COVID-19 in people with ID in Dutch long term care facilities

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Impact of COVID-19 on people with ID

• People with ID: Higher risk of developing (severe) COVID-19
  • Poorer health with higher prevalence of pre-existing conditions
  • In close contact with others

• People with ID: greater impact of COVID-19 measures
  • Limited adaptation skills
  • Difficulty understanding measures

• NOT always possible to
  • identify people with ID in data surveillance
  • include people with ID in national surveys
1. Medical impact: Development of COVID-19 registry

- Construction of nationwide secured multicenter database

- Call to long term care facilities in ID: register suspected or confirmed COVID-19 cases
  - Demographics
  - Medical history
  - COVID-19 related variables

- Over time testing availability increased
  - Only detailed registration for clients with confirmed COVID-19

Start March 24, 2020
End June 1, 2021
• 36 care facilities kept actively participating

• Total number of clients registered 9261

• 95% of registered patients were tested
• 28% received positive PCR test result

• 2599 patients with confirmed COVID-19 infection
Registered COVID-19 infections / week
Characteristics of people with ID and COVID-19

- **Sex**: 58% male
- **Average age**: 49 yrs
  - 55% is aged between 40-69 yrs old
- **Living situation**
  - 86% group home
  - 13% independently, own apartment
- **Level of ID**
  - 26% borderline to mild
  - 36% moderate
  - 38% severe to profound
Deaths with confirmed COVID-19

- Over total registration
  - 100 clients deceased
  - Case fatality rate 4%
  - General population 1%

- Effect of age groups

% death per age group
Conclusion COVID-registration

- Large cohort of COVID-19 in ID
- Needed to visualize different impact of COVID-19 in this group
- Descriptive findings show vulnerability of people with ID to COVID-19: increased mortality from relatively young age onwards
- Does this medical impact imply strict preventative measures in LTC?

- Questionnaire based on national survey
- Rewritten, shortened and tested with target group
- Via inclusive platform Crowdience
- Focus groups to discuss results

- 3 different rounds of questionnaires
  - sept ’20  n=205
  - april ’21  n=216
  - sept ’21  n=187
Mental health outcomes - 1

% never / sometimes happy

% often / always lonely

% often / always worried

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Mental health outcomes - 2

% often / always stressed

% often / always afraid of corona

MID | Round 1 | Round 2 | Round 3
---|---|---|---
27% | 31% | 21%
21% | 19% | 16% | 21%

MID | Round 1 | Round 2 | Round 3
---|---|---|---
26% | 21% | 18% | 13%
10% | 9% | 5%
Our approach was suitable to include people with MID in survey

People with MID report greater impact of COVID-pandemic
  • Daily structure and social contacts are important
  • Clear and unambiguous information is important

Tailor measures, information and activities to the need of this group
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Online platform to share, learn, and connect about the organization of health and medical care for people with intellectual and developmental disabilities worldwide.

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