



Ethics Committee
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Regarding a new petition from Eva Kärfve to the Ethics Committee (2002-12-09) we want to give the following comments.

Dealing with the matter

We note that the Ethics Committee *invited* Kärfve to present a reply regarding our earlier response to the Ethics Committee in this affair. Kärfve's reply arrived 2002-12-09, after a Committee-approved delay. The reason why Kärfve had been offered the approved delay cannot be found in the writings from the Ethics Committee. We further note that the Ethics Committee has kept us ignorant about this investigation, which has strongly contributed to the fact that the period of investigation at this point has exceeded 6 months.

Kärfve focuses in this reply her interest to the same objections and questions as before. These have in detail been investigated and explained in our previous response to the Ethics Committee and thus refuted as misunderstandings and misrepresentations. These questions therefore will not be commented on further. However obvious—which can be expected after an invitation of this kind—Kärfve also presents new distortions, misrepresentations, and questions in her last reply. We however note that Kärfve completely avoids explaining or commenting those by-us-mentioned serious flaws that she has made herself guilty of in the earlier petition.

Kärfve's method of investigation research

As in her original petition about suspicions of misconduct, Kärfve in her new reply makes herself liable to wrongdoings. She cites on page 3 two sentences from our previous response to the Ethics Committee but loses (deliberately?) 3 words in the middle of the second sentence in the cited text. After the citing she gives the wrong page reference. This is significant for Kärfve's method of investigation. To mention just one other example: in her original petition Kärfve wrote in a certain place "39" instead of "29" without feeling that this was wrong (which without doubt, according to her own definition—if we wrote 7 instead of 1—should evoke suspicions about scientific fraud if this was committed by us) and did not consider this to need any further comments in her wordy reply to the Ethics Committee.

Kärfve's style when presenting her criticism

That Kärfve would continue to get hooked up in this net of details into which she has got entangled, despite our explanations and pointing out her mistakes, does not surprise us. We take for granted that this does not impress the members of the Ethics Committee. Actually it does not surprise us either that Kärfve turns to the question of PSQ- and MR- groups (see

below), in the same way that someone grasps for a straw, in an attempt to find ways to criticize our handling of these groups. What however surprises us is when she writes, “I am not aware that I ever expressed myself in an insulting way about any of the researchers in question ...”. We expect the members [of the Ethics Committee] themselves to scrutinize parts of Kärffve’s book *Hjärnspöken—DAMP och hotet mot folkhälsan* [*Idle Imaginings—DAMP and the threat to public health*] as well as the thorough scrutiny of the book that is available at the website of the university of Gothenburg (www.barnneuropsykiatri.org.gu.se). No one who reads these texts can be doubtful that Kärffve has expressed herself in a derogatory way in regard to us. It is also obvious from her book, which is filled with faults, devious allusions, and insinuations.

When we assert that many of Kärffve’s misconceptions about our research could have been solved by normal ways of communication, we of course do not mean at the time when one of us (PR) wrote the letter to Kärffve, which she several times referred to and which she added to her petition to the Ethics Committee. *This letter was written 2 years after* what we call Kärffve’s aggressive campaign. This started almost 3 years ago, when Kärffve from a position as an employee at the cultural editorial section of the daily magazine *Sydsvenska Dagbladet* had a close connection to the media. When Kärffve’s book was published, there was for natural reasons no more room for a constructive communication between Kärffve and us.

In her book Kärffve gives for possible researchers an astonishing map of sloppiness, giving wrong citations, and detail remarks which without explanation are blown up to generalized and unlikely conclusions. She has filled her book and several articles in the media with wrong/disconnected citations about our research and wrong claims about it with aggressive allusions about CG personally and his intents of the type “guilt by association”. She has not refrained from juxtaposition of CG’s research and the evils of the Nazis during the Second World War and comparison with a business venture. These actions from Kärffve show clearly that she never was aiming to achieve any communication regarding our research. Instead she has already from the start chosen a total confrontation—without any sign of willingness to discuss with us. Through her method Kärffve has achieved “fame by association”.

Attached the Ethics Committee will find some examples of above-mentioned.

We repeat: in December 2002 Kärffve writes in her petition to the Ethics Committee, “I am not aware that I ever expressed myself in an insulting way about any of the researchers in question ...”!

Another repeated claim on the part of Kärffve is that the results from our studies would be used “as a base for important decisions in society”. It is not up to us to evaluate if this has happened or if it will happen, but at the same time we want to say that this hardly has anything to do with regard to the question of scientific fraud or not. However this shows clearly what the gist of Kärffve’s assault against us and our research is made of—i.e. an intensive urge from her part to at any price evaporate the possibility that our research results would be able to influence policymakers in the society. This hardly can be seen as a fully honorable task for a “researcher” in a democratic society.

The base population once more

The question about the size of the base population and its composition is something on which we again must comment. Kärffve is trying to make it sound like we in the last minute found an explanation or an “excuse” by describing what it is all about. This is what it is. At the investigations in Phase 1 (see our earlier response), when we thus for the first time met the participants, we defined two groups of children (apart from those with MBD/DAMP, ADHD

and MPD and the comparison group) which it is here a further issue, those are the group “pre-school questionnaire” (PSQ) and the group with “mental retardation” (MR). In the PSQ group children participated who, according to the pre-school questionnaire, had certain MBD/DAMP -suspected difficulties, but at our investigation did not fulfill the criteria for a possible “neurodevelopmental” diagnosis. The MR group consisted of children with a minor psychiatric developmental disorder.

All children (minus drop outs) in the PSQ—and in the MR—group have been examined in the same way as the other participants in the study on all occasions, thus at the follow-up investigations at 10,13, 16, and 22 years of age. This can be concluded from Carina Gillberg’s doctoral thesis (the follow-up studies at 10 and 13 years of age) as well as Lars Hellgren’s doctoral thesis (the follow study up at 16 years of age). The results for the PSQ and MR groups were not presented in detail in the above [two] doctoral theses, as the main purpose had been to focus on the *prognosis for children with DAMP* from different perspectives (social, educational, psychiatric, and medical).

In the publication that focuses on the results from the follow-up at 22 years of age, however, nothing is mentioned about the PSQ and MR groups also being examined, even though this was the case. The results regarding these groups could not highlight the question regarding the long term prognosis about DAMP, and in a summary that is brief and compressed—which it must be in order to be published in a journal with the dignity of a journal like the *Journal of American Academy of Child and Adolescent Psychiatry*—there was no possibility to describe these less interesting groups. The relevant publications where the PSQ and PR groups participated, however, are included in the list of references in the mentioned article. If this summary had been included in a doctoral thesis there could possibly have been room for a presentation of the results for the PSQ and MR groups, for example in the framework of a doctoral thesis.

We thus can prove that Kärffe has not understood the content in our presentations to the extent that would be appropriate when you take the step to accuse somebody (us) of “misconduct and incompetence” (observe that Kärffe now also has extended her accusations to also include “incompetence”). But Kärffe makes a reservation. If now—contrary to her belief—it possibly was correct what we have presented here and in the doctoral thesis, i.e. what we are saying is the truth, she uses the alternative allegation that it would have been unethical not to present the results for these groups. We just would like to make a comment to this claim that this hardly can be a proper basis for suspicions of scientific fraud.

Depression once more

We have openly and clearly in our presentation at the follow-up at the age of 22 shown that a great part of the participants in the control as well as the index group felt that they at least on some occasion during their lives have had a period with symptoms corresponding to depression that it would have been a misrepresentation to use depression as a criteria of “poor outcome”. A considerable part of the control group then would have been classified as “poor outcome” despite that it was most likely that in most cases it was about rather well-functioning persons. How the figures are distributed between the different groups you can find in table 2 in the mentioned summary and anybody can understand this. That we in regard to the above have chosen to define “poor outcome” without accepting depression as a sign of this would not surprise anybody but Kärffe. It has for example not surprised the editors and the reviewers for the *Journal of the American Academy of Child and Adolescent Psychiatry*.

But it is also clear that what bothers Kärffe is something completely different, i.e. that we on other occasions have claimed that children with DAMP more often than children without DAMP have been affected with depression. This has been described in certain studies and is a

common experience in clinical praxis. The study gave, exactly as Kärffve claimed, no proof of that. We have presented this openly which hardly can be viewed in another way than that we honestly report data which do not agree completely with other studies or with clinical praxis. The reasons to suspect misconduct would have, from what we can understand, been much greater if we had not said this.

Under all circumstances: *How our fully open description of the results regarding depression and how we have dealt with them [the results] can be distorted by Kärffve in a such way that it could be used for suspicions of fraud is outside our imagination.*

Epidemiological research

Kärffve claims that only because Sociology often uses population-based research she has vast competence in this field (in medicine you transplant hearts—thus the authors in this petition have the competence to evaluate doctoral theses about heart transplants!). From what we can find, Kärffve has not published a single article in regard to epidemiological matters. In reality Assoc. Prof. Kärffve's list of publications (apart from articles in the media) consists of a handful articles, one of them a research plan for one of Kärffve's students, and another "work" of hers is the debate book *Hjärnspöken—DAMP och hotet mot folkhälsan*. None of the articles she has produced have been published in any international scientific journals with a peer-review procedure.

As we mentioned earlier in detail on the web site of the university of Gothenburg, it has been shown that the critique against our studies that Kärffve put forward in *Hjärnspöken—DAMP och hotet mot folkhälsan*, precisely like the critique she now presents as a support for her accusations about scientific misconduct etc., is baseless. According to our point of view Kärffve has instead shown that she does not have the competence to make the correct judgments in regard to epidemiological research. *Again we must refer to the collective competence [of those] who have assessed and approved our research, i.e. 4 faculty opponents, 12 members of the assessment committee, and at least around thirty reviewers from internationally distinguished scientific journals. All of them have had the scientific competence in the relevant field which Kärffve is lacking.*

Kärffve displays again her insufficient knowledge about medical epidemiological research when she writes "I do not know any other example of a population-based longitudinal study—regardless of what has been examined—where such a low drop-out rate has been reported." We must say that it is irrelevant what Kärffve knows. We do not feel it is our task to educate her in these things, but rather to refer to the final words in an article in the magazine *Dagens Medicin* that was written by professor emeritus Ingemar Kjellmer at a time when Kärffve's collaborator Leif Elinder had sent in his petition but before Kärffve's own petition had been delivered: "I take for granted that there are many of us now, who can look forward to accusations from Elinder and his cohorts, when you discover that there are several Swedish long term follow-up studies, which have remarkably low drop-out rates".

Blindness, an update

Kärffve has correctly pointed out that one of the doctors who examined the participants at the age of 22 must have been Gunilla Carlström. This is correct. Exactly as we have pointed out, she with CG examined the study subjects when they were 7 years old. Kärffve has used "Acknowledgements" in CG's doctoral thesis (from 1981) in her eagerness to show that Gunilla Carlström—opposite what we have reported in papers and in earlier reports to the Ethics Committee—was not unaware about the study subjects' group assignments. Kärffve has underlined part of a quotation from CG's "Acknowledgements", where he thanks Gunilla Carlström, for that she "took part in the global diagnostic procedure". Kärffve thus immediately draws the conclusion that could support her suspicion of lack of blindness—i.e.

in regard to concluding a possible MBD/ADHD/MPD-diagnosis (“Neurodevelopmental” diagnosis = “original diagnostic group status” in the follow-up studies). Perhaps Kärffve should have read CG’s basic research and considered that this “Acknowledgement” could be found in a thesis whose focus is about the prevalence of *psychiatric disturbances* among the investigated 7-year old children. What Gunilla Carlström is thanked for is that she has participated in “*the global diagnostic procedure*” in regard to psychiatric problems in children (where Gunilla Carlström of course could not have been blind), for example depression, anxiety disorders, etc. (not “neurodevelopmental” diagnosis).

To go further into detail, Gunilla Carlström has also been one of the observers/examiners who has contributed to the basic research material, i.e. less than ¼ of the material, to the prevalence of “attention deficits” (which in turn only is a small part of the material to the total “Neurodevelopmental-diagnostic assessment). The foundation for diagnosing those conditions, which the follow-up studies have used to define “original diagnostic group status” (MBD, ADHD, MPD, “Comp 1”, “Comp 2”, “Comp 3”, MR, PSQ), was the neurological and psychological assessment and not the psychiatric (which was done by CG and Gunilla Carlström). This has been described in detail in CG’s thesis. *Thus Gunilla Carlström has not had any knowledge about the children’s “neurodevelopmental” diagnosis.*

After this Gunilla Carlström has had no contact with the study objects, and not with the study as a whole, before she 15 years later met these individuals as young adults, who she thus only has seen once before. We find it difficult to understand that her “blindness” should be questioned and this has not happened except for Eva Kärffve. PR and CG on the other hand have had knowledge about the original group memberships and were thus disqualified to be examiners after phase 1.

Final points

1. “have all participants in phase 5 actually have been examined”.

Not clearly expressed, but you have to guess that Kärffve wants to know if all the participants who were presented in the thesis with results from phase 5 really were examined. *The reply is and will always be: yes.*

2. “these people came from ...”

Yes, all the persons who were investigated you can find in the original study of 141 children. We have not exchanged children from the PSQ or MR-group or from anywhere else and a falsification/fabrication of the research protocol has not taken place. On page 7 paragraph 3 Kärffve writes about the need to clear suspicions about whether “... that you instead have chosen to examine some of the persons in (the excluded) MR group”. Once again: the persons in the PSQ and MR group have been examined. Of course they have not been reported to be included in any other group as Kärffve is insinuating.

3. “... the examining doctors get identified ...”

These doctors are identified both to name and date of birth, however more important: their competence to pursue their task in the investigations is beyond doubt. Relevant information about those researchers, who have had anything to do with the earlier phases of the study or for any other reason could have had any knowledge about the participants’ originally-diagnosed group assignment, have been reported in previous texts as we also have done in this text. Reviewers and other experts in the field (opponents, members of the assessment committee) have been satisfied with our report in this case.

4. “it is confirmed that the participants were unaware of their own diagnoses ...” We have earlier reported how the participants or rather their parents were informed about the results from the individual examinations. For blindness reasons the investigator in the follow-up studies have not asked the parents of the study subjects of their knowledge or their guesses of a possible diagnosis in the earlier part of the study. Kärffve makes an interesting slippery move away from our description when she writes that the participants were “able to discuss their social and psychological problems in neuropsychiatric terms”. Who has told that they would have argued about their problems in neuropsychiatric language? And why would the fact that so many participants experienced that they really have great problems and would be able to get certain help to understand their problems in connection with the investigation contradict the claim that they did not know their *diagnosis*? You can of course be painfully aware of your problems without discussing them and dressing them in neuropsychiatric terms!

Anyone who makes an effort to understand how these investigations have been made understands that it cannot escape an able clinician that one of the examined participants has extremely great problems while the other seems to get along quite well. “Blindness” in this connection is something quite different (which clearly has been documented in all relevant reports)—i.e. that the examiner does not have a knowledge of which original “neurodevelopmental” diagnosed group the individual was recruited from.

Summary

Kärffve’s—as her collaborator Leif Elinder’s—main objection against our study is that the drop-out rate is too low to be believed (about 10%, somewhat lower in the index group than in the control groups). This is a scientifically baseless *opinion*, which Kärffve—like Elinder—has not been able to present any support for. *That such an objection can be taken seriously and used as the only accusation for scientific fraud is absurd*. Some qualifications should be applied on quality and credibility in an accusation in regard to scientific fraud if this should be taken so seriously that it results in an extensive investigation, an investigation, which at this time has been going on for six months. It should here be stressed that the burden of proof according to our tradition of law rests on to the accuser and not the one being accused.

Kärffve has now as before displayed her extremely hostile opinion about our research and also to the neuropsychiatric field of knowledge as a whole. She is not hiding that her utmost goal is showing wrongdoings in our research to prevent that the knowledge that has transpired from these studies will influence public policymakers. Here can be mentioned that a considerable number of international studies in the last years have shown results similar to those that we have found. You can only speculate what reasons Kärffve can have to try to hide and belittle these important research findings for decisions makers and for the public.

Finally we will put forward that what Kärffve accuses us of is very serious and she should understand that her baseless accusations heavily fall back onto herself and her credibility as a researcher.

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