



Quality in Prevention
8th EUSPR Conference and Member's
Meeting
20th – 22nd September 2017
Vienna, Austria



Ethical challenges in studying families at risk

- experiences from the pilot study of the
FamResPlan research project

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**This work has been fully supported by Croatian Science Foundation under the project IP-2014-09-9515*

Research with families

- *Sensitive type of research* - „research potentially posing a significant threat to those involved“
- The sensitivity is even more pronounced when the research involves „hard-to-reach“ and socially excluded families
- Many ethical issues are „intensified“ due to system research,
 - Informed consent (e.g. who gives it – a member, the family, what if all members of the family don't give consent?)
 - Confidentiality of data (e.g. disclosure of confidential information about other family members)
 - Unexpected findings (e.g. information about other family members)
 - And other...

Basic ethical principles in the research and practice of helping professions

- Autonomy – respect for the right to self-determination
- Well being – the obligation of members of the profession to help others
- Confidentiality – safeguarding the confidentiality of information obtained in the context of a professional relationship
- Fidelity – keeping promises
- Fairness – providing just and equal treatment to all
- „Not doing harm“ – the obligation to comply with the rule „do no harm“
- Privacy – respect for the personal decisions regarding when and what information to provide about themselves
- Truthfulness/honesty

Ethical issues in the FamResPlan project

Commitment to ethical principles in defined areas

- Access to research participants/families; informed consent; conducting research; impact of research on participants; the influence of research on the research team

Ethics of the research team

- Establishing the Ethical Council of the Project
- Monitoring all stages of the project through the „ethical prism”
- Monitoring of project phases using meetings, documents/procedures/protocols related to ethical issues

Commitment to Ethical Principles – Part 1

Access to Research Participants/Families

- Gatekeepers
- A protocol on cooperation with gatekeepers

Experiences from the pilot...

Access to Research Participants/Families

- Relationship between gatekeeper and participant
- Compensation for travel costs – motivation?
- Very long informal introduction to interview – culture?

Commitment to Ethical Principles – Part 2

Informed consent (approval) of the research participants

- Informed consent „in phases” that accompany the stages of research
- Confidentiality of data and anonymity
- Data to be collected
- The consent of the family vs. Consent of a member of the family
- Voluntary participation

Experiences from the pilot...

Informed consent of the research participants

- Convincing gatekeepers

Commitment to Ethical Principles – Part 3

Conducting research

- The relationship of trust between participants and researchers
- Unexpected findings
- Research vs. intervention

Experiences from the pilot...

Conducting research

- Parent-child interaction
- Understanding issues
- Length and repetition perceived as possibly manipulative and deceiving
- House visits
- Length of the interview protocols
- Presence of other people?
- Too casual atmosphere? Presence of younger children?

Commitment to Ethical Principles – Part 4

Influence of research on the participants

- Minimal risk for the participants
- Ensuring well-being, loyalty, fairness, privacy, honesty and autonomy
- Reducing the possibility of additional stigmatization
- Informing the participants about the possibilities of additional support
- Compensation for participation/compensation for invested effort, cost and time

Experiences from the pilot...

Influence of research on the participants

- Stressful and potentially uncomfortable topics for the children
- Accusations and scapegoating of several family members
- Be consistent and precise about the topic of the interview and the communication rules
- Staying on topic
- Participants in need of support
- First family conversation

Commitment to Ethical Principles – Area 5

Influence of research on the research team

- Ethics of the research team
- Vulnerability of the researcher
- An external supervisor/independent consultant
- Closure/exit strategy
- Privacy of the researcher
- The research conducting protocol
- The protocol of dealing with high risk situations

Experiences from the pilot...

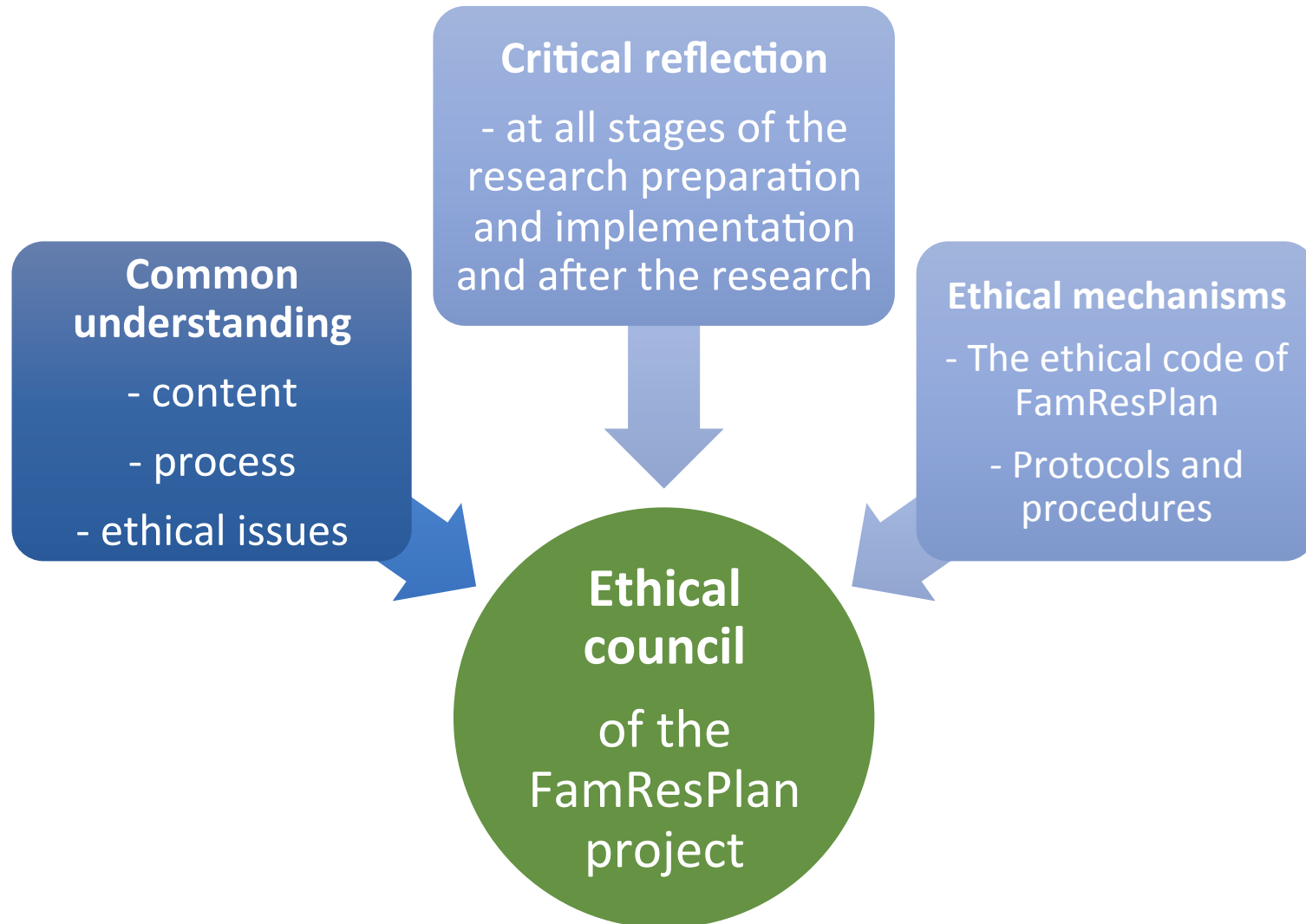
The influence of research on the research team

- Stressful, emotionally demanding
- Urge to help and intervene
- Responsibility for bringing problems in the forefront and not doing anything about it

Conclusion about lessons learned

- Experiences from the pilot confirm the previously anticipated ethical issues
- Family perspective – ethically challenging

Ethical council of the FamResPlan project – main study



Thank you!

More about the FamResPlan project

<http://www.famres.erf.hr/hr/>

<http://www.famres.erf.hr/en/>

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