowed to do Z, provided that you follow certain specified guidelines."). For professionals, the guidance often takes the form of rules ("When in doubt, consult a colleague!") and principles ("A good healthcare professional respects the self-determination of patients.").

Arguably the most convenient tools in practical bioethics decision making are *mid-level principles*. These are *not* fundamental moral norms (which are too clumsy for real-life use), but *not* exactly-defined action-guiding rules or particular contextual judgments, either.[4] A set of mid-level principles is a checklist of concerns that need to be taken into account when important decisions regarding people's lives are made. The set does not necessarily give straightforward answers to problematic questions, but if it is a good fit for the culture in which it is applied, it can help professionals and their support personnel to reach conclusions that are acceptable to all those affected.

Three main sets of principles present themselves in the context of bioethics. The first set was expressed in *The Belmont Report* and then developed by Tom Beauchamp and James Childress.[5] According to this model, we should do good (*beneficence*), avoid causing harm (*nonmaleficence*), respect persons (*autonomy*), and act fairly and equitably (*justice*).[6] The second and third sets can be construed by observing criticisms against the pragmatic "American" approach.[7] Suggested principles in some quarters—the second set here—include *precaution* ("Do not launch hazardous new schemes unless they can be scientifically proven to be safe!"),[8] *subsidiarity* ("Do not interfere with the workings of lower-level operators if they can manage by themselves!"),[9] and *solidarity* ("Recognize your duty to share the burden of helping those in need in your community!").[10] And the third set, strongly influenced by religious thinking, introduces the principles of *dignity* and *vulnerability*.[11]

The principles in all three sets are interrelated. The beneficence of *The Belmont Report* is divided by Beauchamp and Childress into beneficence and nonmaleficence, and then united again in the other models under precaution or vulnerability, emphasizing the avoidance of harm. Subsidiarity is the expression of autonomy on an institutional level: federal or wider regional governments should not meddle in affairs that can be run by states or even smaller units in civil societies. Dignity and autonomy are in some philosophical theories thought to be two sides of the same coin. And the principles of solidarity and justice, and partly also dignity, all remind us to treat each other equally and humanely, although the stress may be on different aspects in different approaches.

In the following, research ethics in Finland is examined from the viewpoint of justice. Research ethics in Finland—its levels in practice and theory; its methods and applications; and its point(s) and justifications—is first described. Mid-level justice will then be clarified by comparisons with other principles; by an exploration of the varieties of mid-level justice; and by a juxtaposition of mid-level and fundamental moral and political deliberations. These preliminaries will lead to an inquiry into which considerations of justice are, and which are not covered by research ethics in Finland; and to some suggestions as to what more could be done to improve the coverage. The course of the considerations so far is summarized in Figure 1.

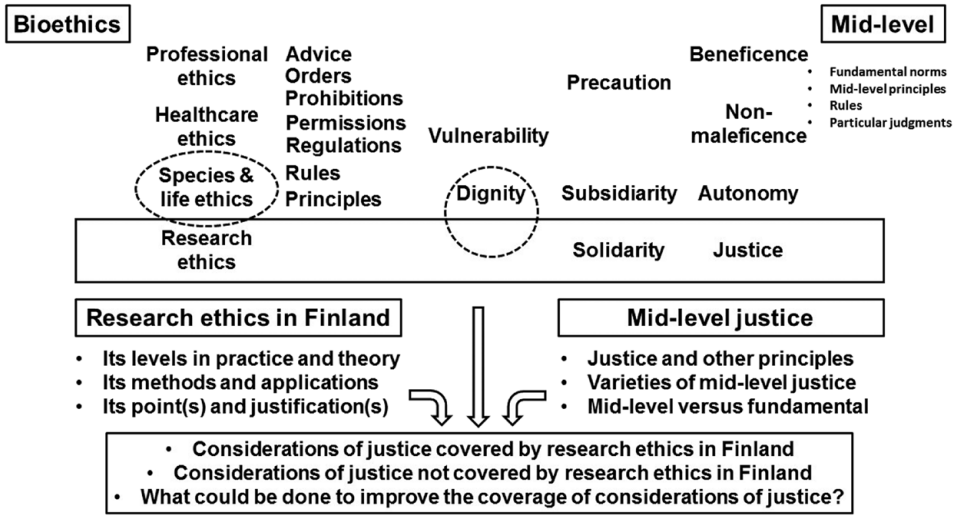

Figure 1. Bioethics, principles, and research ethics in Finland.

Research Ethics in Finland

Practical Regulation

Research ethics has developed in Finland hand in hand with international developments in the field.[12] The official institutional starting point of international research ethics is the *Nuremberg Code* (1947), widely ignored at first, but currently ranked among the most influential documents in biomedical ethics with the *Declaration of Helsinki* (1964), which can be seen as its successor. After the publication of the latter statement, bearing the name of Finland's capital city, civil servants, politicians, and the Finnish Medical Association gradually began to pay attention to the issues raised. A quarter of a century later, Finland commenced more explicit legislative changes that led to the establishment of the current national ethics boards. The interplay between national and international trends, motivations and actions in the creation of these boards has been examined in detail by Jukka Syväterä. According to his analysis, all countries that have founded national bioethics committees (there are over a hundred so far) have left their mark on the existing global model. Against commonly held belief, these nations have *not* just copied a ready-made international structure, but played, in a general spirit of progress and modernization, an active part in producing and shaping it.[13]

Ritva Halila, a recognized expert on Finnish ethics committees, has summarized neatly the goals and tasks of the national boards that had emerged by the beginning of the millennium.[14]

The *Finnish Advisory Board on Research Integrity* (TENK, founded 1991) monitors international developments, collects information on research ethics, gives expert opinions and promotes awareness of the issues among the scientific community and the general public, and makes initiatives in the field, including proposals to ministries and the government.[15] It has also issued instructions for responsible conduct in research and guidelines for handling allegations of misconduct.[16]

The *Advisory Board on Biotechnology* (BTNK, 1995)[17] "promotes communication between authorities and researchers in the field, follows the development of environmental effects and risk assessment, […] advances information and education in the field of gene technology [and] monitors and promotes international co-operation on biotechnology."[18]

The *Board for Gene Technology* (GTLK, 1995)[19] aims "to promote the safe and ethically acceptable use of genetically modified organisms, and to prevent and avert any harm this use may inflict on human health, animals, property, or the environment."[20] It is also the competent national authority in its field at the European Union level.

The *National Advisory Board on Social Welfare and Health Care Ethics* (ETENE, 1998)[21] "follows the development of healthcare and related technologies from an ethical point of view," "collects and shares information about ethics and international debate," "takes initiatives, issues statements and recommendations," and "initiates public discussion on ethical questions in healthcare."[22] Although this Advisory Board has an expert position in national healthcare legislation, legally binding national decisions do not belong to its remit.

The *National Committee on Medical Research Ethics* (TUKIJA), originally for eleven years the *Subcommittee on Medical Research Ethics* for the *National Advisory Board on Health Care Ethics* (also TUKIJA, 1999),[23] gained independent status through legislative changes in 2010.[24] It serves "as an expert on research ethics"; monitors, steers, and coordinates "the processing of issues related to research ethics"; releases "national opinions on clinical trials on medicinal products, unless the duties are delegated to regional ethics committees"; gives "opinions on previously rejected trial proposals to regional ethics committees where these are resubmitted unchanged"; issues "opinions on the conditions for establishing a biobank"; supports and coordinates "the activities of regional ethics committees regarding the procedures for requesting opinions and matters of ethical principle including provision of related training"; participates "in international cooperation on research ethics between authorities"; gathers and conveys "information on research ethics issues" and provides "information on the international debate on research ethics in the form of publications, training sessions and other such activities"; and promotes "public debate on medical [and] biomedical research."[25]

The *Animal Experiment Board* (ELLA, 2013)[26] was established, following changes in European Union regulations,[27] to authorize animal experiments in Finland. Other tasks related to animal welfare, previously covered by the *Co-Operation Group for Laboratory Animal Sciences* (KYTÖ, 2001–2010),[28] were at the same time taken over by the *Council on the Protection of Animals Used for Scientific and Educational Purposes* (TOKES, 2013).[29] The main responsibility of the Council is to promote the 3Rs—i.e., the principles of Replacement, Reduction and Refinement in animal experimentation and teaching use.[30]

Ethics committees and institutional review boards in Finland operate on many levels—university, hospital district, facility, and so on—and laws, common sense, and guidelines issued and training offered by the national bodies provide the foundations of their work. All medical research must be authorized by one of the six regional ethics committees in the country, overseen by the *National Committee on Medical Research Ethics*. All planned clinical drug trials have to be reported to the national committee, and it will then either process the proposal itself or assign

it to a regional committee. Interventional clinical drug trials require a notification to the *Finnish Medicines Agency* (FIMEA).[31] Animal experiments need a project license issued by one of the four sections of the *Animal Experiment Board* or, in case of disagreement, by the entire Board in their joint meeting; and a personal license confirming that the ones performing animal experiments are competent operators in the field.[32] The creation and use of genetically modified organisms require a notification to and an acceptance by the *Board for Gene Technology*. The notification and acceptance procedure is tailored for different cases: contained microorganisms,[33] plants,[34] and animals;[35] and field trials involving the release of the organisms into the natural environment.[36]

As an interesting detail, research on human embryos, an internationally debated practice, is not straightforwardly regulated in Finland. Embryos can, according to the *Medical Research Act*[37] be used, with the consent of the embryo or gamete donors, up until 14 days from their creation, which is on par with most international standards. An ambiguity is produced, however, by the definition of an embryo in the act as "a living group of cells resulting from fertilization not implanted in a woman's body." As notified by all the major national bioethics committees (TENK, ETENE, TUKIJA, KYTÖ, BTNK, and GTLK), this fails to account for embryos produced by the notorious nuclear transfer method (i.e., cloning), which means that "therapeutic cloning" and ensuing studies on nuclear transfer method embryos remain unaccounted for in Finnish law.[38]

Ethical review is required in Finland for research in social and behavioral sciences and the humanities, if the research in question interferes with the physical integrity of its subjects; does not operate on informed consent; involves minors in artificial settings without parental supervision; exposes subjects to particularly strong stimuli; may inflict severe mental harm; or threatens the security of its subjects. Additionally, the need for ethical review can arise externally, by the rules of funding bodies, institutional guidelines, or publishers.[39]

Theoretical Work

Ethical questions in medicine, healthcare, and biomedical research are studied in various ministries, usually in collaboration with universities and university researchers. They are also examined, often indirectly, by the personnel of the *National Institute for Health and Welfare*.[40] Investigations at the institute standardly concentrate on healthcare and social policy, especially their impact on well-being and existing inequalities. Some studies address issues in research ethics—like the recently completed project, *Ethical Review and Administrative Governance of Clinical Research*.[41]

Another potential hub for ethical studies in Finland in the future is the Finnish Institute of Bioethics, founded by young researchers at the University of Tampere in 2015.[42] The Institute aims at raising awareness about bioethics and biolaw in the country, and the academics associated with it are working on several ethics-related themes. Currently, the themes do not include research ethics, and other activities have so far been limited to dissemination of information.

The main operators in the field of theoretical ethics, bioethics, and research ethics are, predictably, university teachers and researchers. A search on the publication databases of Finnish universities turns up hundreds of articles, book chapters, and books on the topics. The search logics may vary, so no far-reaching

conclusions can be drawn from the figures, but Table 1 provides the raw results on some focal concepts in English (E) and in Finnish (F).

We followed this very elementary search up by a cursory content analysis of the publications found; by open-ended questionnaires to some of the key persons in bioethics and research ethics in Finland; and by a Google Scholar search and ensuing examination of the researchers whose work showed the most promise for our purpose, i.e., for finding contributions to bioethics or research ethics involving the concept of justice and related notions (equality, equity, solidarity, etc.).[43]

A vast majority of the publications listed in Table 1 were totally irrelevant to us, as could be expected. The words "research" and "ethics" produced an abundance of false positives, referring to either or both in a manner that did not benefit our inquiry. One of the items was an article in the journal *Bioethics*, regretting in the beginning that for lack of space, the contribution cannot do "justice" to its topic. With some detective work, however, the distribution began to make sense. "Ethics" gets a lot of significant hits in four areas—professional ethics, research ethics, healthcare ethics, and business ethics. Publications on research ethics are more numerous at the Universities of Helsinki and Turku, which can probably be explained by the size of the universities (among the biggest in Finland) and by their many leading roles in practical research ethics. "Bioethics" is a word more readily used among Helsinki academics than others (who prefer "philosophy"), but high numbers in these rows also indicate considerable activity.

As for the content, most "research ethics" findings are practical attempts to explain proper scientific conduct to peers. "Justice" may or may not figure in these efforts, depending on the approach. The few references to justice lead, as a rule, to contributions using or citing a principled, Beauchamp and Childress-inspired model of ethics. The low number of these references is not an indication that matters of justice are forgotten, but a reflection of a particular mindset and vocabulary. Justice in Finland is strongly associated with equality and legislation, and protecting the vulnerable is thought to cover the more specifically research-related

Table 1. Publication numbers from university publication data bases in Finland

Topic \ University of	Eastern Finland	Helsinki	Jyväskylä	Tampere	Turku
Ethics (E)	119	650	116	193	152
Ethics (F)	264	453	167	369	75
Bioethics (E)	1	55	0	5	2
Bioethics (F)	2	29	1	1	3
Research Ethics (E)	5	156	7	8	80
Research Ethics (F)	4	30	0	14	4
Ethics Justice (E)	0	27	0	0	8
Ethics Justice (F)	0	13	0	0	0
Bioethics Justice (E)	0	2	0	0	1
Bioethics Justice (F)	0	0	0	0	0
Research Ethics Justice (E)	0	8	0	0	5
Research Ethics Justice (F)	0	1	0	0	0

considerations. The language is not, however, fixed enough to warrant further word searches, for instance, on "vulnerability." Another justice-related concern that has dominated discussions in recent years has been substandard scientific practice involving plagiarism, inadequate referencing, and authorship issues.

Work in philosophical bioethics in Finland started at the universities of Turku and Helsinki in the 1980s and 1990s. Turku has kept to the agenda more consistently over the years, and the first (and still only) professorship in the field is held by Veikko Launis, Professor of Medical Ethics in Turku.[44] Researchers in Turku have studied the questions of risk management and precautionary measures, the concepts of illness and health, naturalness and normalcy in medicine, terminal care and prolongation of life, the ethics of gene technology and medical research, neuroethics, environmental philosophy, animal ethics, the ethics of climate change, and the philosophical and methodological foundations of bioethics.[45] Researchers in Helsinki have studied most of these issues, as well, but the loss of key personnel and change of focus at the beginning of the millennium spelled the end of their concentrated efforts in Finland.[46] While Pekka Louhiala stayed on as University Lecturer in Medical Ethics, and continues to have a significant impact on the educational front, Turku graduates steadily colonized philosophical bioethics positions at the universities of Eastern Finland,[47] Jyväskylä,[48] and Helsinki.[49] More recently, the University of Turku became the host institution of the UNESCO Chair in Bioethics Finnish Unit, headed by Helena Siipi.[50]

The work of philosophical bioethicists will be elucidated further in the sections below, as will the work done in our newly founded Justice Studies Unit at Aalto University School of Business. A schematic summary of research ethics institutions in Finland is presented in Figure 2.

Mid-Level Justice—Its Varieties and Alternatives

What about justice, then? How should we conceptualize it in our quest for justice in Finnish research ethics?

Figure 2. Research ethics framework and institutions in Finland.

Justice and Other Mid-Level Principles

All mid-level principles are open to many and varied interpretations. The contents of beneficence and harm depend on our theory of value, i.e., what we consider good or bad enough to constitute a benefit or a harm in the relevant sense.[51] Autonomy assumes partly conflicting meanings according to the background doctrine used: Kantian, Millian, relational, and so on.[52] Different views on the proper holders of dignity create different readings of the concept.[53] Precaution and solidarity are understood in particular ways in particular traditions of moral and political philosophy,[54] as is justice.[55]

Tom Beauchamp, well aware of the variety, characterizes the notion of justice on two levels. Beauchamp describes the gist of his early work with James Childress, and the idea of "principles" they employed, as follows:

> Our goal was to develop a set of principles for biomedical ethics. Substantively, our proposal was that traditional preoccupation of health care with a beneficence-based model of health care ethics be shifted in the direction of an autonomy model, while also incorporating a wider set of social concerns, particularly those focused on social justice. The principles are understood as the standards of conduct on which many other moral claims and judgments depend. A principle, then, is an essential norm in a system of moral thought, forming the basis of moral reasoning. More specific rules for health care ethics can be formulated *by reference* to these four principles, but neither rules nor practical judgments can be straightforwardly *deduced* from the principles.[56]

As for the principle of justice, Beauchamp continues:

> There is no single principle of justice in the four principles approach. Somewhat like principles under the heading of beneficence, there are several principles, each requiring specification in particular contexts. But common to almost all theories of justice – and accepted in the four principles approach – is the minimal (formal) principle that like cases should be treated alike, or, to use the language of equality, equals ought to be treated equally and unequals unequally. This elementary principle, or formal principle of justice, states no particular respects in which people ought to be treated. It merely asserts that whatever respects are relevant, if persons are equal in those respects, they should be treated alike. Thus, the formal principle of justice does not tell us how to determine equality or proportion in these matters, and it lacks substance as a specific guide of conduct.[57]

The descriptions given by Beauchamp in these paragraphs are relatively unproblematic. He and Childress wanted healthcare ethics to move from the utilitarian and paternalistic patterns to a more individual-centered model, yet one that could take into account social concerns. As for justice, they wanted to recognize a formal core of the concept, but leave open the possibility of fashioning different applications of the concept to different situations. There are, however, certain tensions and limitations in their approach. This will be shown after a brief commentary on another, competing, view.

Basic Ethical Principles in European Bioethics and Biolaw

European bioethicists have, since the 1990s, been looking for principles that would be more compatible with European values and attitudes than Beauchamp and Childress's versions of autonomy, nonmaleficence, beneficence, and justice. Jacob Dahl Rendtorff and Peter Kemp published, in 2000, a report of their wide-ranging study on the issue, and argued that the best principles for European bioethics and biolaw would be autonomy, dignity, integrity, and vulnerability.[58] Unlike their American predecessors, Rendtorff and Kemp did not want the new principles to be too open-ended or ambiguous; rather, they saw their principles as well defined and interdependent and wanted them to form as compact a unity as possible. This is how they described their endeavor:

> The idea in this analysis of European bioethics and biolaw is to show the limitations of a conception of bioethics and biolaw that is built solely on the concept of autonomy, a concept that has been widely influential in American inspired bioethics and biolaw. By showing the limitations of autonomy and viewing this concept in relation to the principles of dignity, integrity and vulnerability we aim to provide a more secure foundation for the protection of the human person in bioethics and biolaw. In this light we will integrate the principles in the framework of solidarity, responsibility and justice.[59]

An important detail here is that Rendtorff and Kemp saw justice, or solidarity, as the ultimate aim of bioethics and biolaw, and devised their four principles to promote the aims of justice, solidarity, and social responsibility in a modern welfare state.[60] As to their choice of principles, they explain:

> The choice of respect for autonomy, dignity, integrity and vulnerability as the four basic ethical principles in bioethics and biolaw expresses an effort to justify the protection of human beings in the fast developing fields of biomedicine and biotechnology. This should contribute to develop European Ethical and Legal Culture which recognizes the human person as an end-in-it-self, as is seen in the perspective of human rights. Persons are "liberty holders" and "right-claim holders". The ethical principles are not only guidelines for the right of the individual to self-determination, but also for the rights to protection of life and the private sphere of the person (privacy). In this perspective the principles are based on an interpretation of our present European legal culture of human rights, rather than being founded on natural law and renaissance humanism.[61]

So Rendtorff and Kemp's model is based, according to them, on a contemporary concept of human rights, rather than Roman Catholic (natural law) or Enlightenment (following renaissance humanism) thinking. As they go on, there is a further rejection of utilitarianism, coupled with a strong leaning toward the doctrine of personalism:

> The three alternative and supplementary ethical principles to autonomy that we aim to clarify and further investigate (dignity, integrity and vulnerability) preceded the utilitarian account of quality of life that plays an

> enormous role in bioethical decision making. They should be interpreted as expressing the concrete phenomenological reality of the human life-world. So they are understood as accounts of the ethical understanding of existence and the human person in everyday ethical life.[62]

It is focal to Rendtorff and Kemp's view that people are seen as social, not only individual, persons. In their view, the concept of autonomy evoked by Beauchamp and Childress fails because it unjustifiably excludes some people (people who are too young, too demented, or too severely cognitively impaired) from the sphere of personhood.[63] Leaning on existentialist and phenomenological doctrines,[64] Rendtorff and Kemp replace the American view with their own idea of *autonomy with others in just institutions*, preferring Immanuel Kant's reading of self-determination to John Stuart Mill's.[65]

The rejection of Mill's liberal utilitarianism, and all it stands for, allows Rendtorff and Kemp to build their own set of auxiliary principles for autonomy. They assume the view that human dignity originates in human communities, and that it is intersubjective by nature.[66] The integrity of human life for them consists of its physical and psychological togetherness, narrative coherence, and uncorrupted truthfulness, which lay a foundation for related legal notions.[67] From the vulnerability of the "bodily incarnated human being,"[68] they proceed to ideals of recognition, responsibility, and solidarity.[69] After these preliminaries, they conclude that, aided by the principles of autonomy (in the Kantian sense), dignity (in a partly Kantian but also in a human-rights-as-understood-in-European-legislation sense), integrity, and vulnerability, responsibility and solidarity promote justice by properly protecting human persons in a technologically high-risk society, where nation states and their coalitions are morally and politically accountable for social welfare.[70]

Theories of, and Approaches to, Justice

Beauchamp and Childress tried to avoid excessive theoretical depth in formulating their principles, while Rendtorff and Kemp took a more amenable view on philosophical distinctions and deeper normative commitments. Both lines can however, with equal ease, be placed on a relatively uncontroversial conceptual map of theories of, and approaches to, justice. How such a map can be drawn, and what its dimensions are, is described more thoroughly in our earlier work.[71] An outline will be sufficient for our present purposes.

Justice, as noted by Beauchamp,[72] has a formal core that most theorists accept. We should treat similar cases similarly, and different cases differently; all humans are equal, and laws should recognize this; everybody should be counted for one and no one for more than one; in political decision making, all those who are affected by the decisions should be heard or otherwise accounted for; and so on. After this mutual understanding, however, disagreements start to accumulate, resulting in at least seven partly compatible and partly incompatible doctrines, which are, in alphabetical order: the capability approach, communitarianism, the identity approach, liberal egalitarianism, libertarianism, socialism, and utilitarianism. Figure 3 presents these schematically, in a way that reveals some of their relationships and tensions.

In the middle of Figure 3, liberal egalitarianism is a compromise view that can meet most of the others halfway. Libertarianism insists that the rights of

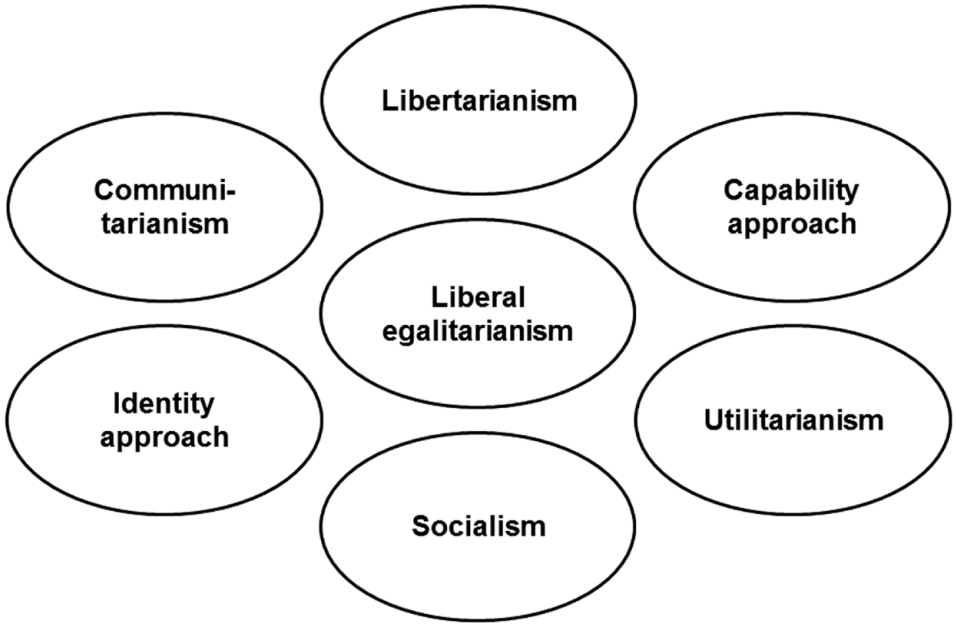

Figure 3. Theories of and approaches to justice.

individuals to life, noninterference, and private property are paramount constituents of justice.[73] Socialists, in contrast, maintain that an over-emphasis on the rights of property-owning individuals leads to social injustice.[74] Liberal egalitarians pick the cherries from both views, arguing that private enterprise should be encouraged and the benefits that it produces be redistributed to address issues of social justice. The theory of justice as fairness by John Rawls is the paragon middle-ground doctrine of this type.[75]

Liberal egalitarianism, especially its Rawlsian variety, also seems to provide the golden mean between utilitarianism and communitarianism. Utilitarians want to see the greatest happiness of the greatest number as the goal of all human action.[76] Rawls eventually rejected the doctrine, but took it seriously enough to stir an ongoing debate on whether his theory is in fact a qualified form of rule utilitarianism.[77] Communitarians firmly reject technical utility calculations, and they value, instead, organically developed traditions and ways of thinking.[78] Rawls's starting point is in a similar idea, albeit in a more abstract guise: he believed that his theory could only be accepted and implemented in a society where citizens have a common understanding of justice to begin with.[79]

The capability approach derives from two sources. Its original formulation is a critical outgrowth of preference utilitarianism, and it takes issue with cultural repression that shapes people's likings and choices.[80] The interpretation that has become more popular aspires to be an improved version of Rawls's theory of justice as fairness.[81] Liberal egalitarianism can live quite peacefully with both these lines of thinking, as long as they are not stretched too far. In the opposite corner of the moral map in Figure 3, the identity approach stresses the recognition of minorities and oppressed groups in political life.[82] Since Rawls focused strongly on the situation of the worst off in societies, his theory can easily accommodate this

tendency, at least to a certain degree. Liberal egalitarianism reaches its limits, however, in relation to the capability and identity approaches when the value systems of the two latter models become closed.

According to one version of the capability approach, we can compile a fairly detailed and comprehensive list of goods that we should promote by our ethical and political decisions.[83] While this is a potentially useful route to take, and a reflection of Rawls's account of primary goods, detailed lists like this come with a price. They need interpretation, someone has to do the interpreting, and the "someone" assigned to the job is usually the philosopher whose list is under scrutiny. This is how we can end up with conflicting views based on almost identical lists.[84] A liberal egalitarian would prefer, at this point, thinner notions and less detailed value catalogues.[85]

According to any version of the identity approach, societies and states should grant recognition and respect to groups whose voices have not been fully audible in decision-making: women, various ethnic groups, people with disabilities, people with diverse sexual orientations, and people living in otherwise precarious conditions. This is quite acceptable to liberal egalitarians until the question of tolerating the intolerant crops up. If members of the precariat feel that they do not have an obligation to tolerate their privileged oppressors, a liberal egalitarian system is hard put to find a proper response. "We do not have to tolerate the intolerant" is the most likely response, but one that prioritizes the dominant view over the more marginal.

Two Types of Bioethical Justice

Theories of justice represent several polarized stands. Figure 4 displays, in a schematic form, three of them: insistence on economic market freedom versus partiality to state control, cosmopolitanism versus nationalism, and universalism versus positionalism.

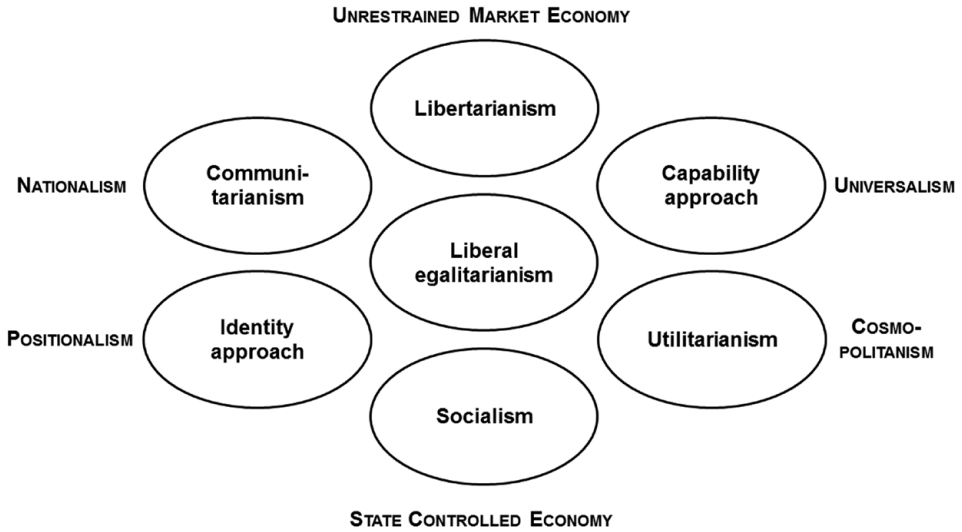

Figure 4. Tensions between views on justice.

Libertarians prefer unrestrained market economy or something as close to it as possible, and socialists see a need for strong state controls in economic transactions. Utilitarians are willing to extend their welfare calculations across borders and communitarians are more prone to give precedence to the needs of their fellow compatriots. Champions of capabilities think that morality is the same to all people, and advocates of identities believe that different groups of people live in different ethical universes.

The two sets of bioethical principles by Beauchamp and Childress and Rendtorff and Kemp find their places quite naturally, if not exhaustively, on the conceptual map presented in Figures 3 and 4. Figure 5 shows their general locations.

Beauchamp and Childress's place is within the individualistic theories favored in the liberal Enlightenment tradition. Their principle of autonomy of choice draws them toward libertarianism, while their principles of beneficence and nonmaleficence extend their normative base in the direction of utilitarianism. Their principle of justice identifies them firmly as liberal egalitarians and prevents them from straying too far into utilitarian thinking or to the extreme excesses of libertarianism. The capability approach is compatible with their set of principles, insofar as the list of desirable powers and abilities remains short and its demands vague.

Rendtorff and Kemp's principles belong to a competing school of thought that could be described as post-Enlightenment or (with qualifications) Romanticism. Dignity in their sense, vulnerability, and integrity prompt them to safeguard people's lives in the way demanded by moderate identity approaches. The same combination also promotes respect for the autonomy of moral agency as cherished by the more Kantian interpretations of liberal egalitarianism. Emerging from these

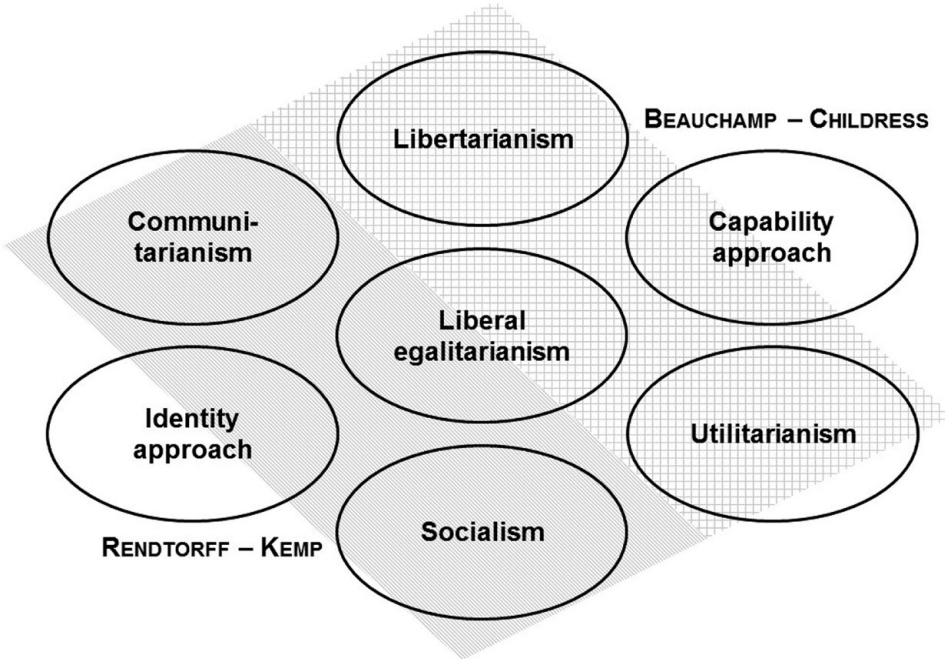

Figure 5. Bioethical principles and justice – two styles.

considerations, communal solidarity guides them toward communitarian thinking, while social solidarity and responsibility for others direct them to uphold some versions of socialism. Taken together, all these form a unified, intersubjective account of social justice.

As Figure 5 indicates, the two sets of bioethical principles share common ground in supporting some kind of liberal egalitarianism. Different understandings of autonomy mark a demarcation between the views, though. For Beauchamp and Childress, autonomy remains an attribute of the nonmoral as well as moral choices that individuals make; for Rendtorff and Kemp, the paramount concern is the morally defined self-determination of socially entrenched agents. In practice, this means that the Beauchamp-Childress doctrine retains its original antipaternalistic flavor – something that the Rendtorff-Kemp creed does not value as highly.

The differences between the sets are remarkable in other areas, as well. Although even Beauchamp and Childress do not seem to endorse fully-fledged utilitarianism, Rendtorff and Kemp are plainly hostile in their comments. Calculations of utility for them are a misguided way of settling ethical issues, and they would like to account for the consequence dimension of political choices in the spirit of responsibility, solidarity, and precaution.[86] Moreover, although Rendtorff and Kemp would probably not sanction all kinds of communitarianism and socialism, the rejection of these two ideologies is much firmer in Beauchamp and Childress's model. Interestingly, if we take the two sets of principles to be somehow distinctly "American" and "European," they could also enter each other's geographic territories, in practice if not in theory. Before the most recent political developments, the "mainstream" ethical atmosphere in the United States was on the way to becoming friendlier toward identity politics than its European counterpart seemed to be. That would have meant an invasion behind enemy lines in the positional corner of Figures 4 and 5. In the opposite corner of universalism in the same Figures, European Human Rights Thinking[87] could find a sounding board in the closed-list version of the capability approach. Since, however, Rendtorff and Kemp explicitly deny the connection to natural law theory and Roman Catholic teaching, we are not pursuing this matter further.[88]

Considerations of Justice in Finnish Research Ethics

How does research ethics in Finland account for considerations of justice, then? Let us answer the question separately from three angles: those of practical governance, political morality, and academic points of interest.

Practical Governance

Practical research ethics in Finland is in the hands of national, regional, hospital, and institutional boards and committees, as summarized in Figure 2. In the last instance, national and international law, supplemented by international treaties, defines the jurisdictions and tasks of these boards and committees. Finland is a relative latecomer in the field, and a top-down legal approach based on the rule of law, equality, and human rights is dominant. Rule of law is the basic requirement: whatever regulation exists, it should be publicly declared, forward-looking, consistent, comprehensible, equal to all, and certain in application. Finnish law secures equality on two separate fronts: one concept ("tasa-arvo"—literally "level value")

applies to equality between women and men, and the other ("yhdenvertaisuus" — roughly "equal worth") covers all other comparisons. Finns tend to be quite legalistic, and morality and law are seen as different only exceptionally—examples of these rare cases are sexual morality (attitudes to gay marriage) and reproductive choices (opinions on the physician's duty to terminate a pregnancy on request). One reason to this can be linguistic: the Finnish word for justice, "oikeudenmukaisuus," translates either as "accordance with what is right" or as "accordance with what is law."

Rule of law, equality, and human rights are at the heart of official research ethics in Finland. Figure 6 shows this, and the location of other important elements of science governance in the country, against the background of the conceptual map of theories of justice introduced in Figures 3–5.

Starting from the communitarian (northwestern) corner of Figure 6, Finnish law does contain peculiarities that are somehow due to the development of the legal system in the land. The prime example is the nonregulation of therapeutic cloning and the ensuing silent acceptance of research on cloned human embryos, which is not usual in other countries. [89] With increased legal harmonization on the European Union level, such cases are becoming exceptional. On the other hand, the legal idiosyncrasies of the European Union will then replace the previous national ones.

The role of informed consent in Finnish research ethics is prominent, as can be expected, but also decidedly equivocal. Informed consent is a requirement in all biomedical and biological research involving humans; and in social, behavioral, and humanities research that interferes with the subjects' physical integrity, exposes them to strong stimuli, may inflict mental harm on them, threatens their security, or involves minors without parental supervision.[90] The requirement

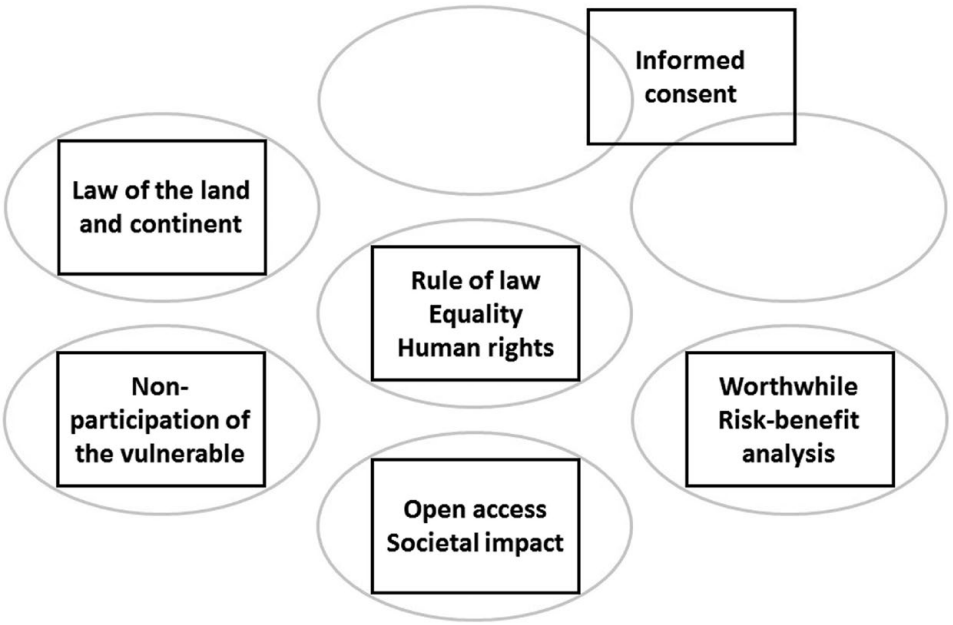

Figure 6. Elements of practical research ethics in Finland.

of fully informed consent is, however, at risk in regulations concerning genomic and genetic databank research. The law on this does not necessitate explicit consent for the use of older diagnostic materials,[91] and it remains vague concerning the future use of collected samples.[92] A partial explanation of the unenthusiastic attitude toward strict consent is that officially, Finland does not recognize any Tuskegee Syphilis Experiment[93]-type national mishaps, and may therefore be more amenable to paternalistic methods.

The exclusion of vulnerable groups from potentially dangerous research is included in Finnish research governance as a matter of course, following international trends and regulation. As in the case of informed consent, there is not much recognition of dubious historical practices like lobotomy operations and involuntary sterilizations.[94] These are cases of bad treatment rather than unethical research, of course, but the spirit is similar. The extension of ethical preview to social and behavioral sciences and the humanities seems to be a step toward more caring attitudes, but even here, the concerns are utilitarian and focus on straightforward physical and psychological harm.

Any research conducted should be worthwhile, and its benefits should be proportionate to its risks. Most preview boards and committees in Finland concentrate on this dimension of ethicalness. The axiology, or theory of value, employed is in the majority of cases materialistic, and focuses on the impact of the research on human and animal wellbeing. This approach is fine and even essential, but it ignores some more abstract moral issues: worries about privacy, personal autonomy, justice (in other senses), and the treatment of human and nonhuman beings as mere means to the ends of others or to the greater good of society (whatever that means).

Open access to the results of research and societal impact are visible themes in Finnish science governance. With the international field of academic publishing in turmoil, universities and national boards are constantly looking for new ways of disseminating the results of science. The Academy of Finland, the main public financer of scientific research in the country, has decreed that projects funded by the Academy must report their findings in open access systems of some kind, although the organization of follow-up and sanctions remain, for the time being, rather unclear. The Academy, as well as most other science funders, also requires research to have societal impacts. What these societal impacts would be, and how their realization could be verified, remains largely unspecified. There are directed calls with more precise goals, but these are either quite general ("To boost national economy" or "To encourage innovative solutions to social problems") or change with changing political situations.

Political Morality

Finland is a Scandinavian welfare state.[95] This means that it has a market driven economy, but the state redistributes tax revenue to provide public health and social services, education, daycare for children, unemployment benefits, services for old people, services for those with limited abilities, and so on. The model leans partly on social democratic principles (as is more prominently the case in Sweden and Denmark), but also on moderate conservatism (originally, industrialists taking care of their own workforce) and religious ideals (over 70 percent of the population are members of the Evangelic Lutheran Church of Finland).[96]

In terms of theories of justice, the ethos of the welfare state extends to all directions but one: it does not accommodate libertarian thinking. Socialism, utilitarianism, the capabilities approach, and social egalitarianism are effortlessly included, communitarian undercurrents have always been there, and identity recognition has been increasingly included. Figure 7 shows the relative positions of the Finnish Scandinavian welfare state (the grey box extending from the middle to the end points marked with grey horizontal and vertical lines) and the main political parties in the country on the conceptual map already used in Figures 3-6.

In government in fall 2017 were the Centre Party, the National Coalition Party, and the populist Blue Reform, which separated from the Finns Party (originally in the coalition) in summer 2017. The spectrum of political moralities within these parties range from communitarian and nationalist to utilitarian and globalist. The National Coalition Party potentially covers the whole range, with voters both in the ideological ("Home, religion, fatherland") and pragmatic ("Let's do what's good for business and economy") ends. The Centre Party also covers most of the same ground, but it is limited at the far ends of the spectrum. Insofar as pragmatism means global cosmopolitan utilitarianism, the Center Party's agrarian roots prevent it from endorsing this fully. At the other end, the party has kept leaking for decades, as populist movements have attracted voters who have felt that the party's elite has forgotten ordinary people and their concerns. Finns Party and Blue Reform are the latest incarnations of this phenomenon, although they have also drawn voters from other marginalized demographics. After their separation, the Finns Party appears to be the nationalist force demanding closed borders and the Blue Reform the reasonable little people's voice, but the situation is unclear.[97] Other European populist parties have witnessed similar splits.[98]

For decades, government coalitions in Finland have consisted of a combination of one or two of the three big parties, traditionally the Centre Party, the National

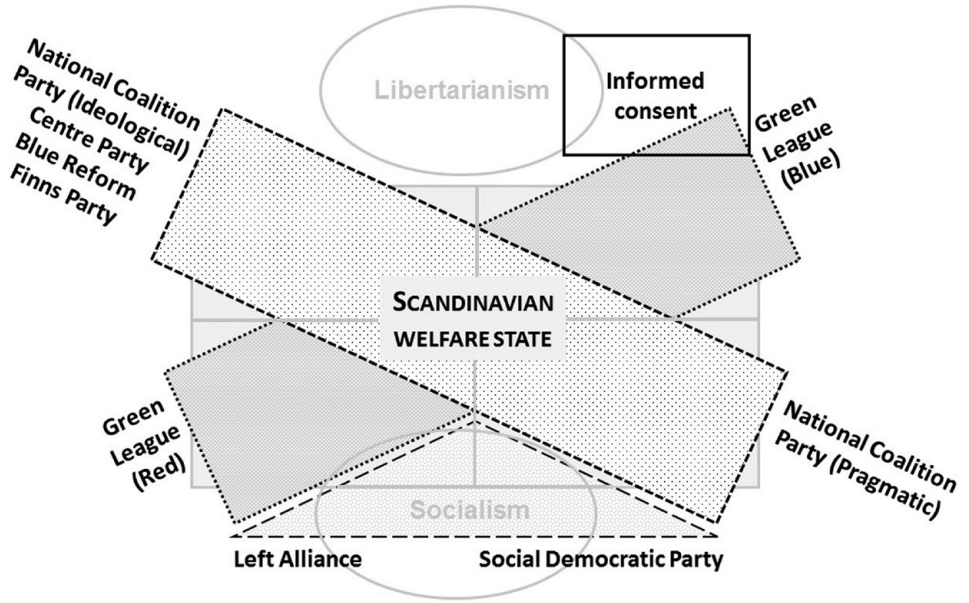

Figure 7. Welfare ideology and party politics in Finland.

Coalition Party, and the Social Democratic Party, together with smaller auxiliary parties.[99] Since the right-wing parties are in government now, a possibility for the next government (2019 at the latest) would be the reemergence of the Social Democrats, but their support does not show strong indications of this, at least not yet. For now, they seem to be searching for their place in a society that has completed many of the reforms they have been advocating. To a degree, this also applies to their rival left-wing party, the Left Alliance. This could change, of course, before the next election.

An interesting development in Finnish politics is the gradual rise of the Green League, who might just pinch a strong coalition position in future elections. This is interesting, because after a radical single-issue (environmental) start, the party is now fully presentable in the no-nonsense welfare state spirit that seems to be a requirement for political power in Finland,[100] yet provides some genuine alternatives to the current government ideology. Like the National Coalition Party, the Green League operates on a wide radius. Its "red" left wing is vocal on identity issues, not a particularly popular field for the conservative and populist front. Its "blue" wing is more inclined to assume the capabilities approach on universalistic terms, not an absolute no-go zone for the pragmatists of the National Coalition Party, but antagonistic to the more conservative and populist fractions.[101]

After this lengthy introduction, here comes the significance of political morality for research ethics and justice. Informed consent, as depicted in Figure 7, falls outside the welfare state ethos. It is an individualistic and libertarian notion that separates persons from one another and makes them more or less responsible for their own choices. This stands in stark contradiction with the socially embedded, intersubjective, and paternalistic ideology that the (historically) big three parties in Finland—the Social Democratic Party, the Centre Party, and the National Coalition Party have embraced. Informed consent, consequently, is a foreign implant in Finnish research ethics. Finns tolerate and sanction it because this is pivotal to the recognition of international treaties, but they do not understand it well or embrace it fully.

Party politics may change, then, the ideological basis of research ethics in Finland in the future. If the conservatives and social democrats stay in power, the situation stays the same and there will always be well-intentioned doubts about the decision-making powers of individuals as research subjects. If, on the other hand, the Green League gains in influence, some evolution is possible.

Academic Points of Interest

Finnish scholars have done bioethical work and published bioethical books and articles on at least five fronts: descriptive, constructive, empirical, conceptual, and critical.[102]

Descriptive reports explain how research ethics in Finland works, and what its aims and challenges are. Ritva Halila and her collaborators have done much work in this field, and covered topics such as the role of national ethics commissions in Finland,[103] children's decision-making powers in medical research participation,[104] international ethical regulations on medical research in emergency settings,[105] ethically-problematic treatment decisions in different medical specialties,[106] and the work of hospital districts' research ethics committees in Finland.[107]

Issues of justice feature in contributions like these, mainly in the forms of formal equality and considerations of utility and consent.

Constructive efforts endeavor to improve the practices in research ethics and in research governance. The most consistent work in this area in Finland has been done by Henriikka Mustajoki (formerly Clarkeburn) and Arto Mustajoki, who have studied science ethics teaching,[108] ethical sensitivity development in science students,[109] honesty in academic writing,[110] the everyday ethics of researchers,[111] and the possibility of using a "guided dialogue" method in promoting reflection in research communities.[112] The justice dimensions of these investigations are deontological and virtue ethical: they concentrate either on the moral rules that researchers or students should internalize and follow, or on the character traits that practices could foster in current and future scientists. Potentially, this can lead to the "responsibilization" of individuals, a trend that Johanna Ahola-Launonen has criticized in a wider healthcare setting,[113] but if the focus is on structures, not necessarily.

Empirical studies on matters related to healthcare ethics in Finland have attracted the attention of two groups: nursing scientists in Finnish universities[114] and researchers at the National Institute for Health and Welfare.[115] Nursing scientists have understandably directed their attention to practical healthcare provision, and so research ethics has not been one of their main objects of interest. At the national institute, research ethics is a topic of investigation among others. Good examples are Elina Hemminki's studies, with collaborators, on Finnish attitudes toward biomedical research in general[116] and biobank research in particular,[117] ethics committee chairpersons' views on changing rules,[118] and similarities and differences in research governance in Finland, England, Canada, and the United States.[119] Justice enters these investigations by the choice of themes, which often have to do with the proper distribution of benefits, burdens, rights, and duties within healthcare delivery and biomedical research.

Conceptual work emphasizes the importance of theoretical coherence and logical consistency. Finnish philosophers have examined practical ethics and bioethical questions from these points of view since the 1970s.[120] The ethics of science became topical with the rise of modern genetics,[121] and the doctoral theses of Tuija Takala[122] and Veikko Launis[123] at the University of Turku took up the topic. Conceptual studies involving, albeit sometimes tangentially, the ethics of scientific research proceeded in Turku in further doctoral work by Helena Siipi,[124] Elisa Aaltola,[125] and Marko Ahteensuu.[126] The scrutiny of ethical theories and principles is, of course, important for the understanding of the fundamentals of research ethics. The justice dimensions of these studies have included analyses of autonomy and solidarity in the quest for genetic information, the ideas of naturalness and unnaturalness, species equality, and precaution in our dealings with the natural environment.

Critical approaches aim to be emancipatory, or liberating, and to challenge current practices and ways of thinking. Traces of criticism can often be found in constructive, empirical, and conceptual endeavors as well, but in some contributions, the challenge is more unmistakably present. In our own work, we have questioned principlist,[127] utilitarian,[128] categorical,[129] sectarian,[130] over-theoretical,[131] gendered,[132] pro-natalist,[133] heteronormative,[134] over-practical,[135] and aimless[136] argumentation in bioethics. More specifically and more closely related to research ethics, we have contested UNESCO's Universal Declaration on Bioethics and

Human Rights for its inherent vagueness,[137] German law on stem cells and stem cell research for its hypocrisy,[138] and human biobank research and its regulation for their tendency to ignore issues of informed consent.[139] The biobank case is especially interesting from the viewpoint of justice. As depicted in Figure 7, consent seems to fall outside the scope of welfare-state thinking. If this is the case (and this is a topic for further studies), then countries like Finland, Sweden, Norway, Denmark, and Iceland should be extra careful in their efforts to keep proper permissions from the study subjects in the prime place they traditionally occupy in international research ethics.

Notes

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63. See note 11, Rendtorff and Kemp 2000 Vol. 1, at 22–3.
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68. See note 11, Rendtorff and Kemp 2000 Vol. 1, at 48.
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88. See note 84, Finnis 2011.
89. See note 38, www.btnk.fi/files/pdf/kantasolu.pdf (last accessed 23 Oct 2017).
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95. "Scandinavian" welfare states include Denmark, Finland, Iceland, Norway, and Sweden. In these countries themselves, the term used is "Nordic", as Iceland is a geographically separate entity and Finland not a part of the Scandinavian Peninsula (although it is geographically adjacent to Sweden and Norway and, with them, a part of the larger Fennoscandian Peninsula).

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99. "Smaller auxiliary parties" can mean all the other parties mentioned in the text, including the Green League, which may currently be moving up in the world, and, in addition, the Swedish People's Party of Finland and the Christian Democrats.
100. The Social Democrats and the Left Alliance have been depicted in Figure 7 as socialist parties, but experience shows that they can expand to the political right (upwards in the figure) if this becomes politically profitable.
101. Blue and white are the colors of the Finnish flag, and political color divisions tend to be along the lines of blue and white (conservative and right-wing) against red (radical and left-wing). This is in contradiction with the right-left color scheme in the United States, where Republicans are red and Democrats blue. In Scandinavian (or Nordic) terms, both main parties in the United States are libertarian, and outside the map of the acceptable welfare state realm.
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