

Proxy Decision-making in a Deprescribing Trial in Nursing Home Residents with Dementia: a Qualitative Analysis

RATIONALE

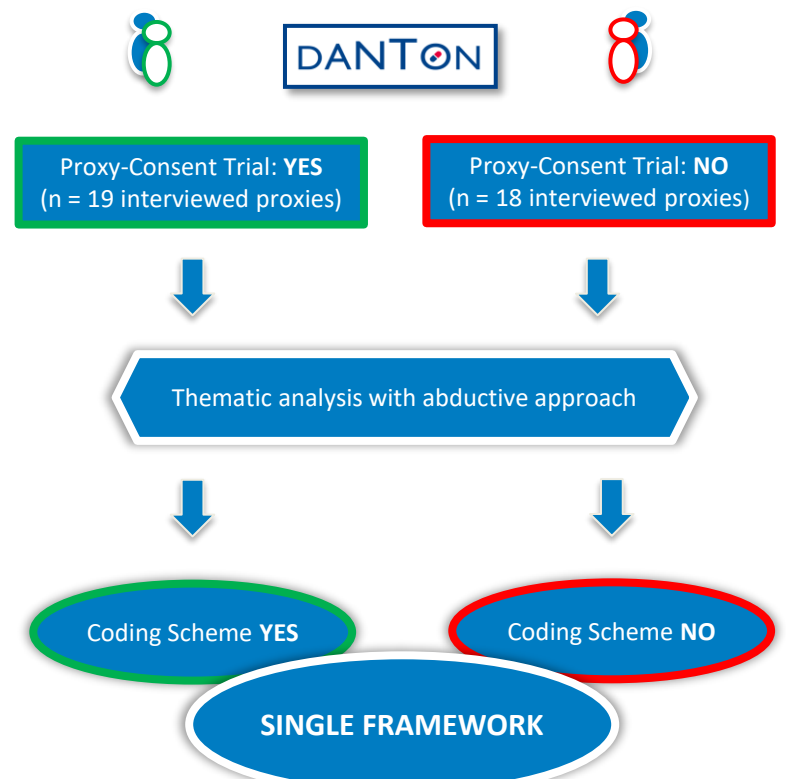
- Due the need for proxy-consent, older adults with dementia are frequently excluded from experimental studies, leading to a questioned net benefit of many medical interventions in this population.
- With a greater risk of severe side-effects, a promising potential clinical target is the reduction of polypharmacy. Hence, older adults with dementia, and especially those living in a nursing home, form a preferable target for a randomized controlled trial (RCT) on deprescribing.

Question is: how do the informed consent procedure and the process of proxy decision-making on the participation in such an experimental trial take place?

CONCLUSION

The process of proxy decision-making on trial participation of older adults with dementia might be considered as a benefit-risk evaluation, guided by study and patient related factors that are weighted on level of the deciding proxy. Other involved proxies or treating healthcare professionals can modulate the final evaluation of these factors.

METHODS



RESULTS

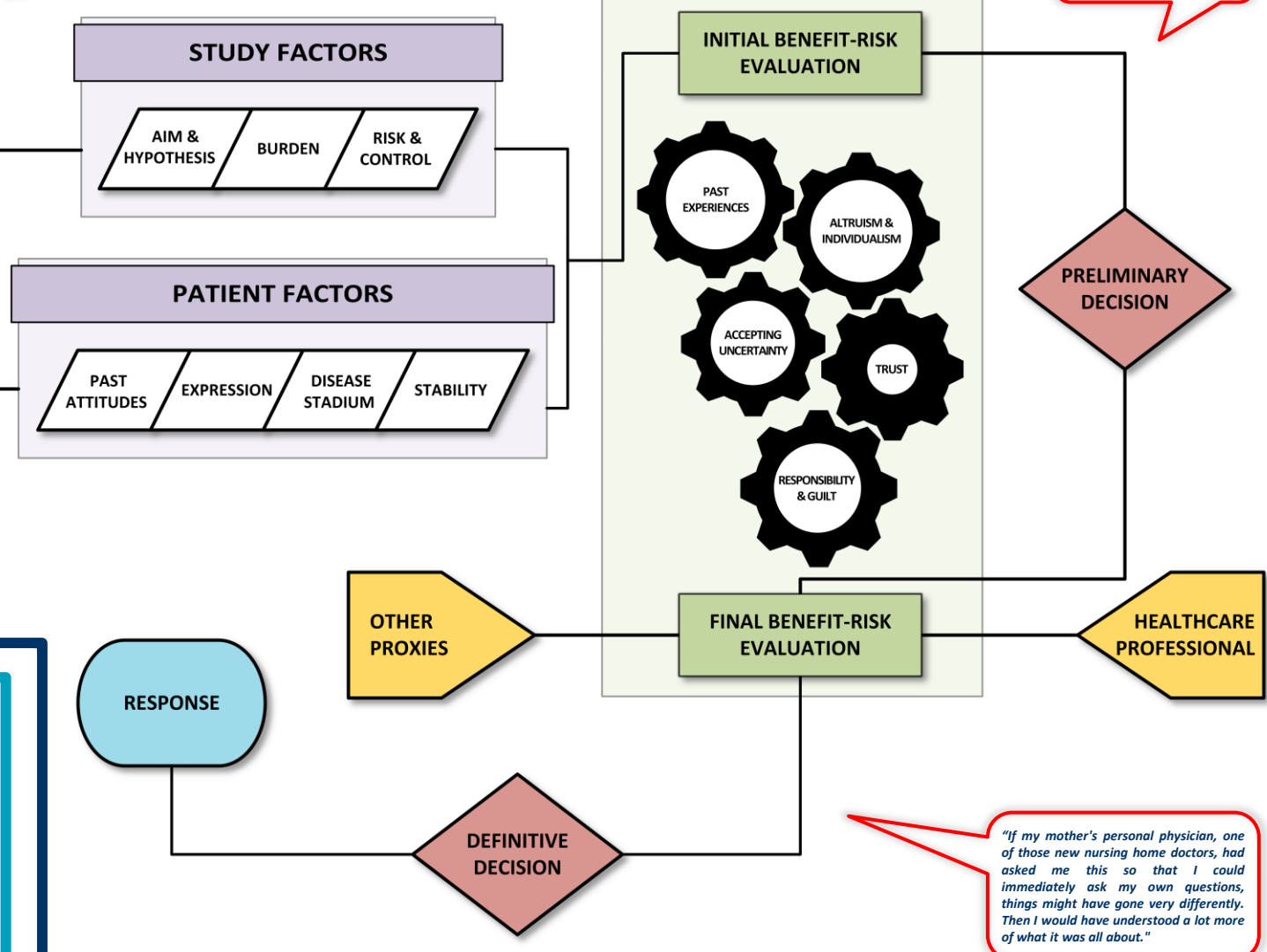
"What was important was that there were assurances, that if things were to go wrong then they would intervene."

"I don't want to be in a situation where something is done accidentally, and then something unintended happens to my mother that causes my father to spend the rest of his life saying 'Do you see now? We really shouldn't have messed about with her blood pressure.'"

"...of course something could go wrong, but whatever, things can also go wrong when crossing a busy road. So yes, it's all in the game, right?"

"...So if she [the doctor] had suggested it as part of treatment or care, I would certainly have gone along. But right now it's really about the experimental character."

"We are so pleased with how she is coping there, we don't want anything at all to interfere with it."



IMPLICATIONS

Individualized information about the possible risks and benefits to expect, communicated by a trusted healthcare professional involved in the primary care for the older adult with dementia, can ameliorate the decision-making process on proxy-participation in an RCT.

"If my mother's personal physician, one of those new nursing home doctors, had asked me this so that I could immediately ask my own questions, things might have gone very differently. Then I would have understood a lot more of what it was all about."

