

Institution: University of Southampton

Unit of Assessment: 30 Philosophy

Title of case study: 30-01 Ethics, Law and Professional Guidance for Birth Choices Outside the Guidelines.

Period when the underpinning research was undertaken: September 2013 – June 2020

Name(s):	Role(s) (e.g. job title):	Period(s) employed by submitting HEI:
Elselijn I	Kingma	Associate Professor in	September 2013 – December 2020
-	-	Philosophy	

Period when the claimed impact occurred: October 2013 – July 2020 Is this case study continued from a case study submitted in 2014? N

1. Summary of the impact

Some women make birth choices that healthcare professionals consider dangerous. Such choices raise urgent questions. Dr Elselijn Kingma's research argues that women have the right to make many such choices; that healthcare professionals ought to proactively support such choices once made; and that understanding the nature of pregnancy can help us to appreciate these and other moral issues surrounding pregnancy and birth. Kingma's research has critically shaped the Dutch legal, medical, activist and policy framework surrounding maternity care. The specific impacts described here are:

- 1) **Changing Dutch legal precedent**, protecting healthcare professionals from prosecution if they assist 'deviant' births.
- 2) **Critically shaping clinical guidelines** issued jointly by the *Dutch Royal College of Midwives* (KNOV) and the *Dutch College of Obstetrics and Gynaecology* (NVOG).
- 3) Directly and indirectly changing Dutch government health policy.
- 4) Influencing key strategic and policy decisions by two Dutch charities: (a) Geboortebeweging (Women's Advocacy) and (b) Clara Wichmann (Litigation)
- 5) Shaping discussion of the landmark Bravis court case.
- 6) Providing professional training for health and social workers.

2. Underpinning research

The rights and obligations of women during pregnancy and birth are the focus of long-standing and recurring discussion in philosophy, ethics and law. Philosophical discussion of this topic often focuses on abortion, leaving other questions underexplored. Kingma has made multiple novel contributions in this field over the last 7 years.

First, Kingma has argued that **women have a near-absolute right to refuse invasive medical procedures**, even if this choice results in the injury or death of another person, including their child [3.1]. Kingma has shown how this idea bears not only on the decision to refuse a caesarean section but also on many other more frequent but theoretically neglected choices, such as the choice of birthplace or whether to use a fetal heart monitor [3.2, 3.3].

Second, Kingma has addressed **neglected questions about the duties of healthcare professionals** in caring for women who make 'deviant' birth choices. Such choices may put healthcare professionals in potentially risky and stressful emergency situations, for which they are not adequately trained. Kingma argues both that women are entitled to make such choices, and that professionals have a duty positively to assist with the chosen alternative.

Third, Kingma has argued that **there is a deep-seated bias in many medical systems and cultures** that downplays or even ignores the risks women face during birth [**3.3, 3.4**]. As a result, official guidance and policies are often driven by maximising outcomes for babies, giving insufficient weight to women's health and well-being.

Fourth, Kingma has tackled **questions about the underlying nature of pregnancy**. Everyone agrees that the issues above are specific to the unique state of pregnancy and birth: there is no comparable debate about whether non-consenting fathers could be *forced* to undergo invasive medical procedures, such as removal of their bone-marrow or organs, for the sake of their children [3.1]; or whether health care professionals have a duty to keep caring for Jehovah's witnesses who refuse a blood transfusion [3.2]; and questions about which patient's outcomes should be considered the main goal of a treatment simply do not arise in other medical contexts [3.3, 3.4]. But despite its importance, the nature of pregnancy is little discussed



in this ethical context. Kingma's 'Better Understanding the Metaphysics of Pregnancy' (BUMP) project was awarded a €1.2 million ERC starting grant in 2016. This ongoing research argues:

(i) that **our thinking about pregnancy is dominated by an incorrect 'fetal container model'** instead of a better 'parthood view' of pregnancy on which the fetus is part of the maternal organism [**3.5**], and

(ii) that **this mistake fuels ethical mistakes**. For example, the fetal container model wrongly encourages us to apply notions such as "doing harm" to maternal-fetal interactions. A better understanding of the nature of pregnancy demonstrates that such familiar moral concepts are at best difficult to apply, and at worst entirely inapplicable in this context [**3.6**]. As a result, nearly all suboptimal choices by pregnant women, including smoking and drinking alcohol, might not qualify as "doing harm" (even if they might nonetheless be wrong on independent grounds).

Kingma's more theoretical research [**3.5**, **3.6**] has been developed in conjunction with and often arising out of thinking about and working on more applied issues – and in turn, this more theoretical work on the nature of pregnancy, and an ethics appropriate to that nature, has shaped and affected her understanding of applied issues.

3. References to the research

3.1 Elselijn Kingma & Lindsey Porter, 2020. "Parental Obligation and Court-Ordered Caesarean Section". *Journal of Medical Ethics*. Published online first: <u>https://doi.org/10.1136/medethics-2020-106072</u>

3.2 Elselijn Kingma, 2013. "Tuchtzaak Verloskundigen Grote Misser" ["Court Case Midwives Big Mistake"]. *Medisch Contact* 40, pp.2020-22 <u>https://www.medischcontact.nl/nieuws/laatste-nieuws/artikel/tuchtzaak-verloskundigen-grote-misser.htm</u>

3.3 Elselijn Kingma and Fiona Woollard, "Why Autonomy Matters: A Philosophical Perspective". Presented at *Transforming Consent in Maternity Care*. Oxford, UK. 10/11/2017

https://www.gtc.ox.ac.uk/wp-content/uploads/2018/12/Transforming-Consent-Report-

<u>Cobranded-Final-April18.pdf</u>. This research was subsequently developed into an article accepted for publication (Elselijn Kingma, "Harming One to Benefit Another: the paradox of autonomy and consent in maternity care", in *Bioethics*). Talk recording and expanded transcript available on request.

3.4 Elselijn Kingma, 2018. "Bevallen is altijd een Dilemma: hoe weeg je uitkomsten voor moeder en kind?" ["Birth is always a dilemma: weighing outcomes for mother and child"] *Podium Bio-Ethiek*, 25, pp.13-16. <u>https://eprints.soton.ac.uk/426429</u>

3.5 Elselijn Kingma, 2019. "Were you a part of your mother?". *Mind* 128, pp.609-646. <u>https://doi.org/10.1093/mind/fzy087</u>

3.6 Elselijn Kingma & Fiona Woollard, 2019. "Schade doen of nalaten voordeel te geven: een nieuwe ethiek van de zwangerschap". ["Doing harm, or failing to provide a benefit: a new ethics of pregnancy"]. *Tijdschrift voor Gezondheidszorg en Ethiek* 219:29, pp.73-77. Available on request.

Grants and Awards

- European Research Council (ERC) Starting Grant for Project 'BUMP': Better Understanding the Metaphysics of Pregnancy. (€1,273,290). [GA 679586]
- Over 15 other conference and workshop grants totalling approximately £13,000, from e.g. Mind Association, Aristotelian Society, BSPS, Analysis Trust, Society of Applied Philosophy, etc.
- "The Philosophy of Pregnancy, Birth, and Early Motherhood" won a commendation from the *Times Higher Education*, 'Research Project of the Year: Arts, Humanities & Social Sciences' 2018.

4. Details of the impact (All translations by case study author)

4.1. Changing Dutch legal precedent

In July 2013, a Midwife was struck off for attending several 'risky' home births, in one of which the baby died. In each case, it was clear that the (legally competent, reasonably informed) parents would attempt the birth at home, with or without a midwife **[5.1 – 2013 case]**.

That October Kingma published an article, "Tuchtzaak Verloskundigen Grote Misser" ["Court Case Midwives Big Mistake"], in *Medisch Contact*, the journal of The Dutch Medical Association, criticising the judgment for being inconsistent, unfair, and unrealistic: women are entitled to



decide not to go to hospital for birth, and they and their baby are entitled to medical assistance. This requires that health care professionals cannot be faulted for assisting with births under such imperfect circumstances.

During the appeal (10 April 2014), Kingma's article was submitted in full by the defence: "Professor Elselijn Kingma has, in *Medisch Contact* dated October 3rd, 2013, placed the shortcomings of the contested decision in the correct perspective. Prior to discussing the individual grounds on which we appeal, here is her article in full" [**5.2**]. The judge overturned the original judgment in line with Kingma's reasoning: "The question is what the medical professional should do if a client persists in her refusal of a hospital delivery.[...] There is no doubt that the midwife has a right, and a duty, to do her work in the interest of mother and child in such an emergency situation". The midwife was reinstated [**5.1 – 2014 appeal**].

This court case remains the landmark case on this matter, setting a legal precedent that changed subsequent practice. After the appeal midwives could feel secure about their legal standing when assisting with 'risky' home births [**5.3**]. The legal precedent set by the appeal was confirmed in a 2018 court case about another midwife who attended a 'risky' home birth where the baby died. Though the midwife was struck off, the court explicitly clarified that it was not the midwife's attendance at a 'risky' home birth that was problematic, but instead other aspects of the case (e.g. improper resuscitation practices) [**5.1 – 2018 case**].

4.2. Critically Shaping Clinical Guidelines

The above court case, and more general questions about women making such choices, generated considerable upheaval, concern, and division amongst Dutch midwives and gynaecologists. This motivated the Dutch Royal College of Midwives (KNOV) and the Dutch Royal College of Obstetrics and Gynaecology (NVOG) to develop formal guidance for professionals facing birth choices beyond the medical guidelines [5.4]. Kingma was the only philosopher/ethicist consulted in this process, first, by presenting at an initial invitation-only workshop in October 2013, then by being selected to give a plenary presentation to all Dutch gynaecologists on this topic in November 2013 [5.3, 5.5]. These processes ultimately resulted in the 2015 ratification of joint guidelines by the NVOG and KNOV, which follow Kingma's recommendations: respect women's informed choices, even if those choices go against medical advice, and never leave women and babies without the best care they are willing to accept in the resulting situation [5.3, 5.5]. Kingma's work, both on the metaphysics of pregnancy, and the more applied ethical issues, made a crucial difference to these guidelines and in turn to subsequent practice [5.3, 5.5].

4.3. Changing Dutch Government Health Policy

In 2016, a new 'integrated' funding structure for gynaecologists and midwives was being considered in the Netherlands. In response, Kingma submitted a research-based [**3.4**] policy brief to the Dutch government and MPs [**5.6**]; wrote op-eds for a national newspaper (*the Volkskrant*, comparable to *The Guardian*) [**5.7**], and the *Dutch National Midwifery Journal* [**5.7**]; and by invitation spoke at a public event – "De Geboortezorg: een nieuw begin" ["Maternity care: a new start"] – to approximately 200 attendees, including professionals and politicians. Kingma argued that the proposed changes might impede women's freedom of choice, and their health and wellbeing. This resulted in the following direct impact:

- An MP directly quoted Kingma's work in Dutch Parliament when arguing against the new policy [**5.8**].
- Kingma's words were also used in an invited submission by the charity *Geboortebeweging* to the relevant parliamentary committee [**5.9**].

After these interventions, the government's plans were changed: instead of a compulsory national implementation of the new system over two years, they instead opted for a two-year optional pilot scheme, subject to subsequent evaluation. By invitation, Kingma emailed expert advice to the ministry on how this pilot should be evaluated, so that it should measure outcomes not just for babies but also for mothers. The relevant body (RIVM) has since included maternal outcomes and maternal freedom of choices among its performance indicators [**5.10**].



The change to a two-year evaluable pilot has proven consequential – the two-year evaluation shows mixed results and recommends further evaluation; no compulsory national implementation has followed so far [**5.11**].

4.4a. Influencing Key Decisions by Charities: Geboortebeweging

Geboortebeweging (GB) is the only Dutch birth-rights charity and is the key social partner in national policy discussions surrounding birth care. Kingma is an important intellectual influence on their work, having collaborated with them continuously for the past 7 years as the only philosopher/ethicist involved. For example, by invitation, Kingma has presented her research at multiple National GB events [**5.9**]. She has also advised GB on their opinion pieces, policy submissions and press releases. In this way, Kingma's research has directly shaped GB's response to health policy changes (section 4.3, above), the Bravis case (section 5, below), and to changes and restrictions placed on pregnant and birthing women in response to the 2020 COVID-19 pandemic [**5.9**].

Kingma's collaboration with GB has been a two-way exchange. Kingma's thinking and research have been enriched and shaped by her interaction with GB and with the women seeking advice on their rights via GB's closed Facebook page. Vice versa, through both official and informal discussion, GB and its leaders have come to closely adopt the views developed and defended in Kingma's work [**5.3**, **5.9**].

4.4b. Influencing Key Decisions By Charities: Clara Wichmann Fund

Clara Wichmann Fonds (CW) is a Dutch charity that funds landmark litigation furthering the legal rights of women. In 2014, the charity was considering whether to try to establish a clear legal precedent that women have a right to refuse medical intervention intended for their fetus's benefit. Kingma was invited (as the only ethicist/philosopher) to consult with the charity. At first, the committee was very unsure about this goal, worrying that women might in fact be under a moral and legal obligation to undergo some medical interventions for the sake of their fetus. But later, after Kingma presented (an early version) of her research to the committee, they decided to try to establish a precedent for the right to refuse treatment, once a suitable case presented itself [**5.12**]. This resulted in CW's funding of the *Bravis* case (below).

5. Shaping Discussion Of The Landmark Bravis Court Case

The *Bravis* case (March 2018) was funded by Clara Wichmann Fonds, and co-litigated by Geboortebeweging. *Bravis* (the name of the hospital) concerned a pregnant woman with a previous caesarean section. She demanded a court order forcing the hospital to let her give birth on the midwife-led ward (rather than, following medical guidelines, the obstetric ward), in water and without a fetal heart monitor (again against hospital protocol), and with her personal midwife who works in a different region (and hence for a different regional 'integrated birth care organisation').

The case is intricate and combines questions about women's rights to refuse treatment and demand alternatives, questions about healthcare professionals' duties to assist such women with (less safe) alternatives, and questions about the financial organisation of Dutch birth care and how that impacts on women's freedom, autonomy and health, and on hospitals and other autonomous health care providers [**5.6**]. In short, it combines all the questions Kingma has been working on with various stakeholders and in her research since 2013. Kingma shaped the public and legal conversation surrounding the case in three primary ways.

First, Kingma contributed to public discussion of the case, which received widespread media attention. Kingma wrote research-based articles for two quality national newspapers: Trouw (circulation: 102,631) [**5.13**] and NRC (circulation: 136,000) – comparable to *The Independent* and *The Times*. The op-ed in Trouw was the focus of the Newspaper's in-house editorial [**5.13**]. Kingma also directly advised GB on its press contributions [**5.9**].

Second, Kingma continues to influence those pursuing the case. The initial case was lost, but this was expected: CW only takes cases that are expected to travel all the way to the supreme court. CW and GB are therefore preparing an appeal in collaboration with a law firm and a team of legal scholars and students at the University of Amsterdam (for whom this also doubles as a practical teaching exercise). Kingma has been closely involved, presenting her research to students and the lawyers, and providing detailed feedback on their drafts of the court order,

Impact case study (REF3)



which states the grounds and reasons for the appeal. This has changed the text of that document, as well as the underlying legal strategy pursued; instead of just focusing on a right to "personalised best care" (as the academic lawyers advised), the litigator is now pursuing a twopronged appeal that *also* pursues an argument that directly follows Kingma's research: an argument based on the combination of (1) a woman's right to refuse certain interventions, and (2) her right to receive the best care available given those choices, even if this pushes healthcare professionals outside their ordinary professional boundaries [**5.9**, **5.12**].

6. Providing professional training for health and social workers

Third, by request, Kingma has delivered training for the NVOG and KNOV, and is revisiting the guidance for professionals on birth outside the guidelines. Whereas the legal situation surrounding birth outside the guidelines seemed to have settled between 2015 and 2018, the Bravis case complicated it again. The Bravis case was widely interpreted as showing that healthcare professionals are only permitted, rather than required, to assist women with birth requests beyond the guidelines. As a result, some hospitals refused to provide 'care outside the guidelines' [5.5]. Consequently, Kingma has been invited to train professionals for the NVOG and KNOV on their moral obligation to provide such care at meetings and conferences [5.14]. She is also consulting with the subcommittee of the NVOG in charge of writing further clarifications for the guidelines, who plan to revise the guidelines in accordance with detailed verbal and written ethical analysis provided by Kingma [5.5]. Kingma also provides research-based training to other health-care workers, such as social workers and others involved in the care of pregnant women with a substance addiction [5.14].

5. Sources to corroborate the impact

- **5.1** Relevant details of (i) 2013 Court Case (ECLI:NL:TGZRAMS:2013:13); (ii) 2014 Appeal (ECLI:NL:TGZCTG:2014:263); (iii) 2018 Court case (ECLI:NL:TGZRZWO:2018:147).
- 5.2 Testimonial from lawyer for 2014 appeal.
- 5.3 Testimonial from Rebekka Visser, midwife.
- **5.4** NVOG/KNOV joint guidelines on maternity care requests outside the guidelines <u>https://www.nvog.nl/wp-content/uploads/2018/02/Leidraad-Verloskundige-zorg-buiten-</u> <u>richtlijnen-1.0-30-11-2015.pdf</u>
- 5.5 Testimonial from Gunilla Kleiverda, obstetrician.
- **5.6** Recommendations on the "Integrated Care" debate to the ministry of Health; the Parliamentary committee on Health, Well-being and Sport; and the Cross-Parliamentary Committee on Pregnancy and Birth Care.
- **5.7** Public interventions on 'integrated care': (i) newspaper article 'Integraal zorgtarief zet deur open tot verschraling geboortezorg' [Integral care-payment opens the door to impoverished birth care], *Volkskrant*; (ii) article in *Dutch Journal for Midwifery*, 'Gezondheid en Keuzevrijheid zijn in Gevaar' [Health and Freedom of Choice are in Danger]. *Tijdschrift voor Verloskunde*, 2016 (5): 12-14.
- 5.8 Citation in parliament during debate on integrated care:01-09-2016 09:26 Tweede Kamer der Staten-Generaal 2015-2016 32279 nr. 96 <u>https://zoek.officielebekendmakingen.nl/kst-32279-96.html</u>
- **5.9** Testimonial from *Geboortebeweging*.
- **5.10** "Insight in outcomes, utilization and medical spending of maternity care and the first experiences with bundled payments". <u>https://www.rivm.nl/publicaties/geboortezorg-in-beeld-nulmeting-en-eerste-ervaringen-met-werken-met-integrale</u>
- **5.11** "Bundled payments in Dutch maternity care: insight in experiences after three years and early effects on healthcare utilization, spending and health outcomes" <u>https://www.rivm.nl/publicaties/integrale-bekostiging-van-geboortezorg-ervaringen-na-driejaar-en-eerste-zichtbare</u>
- 5.12 Testimonial from Anniek de Ruiter, Chair of Clara Wichmann.
- **5.13** Newspaper articles on Bravis: (i) *Trouw*: 'Geboortezorg is ook zorg voor moeders' [Birth Care is also care for mothers]; (ii) *NRC Handelsblad*: 'Twistgesprek: Mag een vrouw zelf bepalen waar en hoe ze bevalt?' [Debate: May a woman decide where and how to give birth?]; (iii) *Trouw* editorial.
- 5.14 Schedule + feedback from healthcare professional training.