

Program Summerschool 'What about the Family? –An interdisciplinary course on ethical issues in health and social care', August 19-26, 2017 Groningen

Description

Recent developments in healthcare and social care policy are challenging the scope of and theoretical justification for claims based on notions of family responsibility. The considerations cover a wide range, from normative issues of (for example) the basis on which we should expect responsibility to be present, to empirical considerations of how responsibilities come to exist and are enacted in a range of familial situations.

This summerschool will explore new theoretical and practical approaches to address the challenges posed by responsibilities generated by new forms of healthcare and social care practice. In particular, we will examine the significance of people's key relationships (such as with family and community), and how people deliberate and decide about their responsibilities. Research questions and themes to be addressed include (1) what 'family' means; (2) why families matter; (3) negotiating responsibilities; (4) familial roles in decision making; and (5) justice within families.

- Participants will enhance their knowledge and understanding of the theoretical approaches to ethics of families, and their applications.
- Participants will have ample opportunities to present their own research and benefit from feedback from internationally renowned scholars.

Lecturers

Prof. dr Jackie Leach Scully, Newcastle University; Prof. dr Veerle Provoost, University of Ghent; Dr. Ulrik Kihlbom, University Uppsala; Dr. Simon Woods, Newcastle University; Prof. Jamie Nelson, State University Michigan; Prof. Hilde Lindemann, Michigan State University; Prof. dr Christian Munthe, University of Gothenburg; dr. Kristin Zeiler, University Linköping; Dr. Katherina Beier, University of Göttingen; Dr. Sabine Woehlke, University of Göttingen; Prof. dr Marian Verkerk, University of Groningen, Dr Ainsley Newson, University of Sydney.

Study load: 5 ECT's= 5 x 28 hours

- Preparatory readings before Summerschool: 20 hours (120 pages; 6 pages per hour)
- Lectures during Summerschool: 40 hours
- Research paper: 80 hours

Preparatory assignment

1. Preparatory readings. A reading list will be available at 14th of June. Each participant is expected to prepare questions for discussion. For each session, one of those questions should be sent to the lecturer in charge of that session before the 14th of August.
2. Prepare a topic for research paper.
3. Prepare a case for discussion related to the theme of discussion making in health and social care. You are expected to select and prepare a case for discussion on day 4. This case can come from your own research project, your own professional practice or personal experience, or from research or public reporting/debate. It should somehow be about ethical issues, complications or challenges for decision-making in health or social care that connect to the reality of patients to be embedded in close social relationships and real or imagined responsibilities. The preparation should include that you assemble sufficient detail and related information (e.g., links to news items or discussions, literature that you bring with you, etc.) to launch a group discussion that can lead to a public presentation at the end of the day.

Final assignment (to get ECT's):

Research paper that connects course theme to the student's own PhD work. Topic prepared in advance. Deadline for final version: 3-4 weeks after course.

To promote analysis and integration of material from Summer School discussions and readings, the student will write a research paper (minimum of 6 and maximum of 10 double-spaced, typed pages). In the paper, students will develop their research question and their argumentation, integrating their understanding and views on at least one of the topics covered in the Summer School. The writing of the research paper will be mentored during the week and a draft of it will be presented during the last day of the Summer School in the form of a Master class.

STRUCTURE

Sunday, 20 August

- City tour 3-5 pm
- Welcoming drinks in the Academy Building

Monday, 21 August (Day 1)

9.00-9.15: Opening words by Academic Coordinators

9.15-10.00: Short intro to organisation & logistics of the week (Marian Verkerk)

10.00-12.30: Each student present their *topic of research paper*, 5-10 minutes

12.30-13.30: Lunch

13.30-14.45: ***Introduction family ethics (Marian Verkerk).***

Health care is not only of great importance to individual patients. The impact of medical decisions can also have a devastating effect on a patient's family and relations. Having said this, care providers have very little opportunity to involve the family in the care given to a patient. Legislation and guidelines relating to healthcare revolve around the individual, despite the fact that patients make many of their decisions in consultation with the family. This area needs more attention. It's time for family ethics in healthcare. Questions needing more family-based medical ethics arise throughout the care sector, from home care and genetics to questions concerning the beginning and ending of life.

14.45 – 15.00: Break

15.00 – 16.15: ***Modes of Inquiry (Simon Woods & Veerle Provoost).***

Rather than adhering to the idea of one single, correct method for moral deliberation, a pluralistic use of methods will be explored, that all centre on the examination of lived experiences, norms, values, demands and responsibilities, within concrete care practices, and that seek to make sense of and critically engage with these.

16.15-17.30: Mentoring related to research papers with lecturers of the day

Tuesday, 22 August (Day 2).

9:00-10:00 ***What is a family and why does it matter (Hilde Lindemann).***

In her presentation on “Why Families Matter” Hilde Lindemann will discuss the way families forge selves and initiate their young into personhood. What is required for personhood and how families reproduce persons? She will draw on the literature in child development and on Ludwig Wittgenstein’s remarks about the acquisition of language.

10.00-11.30: Small group exercise: formulating discussion questions related to theme

11.30-12.30: Presenting discussion questions to peers and lecturers

12.30-13.30: Lunch

13.30-14.30: ***Recognizing family by Jackie Leach Scully.***

In this session, we’ll be considering the wider significance of the family (however we define it) to healthcare ethics and bioethics. Both these areas have tended to favor analytical frameworks that prioritize the individual within the healthcare system. This tendency has been challenged by the increasing prominence of relational approaches that understand an individual’s capacities and choices as inextricably part of the network of relationships that shape and sustain them as persons. It is still important to bring a critical eye to relationality, however; one trap is to value family relationships simply *because* they are familial, and to exclude other kinds of relationship that fail to fit to a preconceived idea of relationships that matter.

14:30-15:00: Small group exercise: formulating discussion questions rel. to theme

15-15:30 Break, coffee

15:30-16:30 Presenting discussion questions to peers and lecturers

16:30-17:30 Mentoring related to research papers w lecturers of the day

Wednesday 23 August (Day 3).

9.00-10:00 :

Justice and families, Jamie Nelson.

What can justice—the “vain and jealous virtue,” a la David Hume—have to do with families and other intimate, small-scale social units, where presumable people have other motives than to safeguard their own interests and stand on their rights? Building on the chapter I wrote with Simon Woods, I explore how justice takes new forms in families and how its demands and promptings are shaped by its encounters with healthcare

10:00-11.30:

Small group exercise: formulating discussion questions rel. to theme

11:30-12:30:

Presenting discussion questions to peers and lecturers

12:30-13:30: Lunch

13:30-14:30:

Responsibilities in families (Katherine Beyer and Sabine Wölkhe).

We will present a comparative ethical analysis of surrogate motherhood and living organ donation with special focus on the relational implications of these practices.

14:30-15:00

Small group exercise: formulating discussion questions rel. to theme

15:00-15:30 Break, coffee

15:30-16:30

Presenting discussion questions to peers and lecturers

16:30-17:30

Mentoring related to research papers with lecturers of the day

Thursday, 24 August (Day 4).

Description of this day

This day aims to draw together the various general issues and concerns related to families, responsibilities and related ethical, methodological and philosophical implications and use this to develop our thinking about and study of the ethics of clinical decision-making. The lecturers will provide distinct introductions that extend the general presentation in the course literature, relating this to debates and research about shared decision-making

and "family centred" care, as well as about reproductive and genetic healthcare, e.g., preconception reproductive planning. However, most of the day will be spent on group work on the cases that are part of the student's preparatory assignments.

9:00-10:30: ***Decision making in health and social care (Christian Munthe & Ulrik Kihlbom)***

10:30-12:30: Work in groups based on prepared cases. Incl. research online and preparation of plenary presentation.

12:30-13:30 Lunch

13:30-14:30 Group work continued.

14:40-15:00 Coffee break

15:00-16:30 Plenary presentations of group work

16:30-17:30 Mentoring related to research papers with lecturers of the day

Friday, 25 August (Day 5)

9:00 – 10:00: **New directions in family ethics research (Kristin Zeiler).**

At the heart of discussions about family ethics lay concerns with how to make sense of emotional and/or biological bonds and their possible normative pull. Starting in the notion of entangled bodily sharing and combining this with an eye for the visible and invisible work that takes place in medical practices where cells or organs cross corporeal boundaries between family-members and friends (or where such crossing take place between strangers, engendering new social relations), this lecture intends to offer a novel approach to the analysis of these bonds, within these practices. This approach cross-pollinates phenomenological philosophy with science and technology studies, discuss what this cross-pollination helps us do, and why it is helpful for family ethical inquiries in medicine and for bioethics more broadly.

10.00- 12.30 **Coming Emerging challenges in reproductive and genomic technologies development and their impact for family ethics by Ainsley Newson**

We have long known that genetic information is inherently familial. But the emergence of genomics may re-emphasie the individual. Traditionally, DNA testing has often involved caring for families as opposed to individuals. Now, individuals are increasingly able to access whole genome sequencing. While familial information can be useful

for interpretation, it is not always required. How might this impact concepts such as privacy, the right not to know and the duty to inform? And how should we construe concepts such as 'best interests' when we are balancing individual and family interests?

While genomics may de-emphasise familial kinship; emerging reproductive technologies may be increasing the emphasis on genetic ties. Mitochondrial replacement, for example, exists to allow couples to have a child free of mitochondrial disease who is genetically related to both 'parents'.

This session will draw on case studies and relevant concepts to draw together and critically apply discussions from throughout the course so far.

12:30-13:30: Lunch

13.30-15:00 "Master class": Presentation of draft synopsis of research paper, based on developments in previous days

15:00-15:30 Coffee

15:30-17:00: "Master class": Presentation of draft synopsis of research paper, based on developments in previous days (continued)

END

