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The course of frailty in older persons with intellectual disability

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Background

1. Until today, there is no widely accepted definition of frailty. The literature abounds with different models, criteria and definitions (Hogan et al., 2003).
2. Despite this problem there has been an exponential increase in the number of “frailty publications” for the general population and also the word “frailty” is increasingly used in publications about PWID.
3. 2006 first frailty measurement in the ID population (Brehmer, 2008)

Frailty measurement

- No accepted definition of frailty leads to no clear measurement strategy, also because there is no active discussion on operationalisation of this phenomenon.
- Mostly researchers used their well known techniques to describe the new concept of frailty (e.g. Mini Metal State Examination)
- Also these instruments were not usable for the ID population (see Brehmer & Weber, 2009).

⇒ **Therefore a new instrument was created 2006 that**

1. Uses frailty criteria (Rockwood, 2000 & Fried, 1994) that can be operationalised and
2. Comprises all variables that were recorded in other research projects that tried to describe frailty.

Frailty Criteria (Rockwood, 2000)

1. **Multisystemic Impairment** (social, psychological, cognitive and physical domain)
2. Instability
3. **Change over time**
4. An allowance for heterogeneity within a population
5. An association with aging
6. **An association with an increased risk of adverse outcomes**

Frailty Questionnaire

(see Brehmer, 2008 or Brehmer & Weber, 2009)

1. **Physical domain (16 Items) :** Decrease of physical strength, vision, hearing, mobility; ADL (washing, eating, transfers, dressing, toilette), increase of medication, unintended weight loss, grip strength, falls, incontinence, usage of walking frame; General health decline
2. **Psychological domain (6 Items):** Fear of falling, Exhaustion, memory skill decrease, nervousness and anxiety, sadness, other psychological changes,
3. **Cognitive domain (7 Items):** IADL (household chores (complex/ easy); shopping; handling money; use of telephone; preparing meals; independent medication use)
4. **Social domain (4 Items):** Work, friends, family, member of a club/ association

⇒ **Negative Changes? Since when?**

Frailty Study 1
(2005 – 2008)

Evaluation of the Frailty Questionnaire

- **Frailty was coded as the fulfilment of two conditions:**
  1. **Negative health outcomes in 3 or 4 domains**
  2. **Minimum of 6 negative health outcomes**
- Statistical analysis revealed third party data to be more reliable, confirming the assumption of substantial psychometric differences between those parts of the instrument that were assessed by different respondent groups.
- Item reliability **.854** (Cronbach's Alpha) & Guttmann's split half reliability **.72**
- Exploratory factor analysis: 3 factors (physical, cognitive, psychological) explained a total variance of **59.81%**

Some frailty results

- Representative sample of 190 adults with ID
- **Results frail sample:**
  - 17 (9%) of the 190 adults were coded as frail
  - 27% frail subjects with ID older than 50 vs. 10-25% general population older than 65 (Ostir, 2004)
  - Median Age: 61 frail vs. 39 non frail (Spearman's Rho; p<.001)
  - 82% (n= 14) mild or moderate ID
  - No statistically significant differences to non – frail
    - Gender: women with ID (frail 53% vs. non-frail 48%) are more frequently frail than men (frail 47% vs. non-frail 52%).
    - Living situation: institutional settings (65%) and urban regions (53%)
- **Results pre-frail sample:**
  - 22 persons (12%) fulfil one frailty criterion
  - Median age: pre frail 45.5 vs. non-frail 39.5
  - more women (13 of 22) and more institutionalised (16)

Critic concerning frailty study 1

- **Interviewer training:** to gain this specific health information (temporal relations) and frailty coding
- Instrument changes necessary
  - Social domain: irrelevant item *club membership*
  - Cognitive domain: IADL changes can have physical reasons too
  - Physical domain: more precise questions are needed so that self-advocates can answer them too
  - Psychological domain: missing psychological symptom *anger*
  - No split in self report and third party data!
  - Opinion of self-advocates should be gathered and included
- Missing psychometric properties: validation, retest reliability,..

Frailty Study 2 (2009)

Extended interviewer training

- More training phases and individualised
  - Theoretical input by clinical psychologist
  - Role plays with the frailty questionnaire
  - Observation of at least 7 interviews conducted by experienced interviewers
  - Conduction of interviews and frailty coding under supervision of project coordination
  - Regular intervisions on already conducted interviews

Adapted frailty questionnaire

1. **Physical domain (min. 20 items)**
   - New: Physical strength spilt into: legs/ arms, ability to keep balance
2. **Psychological domain (7 Items)**
   - New: anger
3. **Cognitive domain (max. 7 items)**
   - Information from participant whether the negative changes are cognitive or physical symptoms
4. **Social domain (10 items)**
   - quantitative and/or qualitative changes
   - New: spare time activities, intimate relationship
   - Deleted: club membership

⇒ **Review of frailty criterion 2 will be necessary!!**

Current standing of frailty study 2

- 141 finished interviews (April to August 2009)
  - 16 interviews to come
  - 33 drop outs
    - 23 refusals of self-advocates and 3 refusals by organisations
    - 1 person died and 4 persons with worsened health
    - 2 moved to a unknown town
- 108 interviews recorded in the SPSS file
- 19 interrater interviews (approx. 6 to come)
- 9 retests (approx. 11 to come)

Case Studies:
Persons with frailty and pre-frailty

Case Study (Code 7):

- 40 year old man: mild intellectual disability and autism
- 2006: 5 changes in 3 domains (no social changes): third party data
  - money use, fall and fear of falling, increased medication, general health decline
- 2009: self report
  - Ever since: anxiety
  - 15 years: balance
  - 10 years: shopping
  - *9 years: gained more weight*
  - 4 years: reduction of telephone use
  - 3 years: mobility decrease & increase of exhaustion
  - 2 years: reduction of spare-time activities (more passive)
  - 1, 5 years: reduction of working hours
  - 1 year: decreased vision; fall
  - No date: decrease of memory skills

Case Study (Code 61):

- 60 year old man with a mild ID, who lives alone.
- 2006: 7 changes in 4 domains
  - 8 years: work
  - 5 years: Increased medication, general health decline, anxiety
  - 2 years: reduction of family contacts, decrease of memory skills
  - No date: telephone usage
- 2009:
  - Ever since: incontinence, anxiety and anger
  - 25 years: reduction of spare-time activities (more passive) & less fun
  - 8 years: decrease of mobility & balance, decreased physical strength (arms/ legs), *gained weight*
  - 5 years: grip strength
  - 3, 5 years: reduction of working hours
  - 1 year: less contact to family, increasing sadness
  - No date: reduction of friends and less contact to remaining friends; reduction: handle money and do shopping

Conclusion

- Instrument changes positive for the interview conduction
- Training was positive for the interviewers and the participants
- Currently no psychometric properties on the new frailty questionnaire
- Currently no report on the influence of the disability level on the frailty syndrome possible
- Important to analyse the difference between third party data and self report
- Instrument is a promising tool to follow health changes in the ID population for people with ID themselves as well as for their supporters

Literature

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