



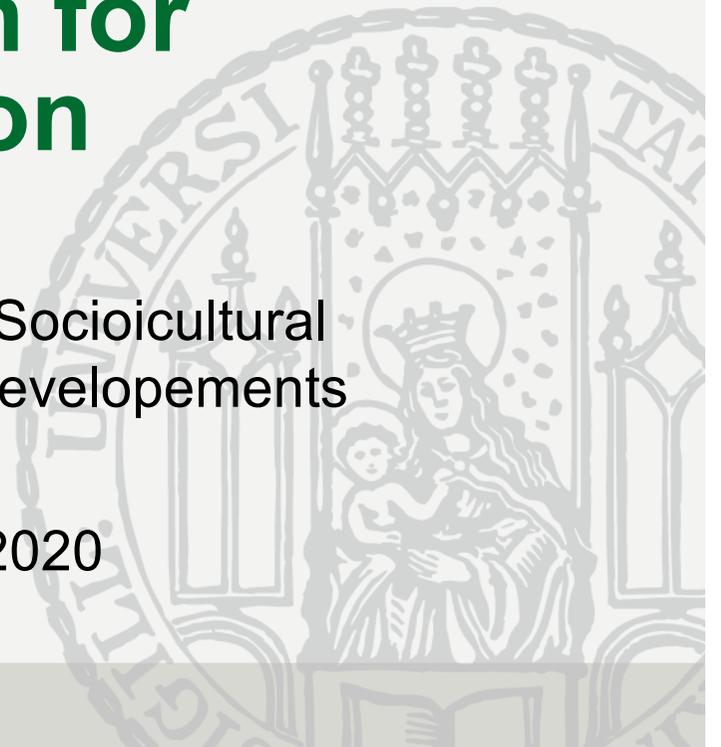
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Ethical reflection on public health communication for dementia risk reduction

Dementia Prediction and Risk Reduction: Socio-cultural Insights, Ethical Reflections, and Future Developments

Göttingen & elsewhere in the world, 07.12.2020





- *Potentially modifiable* risk factors for dementia (e.g. report of the Lancet Commission 2020)
- ⇒ Modifying 12 risk factors might prevent/delay up to 40% of dementias
- ⇒ *Social determinants of health* (education, poverty, inequality, social contacts....)
- ⇒ *Population* based (“public health”) and *individual* focused *prevention* across the life-course required
- ⇒ Implications on well-being (benefit vs. harm), autonomy & equality
- ⇒ *Systematic* assessment of the *ethical* implications of preventive interventions
- ⇒ Basis: **public health ethics framework**

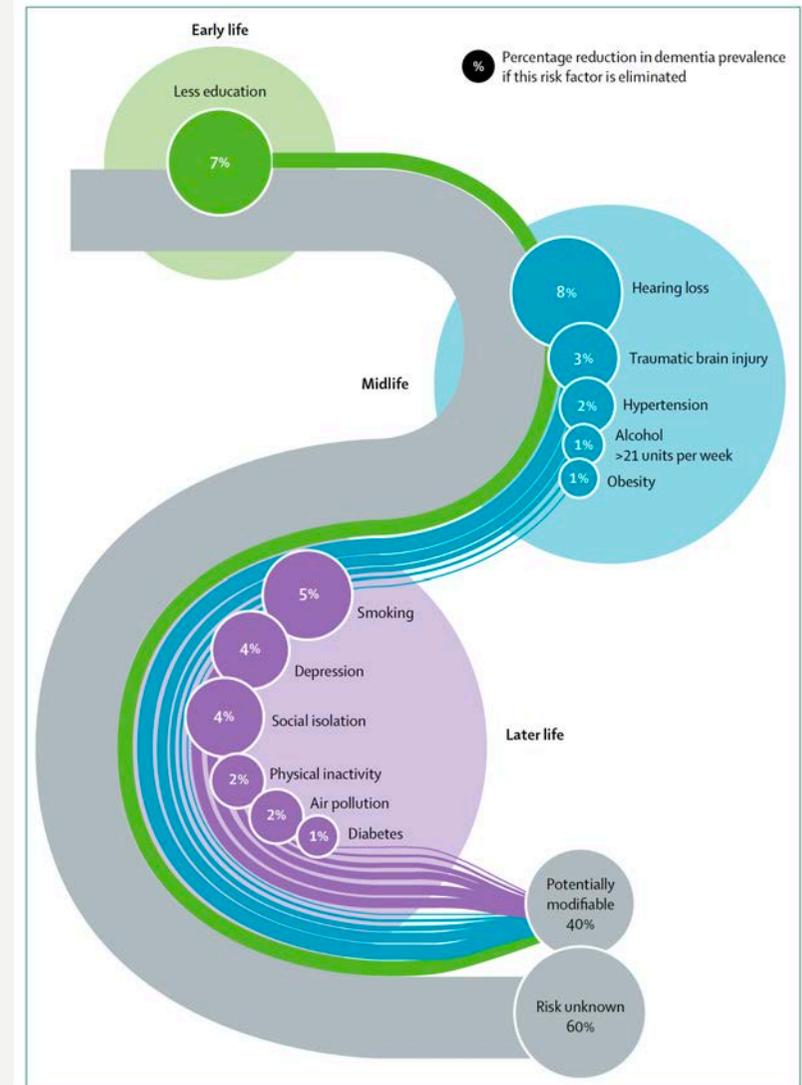


Figure 7: Population attributable fraction of potentially modifiable risk factors for dementia

Lancet 2020, 396: 413-46



- PH-I (often) aim at healthy subjects ⇒ special legitimation required
 - Initiative usually comes from PH-professional, not from the individual
 - Focus on populations: benefits for some, burden and risks for many
⇒ ethically more “delicate” benefit-harm-evaluation
 - E.g. breast cancer screening (false positives, overtreatment, etc.)
 - Effective PH-I often require behavioral changes ⇒ which restriction of individual autonomy is acceptable?
 - E.g. mandatory immunizations, tobacco/alcohol regulation
 - Focus on average population health ⇒ distribution of benefits and harms must not be neglected
 - High risk populations are often more difficult to reach
 - Many (positive & negative) effects of PH-I have a long time horizon
⇒ valid assessment of benefits & harms more difficult
⇒ decision under empirical uncertainty
- ⇒ systematic ethical analysis of PH-I (*public health ethics*) “indicated”



Goals of public health ethics

- (1) *Identify* ethical issues in the field of public health
- (2) Ethically *evaluate* individual public health interventions (PH-I)
- (3) Develop ethically justified *recommendations* for the development and implementation of PH-I ⇒ *constructive role* of ethics in shaping the design & use of PH-I

Requirements

- (1) (Comprehensive & flexible) **normative framework** ⇒ explicit ethical justification
- (2) **Systematic methodological approach** ⇒ transparent evaluation, process quality assessment, education & guidance for public health professionals

Normative framework for public health ethics (Marckmann et al. 2015)

| | Normative criterion | Ethical justification |
|---|---|---|
| 1 | <p>Expected <i>health benefits</i> for target population</p> <ul style="list-style-type: none"> • Goal of the intervention/program • Effectiveness in achieving the goal • Impact on morbidity, quality of life, mortality (=benefit) • Validity (strength of evidence) of benefit | Beneficence, utility (benefit) maximization |
| 2 | <p>Potential <i>harm & burdens</i> for participants</p> <ul style="list-style-type: none"> • Health risks, burdens/discomfort • Validity (strength of evidence) of harms/risks | Nonmaleficence |
| 3 | <p>Impact on <i>autonomy</i></p> <ul style="list-style-type: none"> • Health-related empowerment (e.g. improved health literacy) • Respect for informed individual choice (“informed choice”) • Least restrictive intervention • Protection of privacy and confidentiality (data protection) | Respect for autonomy, beneficence |
| 4 | <p>Impact on <i>equity</i></p> <ul style="list-style-type: none"> • Equal access to the public health intervention • Fair distribution of benefits and risks • Reduction of existing health disparities • Need for compensation? | Justice |
| 5 | <p>Expected <i>efficiency</i></p> <ul style="list-style-type: none"> • (incremental) cost-effectiveness ratio • Validity (strength of evidence) | Utility (benefit) maximization, justice |
| 6 | <p><i>Legitimacy</i></p> <ul style="list-style-type: none"> • Legitimate decision maker • Fair & transparent decision procedure | Justice, respect for autonomy |



Criteria for a fair decision process

| | |
|--------------------------------------|---|
| Transparency | Decision process including data base and underlying normative assumptions should be transparent and public |
| Consistency | Application of the same rules and criteria for implementation of public health programs ⇒ equal treatments of different populations |
| Justification | Decisions should be based on relevant reasons (based on the normative criteria for public health ethics) |
| Participation | Populations affected by the PH-program should be able to participate in the decision about the implementation |
| Minimize conflict of interest | Decisions about PH-programs should be organized to minimize conflict of interests |
| Open for revision | Implementations of PH-programs should be open for revision (e.g. if data basis changes or certain aspect have been neglected) |
| Regulation | Voluntary or legal regulation should guarantee that these criteria for a fair decision process are met |



Steps of an ethical evaluation of public health interventions

| | | |
|---|-----------------------|--|
| 1 | Description | Thorough characterization of the PH-I: goals, methods, target population, etc. |
| 2 | Specification | Specification (if necessary) of the normative criteria for PH-I |
| 3 | Evaluation | Step-by-step evaluation of the PH-I based on each of the 6 normative criteria |
| 4 | Synthesis | Overall evaluation of the PH-I by integrating & balancing the 6 single evaluations of step 3 |
| 5 | Recommendation | Development of recommendations for the design, implementation, or modification of the PH-I |
| 6 | Monitoring | Monitor and re-evaluate the ethical implications in regular time intervals |

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Ethical assessment of interventions for dementia prevention

| | Normative criterion | Application to dementia risk reduction |
|---|--|--|
| 1 | Expected <i>health benefits</i> for target population | <ul style="list-style-type: none"> - Based on valid assessment of dementia risk factors - Proven effectiveness to prevent/delay dementia (⇒high risk groups) - Design (communication) strategies to improve adherence to effective life-style interventions (motivation↑) |
| 2 | Potential <i>harm & burdens</i> for participants | <ul style="list-style-type: none"> - Minimize esp. psychological harm by understandable, careful & empathic <i>risk communication</i> tailored to the target group - Minimize burden by tailoring risk prevention strategies to living conditions of target population |
| 3 | Impact on <i>autonomy</i> | <ul style="list-style-type: none"> - Improve general <i>health literacy</i> as basis for healthier life-style - <i>Health-related empowerment</i> through evidence-based, balanced communication about dementia risk reduction - Support <i>self-determined</i> behavioral life-style changes (“nudging”) |
| 4 | Impact on <i>equity</i> | <ul style="list-style-type: none"> - Target dementia prevention to disadvantaged, vulnerable groups with lower socioeconomic status & higher risk of dementia ⇒ <i>priority to the worst off, reduce inequality</i> - Secure individuals’ <i>equal access</i> to dementia prevention |
| 5 | Expected <i>efficiency</i> | <ul style="list-style-type: none"> - Assess cost-effectiveness of different preventive strategies - Use most efficient prevention strategy to achieve certain public health goal (= level of dementia risk reduction) |
| 6 | <i>Legitimacy</i> | <ul style="list-style-type: none"> - Prevention program established by legitimate PH authority - <i>Participation</i> of target groups in design & implementation |



- Public health ethics framework: methodological approach for assessing ethical implications of dementia prevention
- Requires close cooperation with *empirical sciences*: Public health sciences & socio-cultural sciences
 - ⇒ *Multidisciplinary approach* (like in this meeting 😊)
- Goal of structured ethical assessment: *shape* design & implementation of dementia prevention according to ethical principles
 - ⇒ *Constructive, practice oriented* approach to public health ethics



Thank you very much for your attention!

Questions?

Objections?

Discussion!

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Putting public health ethics into practice: a systematic framework

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