



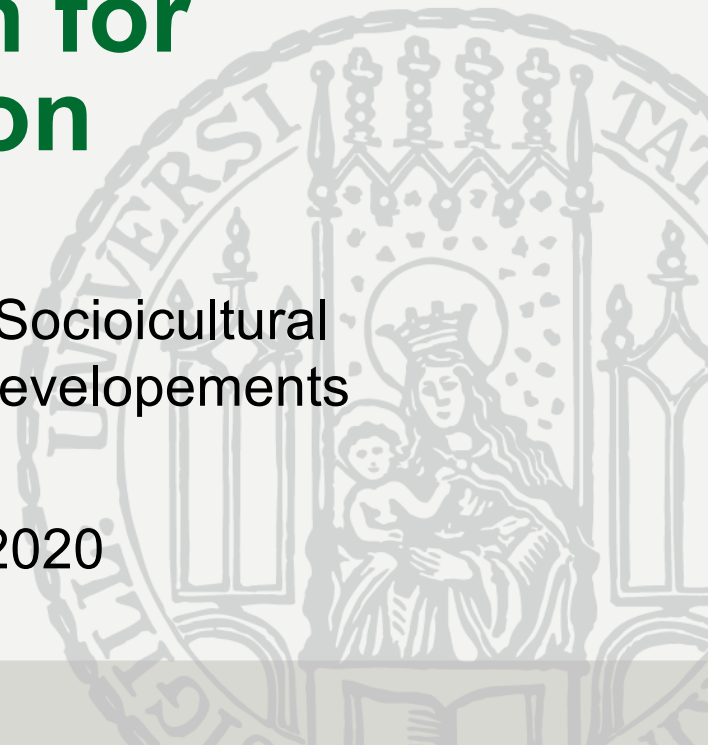
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Ethical reflection on public health communication for dementia risk reduction

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**

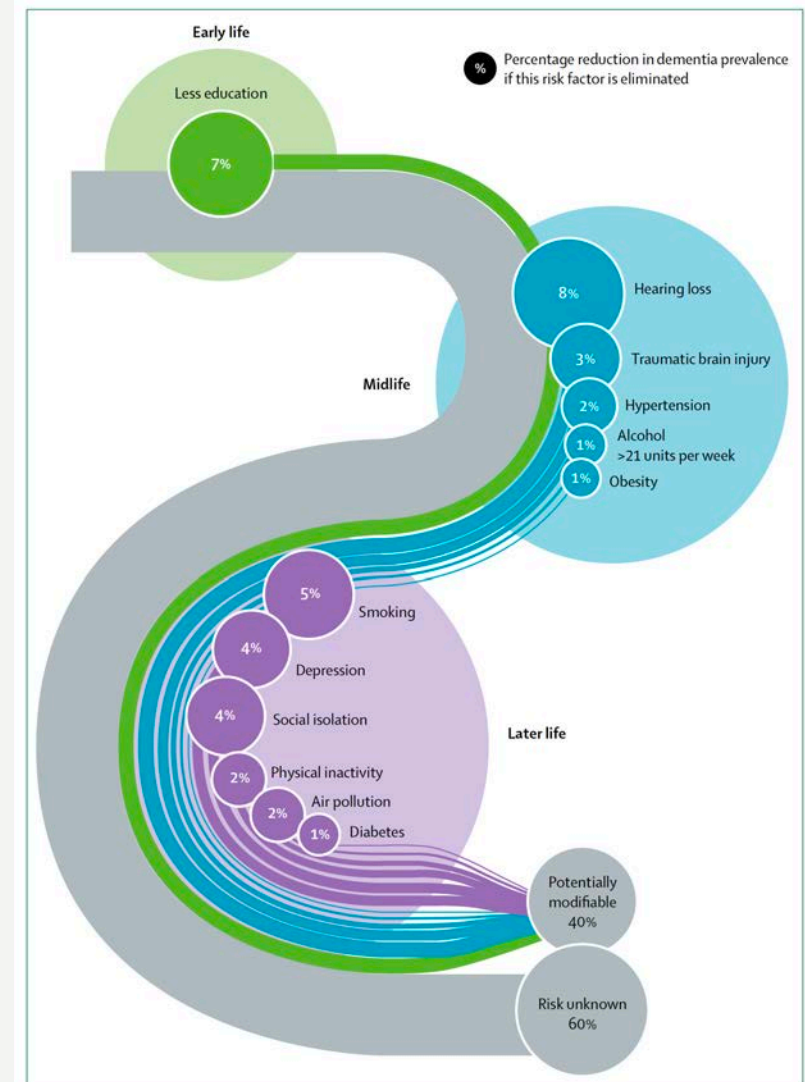


Figure 7: Population attributable fraction of potentially modifiable risk factors for dementia

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	Expected <i>health benefits</i> for target population <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	Potential <i>harm & burdens</i> for participants <ul style="list-style-type: none"> • Health risks, burdens/discomfort • Validity (strength of evidence) of harms/risks 	Nonmaleficence
3	Impact on <i>autonomy</i> <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	Impact on <i>equity</i> <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	Expected <i>efficiency</i> <ul style="list-style-type: none"> • (incremental) cost-effectiveness ratio • Validity (strength of evidence) 	Utility (benefit) maximization, justice
6	<i>Legitimacy</i> <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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