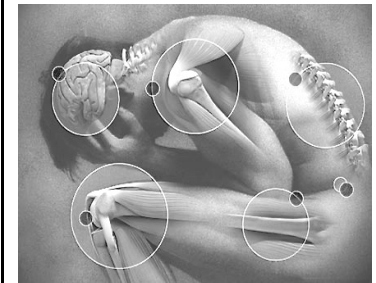


Cancer pain in people with intellectual disabilities

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People with intellectual disabilities (ID)

Heterogeneity

- Cause of ID (e.g., genetics)
- Severity of ID (cognitive, social-emotional)
- Comorbidity (psychological, medical)

Medical complexity

- Abnormal processing of medication
- Drug-to-drug interaction

Challenges in pain and disease

- Less participation in population screenings
- Fear and maladaptive pain coping
- Difficult pain measurement
- Atypical pain expression



Cancer pain in health care

Heterogeneity and variability

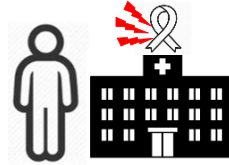
- Cancer (type, severity, location, treatment)
- Pain (type, chronicity, frequency)
- Pain treatment (type, combination)
- Change of pain over time

Insufficient effect of medication for pain relief

- Opiates (e.g., renal failure)
- Co-medication for neuropathic pain

Challenges

- Insufficient knowledge (e.g., WHO pain ladder)
- Insufficient pain assessment
- Assumptions about pain and pain medication



People with ID and cancer pain in health care

Fewer cancer patients with ID in hospitals (less knowledge)
 Under recognition of pain (diagnostic overshadowing)
 Late diagnosis of cancer (missed symptoms, e.g. pain)
 Talking about instead of with patients in acute settings
 Risk for ineffective pain treatment and side effects
 Pain not standard in medical/communication passport (NL)
 'High pain threshold' and 'pain insensitivity'



Care centers for people with ID

- Individual pain signalling plan
- Recognizing cancer symptoms (e.g., pain)
 - > registration > early warning (text mining)



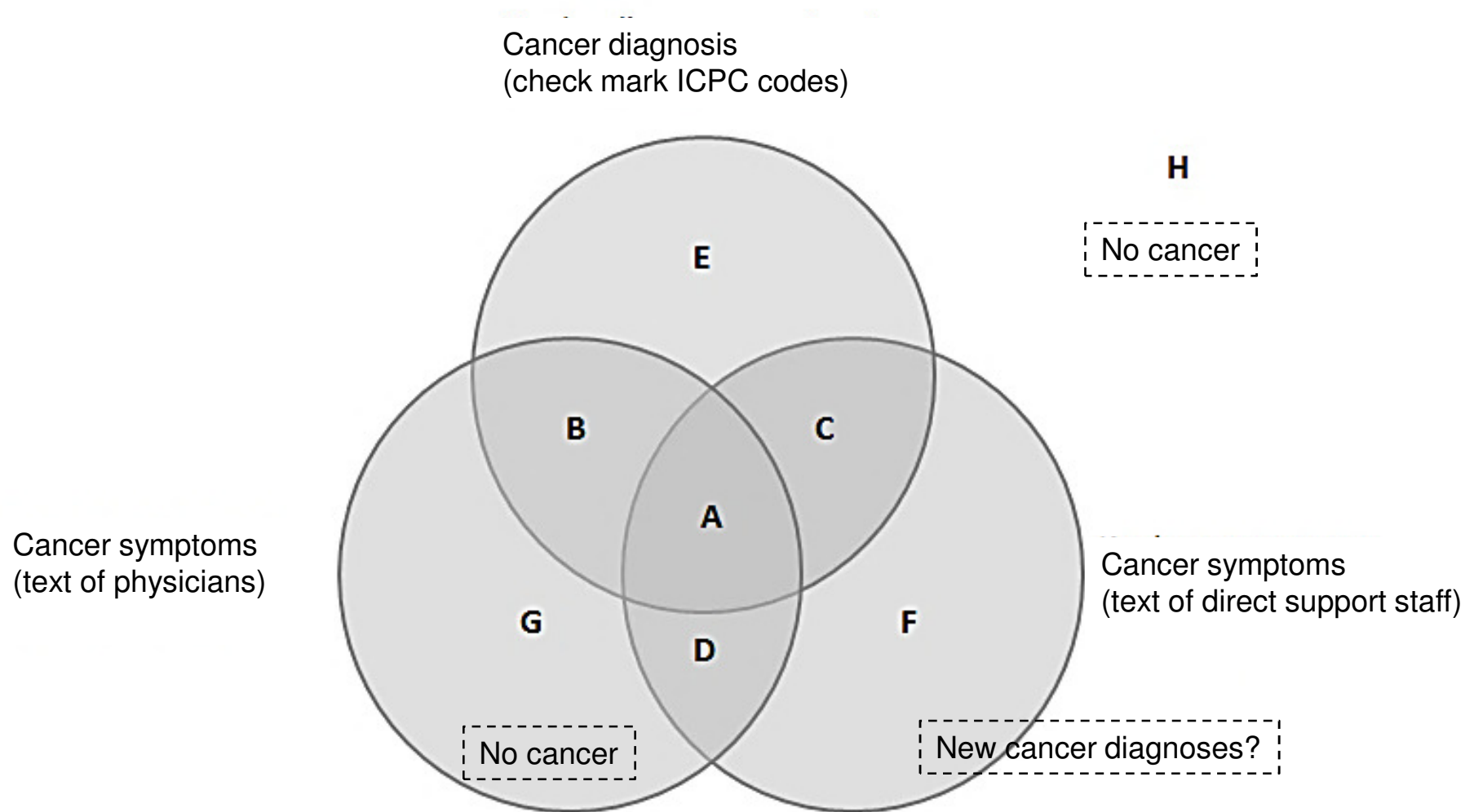
Hospitals:

Work instruction about cancer pain in ID

- Tailored to target group and individual
- Signalling, assessment, treatment, coping
- Collaboration with family member, personal caregiver, nurse / physician for people with ID



Text Mining in files

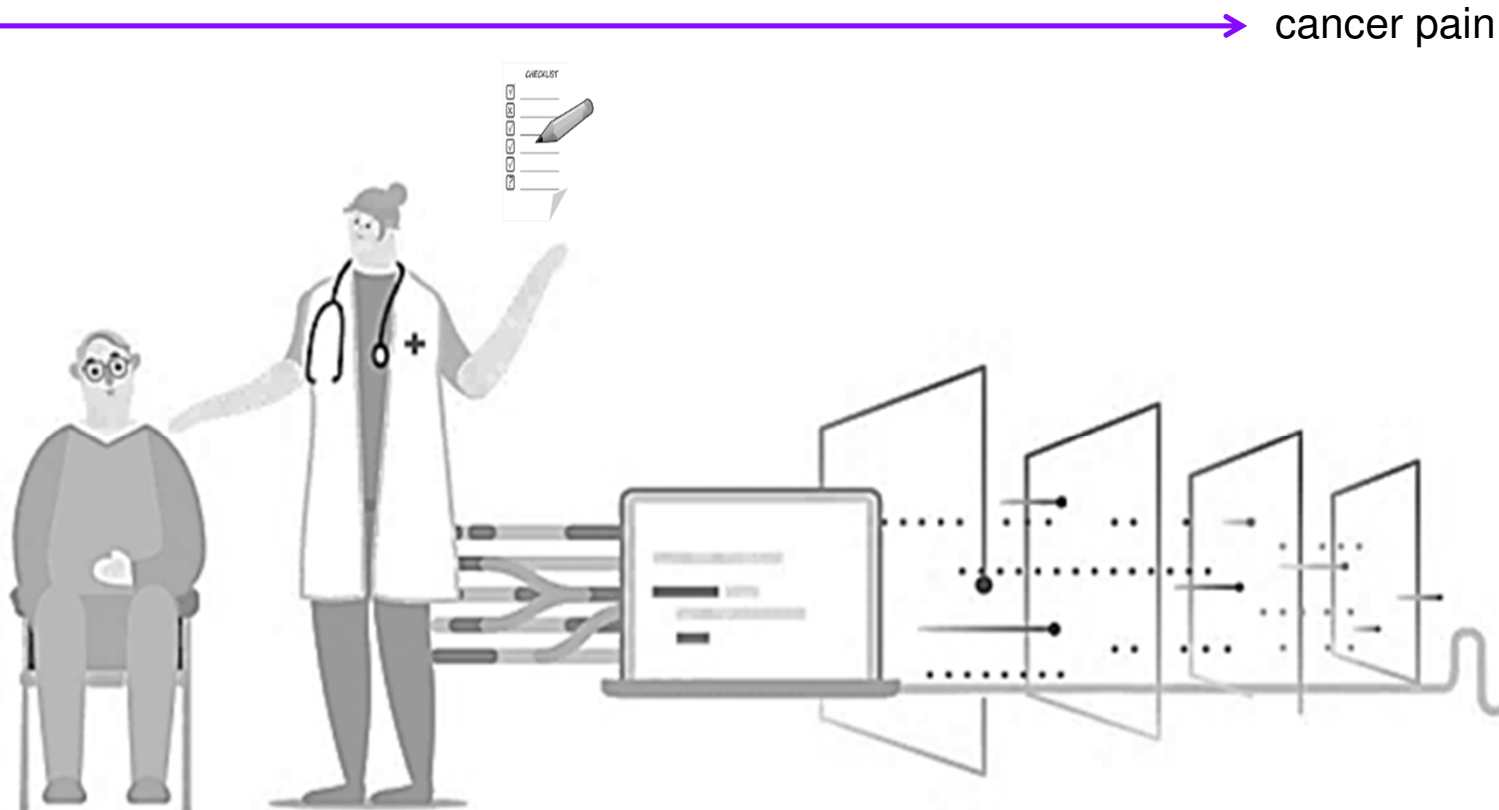


Search criteria TM model Literature: 'red flag', general, intellectual disabilities
Search criteria TM model Machine Learning: comparing cancer/no cancer in texts

Text Mining in files

Outcome measures:

- Criteria of best TM model and most common cancer symptoms: 0/1 list
 - Checklist: early signalling of cancer symptoms during observation/(hetero)anamnesis
- Tested TM model(s) for screening of electronic resident files for possible cancer diagnosis
 - Tool (future): automatic early warning in files



Work instruction in hospitals

What do we know?



Health care professionals (N = 63)

- Individual pain behaviours: used by 92%, effective in 69%
- Standard pain behaviour checklists: used by 67%, effective in 31%
- Self-report patient: used by 51%, effective in 35%

Oncological nurses (N = 3)

- Complement national cancer pain guideline with information about people with ID
- Prevent under and over treatment of pain by using more information than NRS:
 1. Assessment of pain intensity (faces, words, observation) and suffering (vitality)
 2. Ask family and caregivers to assess pain location and intensity
 3. Ask about personal situation/environment to discriminate pain from fear

Staff of care centers for ID (N = 6) about oncological nurses

- Use the same staff members during oncological care period
- Learn to know the characteristics of the person. Ask the personal caregiver.
- Use simple language and pictograms. Be aware of overwhelming situations.

Work instruction in hospitals

What will we do?



Health care professionals, family, and personal caregivers (N = 10)

- Information, education, collaboration, solutions
- Aim: to be more prepared and to support the person with cancer pain

Grant proposal (focus group and pilot study)

Questions / discussion



Thank you for the attention

Literature (selection)

- 1) Doody, O., & Bailey, M. E. (2017). Pain and pain assessment in people with intellectual disability: issues and challenges in practice. *British Journal of Learning Disabilities*, 45(3), 157–165.
- 2) Lemaire, A., George, B., Maindet, C., Burnod, A., Allano, G., & Minello, C. (2019). Opening up disruptive ways of management in cancer pain: the concept of multimorphic pain. *Supportive Care in Cancer*, 27(8), 3159–3170.
- 3) Lonchamp, S., Gerber, F., Aubry, J. M., Desmeules, J., Kosel, M., & Besson, M. (2020). Pain interventions in adults with intellectual disability: a scoping review and pharmacological considerations. *European Journal of Pain*, 24(5), 875–885.
- 4) Millard, S. K., & de Knecht, N. C. (2019). Cancer pain in people with intellectual disabilities: systematic review and survey of health care professionals. *Journal of Pain and Symptom Management*, 58(6), 1081-1099.e3.
- 5) Segerlantz, M., Axmon, A., Gagnemo Persson, R., Brun, E., & Ahlström, G. (2019). Prescription of pain medication among older cancer patients with and without an intellectual disability: a national register study. *BMC Cancer*, 19(1), 1–8.

