

Brief Report

Prevalence of dementia and organization of dementia care in Swiss disability care homes

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Abstract

Background: With higher life expectancy an increasing number of people with intellectual disability (PWID) are at risk for developing dementia.

Objective: Since PWID are an often neglected patient population, the objective of this study was to investigate the prevalence of dementia in residential disability homes in Switzerland and to describe how residential homes organize dementia care.

Methods: All residential homes for adults with disabilities in Switzerland ($N = 437$) were invited to participate in a cross-sectional survey. A subset of questions covered the number of residents with diagnosed and suspected dementia and the organization of dementia care. The response rate to the dementia-related questions was 32% ($n = 140$ care homes with 10403 residents).

Results: In residential homes specialised in PWID, 5.8% of the residents were reported to have a diagnosed or suspected dementia. In 140 deaths of PWID, 26% ($n = 37$) died with a diagnosed or suspected dementia. Residential homes for PWID mostly rely on internal resources (67.7%), general practitioners (61.3%) or psychiatrists (45.2%) for the care of residents with dementia, while specialized dementia nurses are rarely involved (16.1%).

Conclusion: This is the first study in Switzerland to assess the prevalence of dementia in PWID. The study indicates a diagnostic gap. Dementia care is provided in a heterogeneous way across Swiss residential homes for people with disability. Since the number of PWID requiring such care will likely increase in the future, best-practice examples and guidelines are needed. © 2016 Elsevier Inc. All rights reserved.

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Increasing longevity has been one of the most remarkable changes in people with intellectual disability (PWID) over the last decades. As life expectancy of PWID extends into older age, dementia is an increasing cause of morbidity and mortality. The prevalence of dementia in PWID is comparable with or even higher than in the general population.^{1–4} Preexisting cognitive impairment may complicate the diagnosis of dementia in PWID possibly leading to underdiagnosis and consequently mismanagement.⁴ It is therefore of interest to characterize possible diagnostic and care provision gaps in order to provide a rationale for improvement of care.

In Switzerland — like in many other countries — the majority services for PWID have historically evolved not from the medical or nursing sector but from the social work and pedagogical sector.⁵ In care homes for PWID, staff may mainly come from non-medical, non-nursing background and may therefore lack the specific knowledge and skills for the new challenge which is dementia care, particularly in areas such as pain and symptom

Table 1
Characteristics of residential homes

	Residential homes for people with ID ^a (in percent, <i>n</i> = 93)	Residential homes for people with other disabilities (in percent, <i>n</i> = 47)	All residential homes (in percent, <i>n</i> = 140)
Capacity (beds)			
<50	58.8	74.0	64.9
50–100	28.7	20.5	25
>100	12.5	5.5	10.9
Mean age of residents (ys)			
<35	17.2	9.5	14.7
35–44	36.9	21.5	31.8
45–54	37.9	57.1	44.2
>55	8.0	11.9	9.3

^a ID: intellectual disability.

management.⁶ In order to improve care competencies in these areas, knowledge transfer from non-ID dementia care seems to be a promising approach: a specialized accessible environment based on non-ID dementia care principles was found to contribute to maintenance of skills and activities in older PWID, likely by facilitating participation on an individual level and providing appropriate intellectual challenges.^{7,8} Consensus recommendations for the evaluation and management of dementia in PWID have recently become available for the United States,⁹ but there is currently no specific guidance for Switzerland. Furthermore, dementia in PWID is not covered in detail in the Swiss dementia strategy,¹⁰ i.e. no specific diagnostic or therapeutic measures or service development aims are included in the strategy despite the approximately 27,000 PWID in Switzerland.^{11–13} Again, this lack of consideration for the special needs of PWID with dementia may be at least partially explained by the historical development of disability care services outside the medical paradigm.

The purpose of our study is to broaden the necessary database for a discussion on care organization for dementia in residential homes for PWID in Switzerland. The objectives of our study were to investigate for the first time the prevalence of dementia in residential homes for PWID in Switzerland and to explore the organization of dementia care in these facilities. We hypothesized that dementia is currently underdiagnosed in

Swiss PWID living in residential homes and that dementia care is fragmented due to the lack of specific guidelines and care pathways.

Methods

All residential homes for adults with disabilities in Switzerland (*N* = 437) were invited to participate in a cross-sectional survey. The list of residential homes was obtained from the national association for service providers for people with disabilities (INSOS Switzerland) and the IVSE (Intercantonal cooperation of social-medical organisations). The survey was distributed on paper to the directors of the residential homes from Oct. 2012–Jan. 2013 and was available in German and French. The directors were asked to serve as informants on PWID living in their corresponding residential homes. In order to improve response rates, non-responding directors received a reminder phone call one month later. Questionnaires were returned to the investigators by mail. The survey was based on the questionnaires developed by D'Haene et al¹⁴ and Wagemans et al¹⁵ and is available from the corresponding author upon request. As previously published,^{16,17} the survey comprised two parts, one part focusing on written policies on palliative care and training in palliative care (40 questions), the other on people who died within the last five years, including demographic variables (26 questions). Regarding dementia, four questions investigated the prevalence and organization of care: (1) number of residents and number of residents with diagnosed dementia at present time, (2) number of residents with suspected dementia at present time, (3) number of deaths and number of deaths with diagnosed or suspected dementia in the last five years and (4) organization of dementia care. For the last question, directors could choose several answers from the following options: care in residential home by regular staff (use of internal resources), consultation with psychiatrists, neurologists, geriatricians, general practitioners, specialized nurses for people with dementia, change in accommodation such as transfer to nursing home, or other. Due to the type of study, the cantonal ethics committee Zurich, Switzerland, waived the necessity for ethics approval. Data from the paper questionnaires was entered into spreadsheet format manually and analyzed using

Table 2
Dementia prevalence in Swiss disability care homes

	Residential homes for people with ID ^a (in percent; <i>n</i> = 93 homes, 7468 places)	Residential homes for people with other disabilities ^b (in percent, <i>n</i> = 47 homes, 2935 places)	All residential homes (in percent, <i>n</i> = 140 homes, 10403 places)
Diagnosed dementia	1.8	1.7	1.8
Suspected dementia	4.0	1.8	3.5
All dementia	5.8	3.5	5.3

^a ID: intellectual disability.

^b Other disabilities: primarily sensory, physical or psychological impairment.

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