



Mental Health Nursing of Adults With Intellectual Disabilities and Mental Illness: A Review of Empirical Studies 1994–2013

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A B S T R A C T

Mental health nursing for adults with intellectual disabilities and mental illness is underresearched. The aim of this review is to summarize empirical mental health nursing studies including adults with intellectual disabilities and additional mental illness. Out of 137 hits, 16 articles were reviewed in full text. Thirteen of the articles presented modified nursing interventions. Three articles discussed training and education. The main finding is that mental health nursing interventions in patients with intellectual disabilities and additional mental illness are in line with mental health nursing for the general population. There are still not many publications on empirical studies concerning mental health nursing for adults with intellectual disabilities. Clinical implications are primarily related to the need for facilitated nurse–patient communication adjusted to the patients' cognitive levels. Insights drawn from this review illuminate the importance of mental health nursing interventions adjusting to the particular patients' symptoms, instead of targeting behavior change. The findings underpin factors found to have a positive impact on patients with mental illness in the general population as relevant topics for future research.

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Epidemiological studies underpin findings that people with intellectual disabilities develop mental illness more often compared to the general population (Bakken et al., 2010; Cooper, Smiley, Morrison, et al., 2007; Deb, Thomas, & Bright, 2001; Einfeld & Tonge, 2007; Emerson & Hatton, 2007). It is accepted that people with intellectual disabilities may develop all kinds of psychiatric illnesses (Jacobsen, 1999; Smiley et al., 2007). Schizophrenic and affective psychoses were the first mental illnesses described in a population sample (Reid, 1972a, 1972b). Since the 1970s, a broad range of mental illnesses has been described in people with intellectual disabilities. The main groups of axis 1 disorders, psychoses, affective disorders, and anxiety disorders, including obsessive–compulsive disorder and post-traumatic stress disorder, have attracted increasing scientific interest within the last two decades. Most of the published papers encompass prevalence of mental illness in both clinical and representative samples, diagnostic assessment challenges, and medication.

Symptoms of mental illness present both typically and atypically in persons with intellectual disabilities. Symptom presentation will tend to be more atypical where the intellectual disabilities are more severe (Fletcher, Loschen, Stavradi, & First, 2007). Intellectual disabilities entail impairments in adaptive functioning related to communication, self-care, functional academic skills, and interpersonal skills. Diagnostic

assessment is more complicated and requires the use of behavioral equivalents to typical diagnostic criteria in patients with severe or profound intellectual disabilities (Fletcher et al., 2007). Having autism additional to intellectual disabilities increases the occurrence of atypical symptom presentation of mental illness, which will complicate both diagnostic assessment and psychosocial interventions (Bakken, Eilertsen, Smeby, & Martinsen, 2008; Helverschou, Bakken, & Martinsen, 2011; Mohiuddin, Bobak, Gih, & Ghaziuddin, 2011). Atypical symptoms in those with both intellectual disabilities and mental illness frequently present as aggressive behavior, or altered behavior in social interaction (Bakken, Friis, Lovoll, Smeby, & Martinsen, 2007; Lainhart, 1999; Myers & Winters, 2002). Symptoms may present as behavioral equivalents to typical symptom presentation; for example psychotic disorganization presents typically as derailment and incoherent speech (Bakken et al., 2007). In people with intellectual disabilities, disorganization may be observed as task interruption by change in focus, aimless wandering or other aimless acts and impaired sequential organization (Bakken et al., 2007).

Behavior problems in people with intellectual disabilities may wrongly be attributed to their intellectual impairments, and understood as “behaviour problems”, not as symptoms of an additional mental illness. The tendency to attribute the symptoms and behaviors originating in mental illness to the intellectual disability itself, and thus overlook mental illness, is referred to as diagnostic overshadowing (Jopp & Keys, 2001; Reiss, Levitan, & Szyszko, 1982). Diagnostic overshadowing is a core concept in the mental health and intellectual disability discipline, and explains why, until recently, mental illness in people with

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intellectual disabilities has been largely overlooked. Mental illness frequently elicits behavior problems in these patients; for example aggression is frequently seen in people with intellectual disabilities and affective disorder, psychosis or anxiety disorder (Bakken & Martinsen, 2013). Behavior problems might be caused by medical conditions such as headaches, toothache, delirium, inability to interact in a social setting, or a negative life event (Chadwick, Cuddy, Kusel, & Taylor, 2005; Hurley & Silka, 2004; Rojahn, Matson, Naglieri, et al., 2004). Consequently, this study will not review articles encompassing mental health nursing of people with behavior problems not directly linked to mental illness.

Until the last two decades, in “developed countries”, people with intellectual disabilities and additional mental illness have mostly spent their adult lives in institutions for people with intellectual disabilities (Nøttestad & Linaker, 2001). During the deinstitutionalization of the services for people with intellectual disabilities, an ideal has been that they should profit from attending general psychiatric services when they suffer from mental illness. It is also claimed that the main challenge for professionals facing mental illnesses in people with intellectual disabilities is not the organization of services (general or specialized, inpatient or outpatient), but the degree of competence or lack of competence of the caring staff (Fleisher, Faulkner, Scalock, & Folk, 2005; Friedlander, 2006; Hall, Parkes, Samuels, & Hassiotis, 2006; Raitasuo, Taiminen, & Salokangas, 1999). It is underpinned that general psychiatric services lack knowledge on the special challenges of both assessment and treatment of psychiatric disorders in people with intellectual disabilities (Chaplin, 2009; Chaplin, O’Hara, Holt, & Bouras, 2009; Lunsky, Gracey, & Bradley, 2007; Lunsky et al., 2010; O’Brian, 2007; Weiss, Lunsky, Gracey, Canrinus, & Morris, 2009).

However, whether the person is receiving services from general or specialized psychiatric units, inpatient or outpatient treatment, mental health nursing will be a core element of these services. Mental health nursing of patients with intellectual disabilities has only been sparsely studied. Although the number of articles has increased since about 2000, most articles are opinion based (Taua, Hepworth, & Neville, 2012). Results from empirical studies may provide useful information for mental health nursing of patients with intellectual disabilities. Clinical experience indicates that modified mental health nursing interventions used in the general population are feasible for patients with intellectual disabilities and additional mental illness.

Consequently, we wanted to answer the following research question:

Do empirical studies of mental health nursing for patients with intellectual disabilities support the use of interventions used for patients in the general population?

METHODS

Review Method

From our experience in mental health nursing of people with intellectual disabilities and mental illness, we acknowledge that there are not many relevant empirical studies on this topic. We did not expect to find articles presenting mental health nursing interventions measuring effect, as for example recommended in the Cochrane Reviews (Van Tulder, Furlan, Bombardier, et al., 2003). In order to include the largest possible number of empirical studies, we chose an integrative approach to the review, which made it possible to include studies with different methods, samples and topics (Whittemore & Knafel, 2005). As the first articles on mental illness in people with intellectual disabilities were published in the 1970s, we limited the search to the years 1970–2013.

Inclusion criteria for the articles were: 1. the article should represent an empirical study, naturalistic (observations from naturalistic situations) or experimental, 2. the article should include subjects with both intellectual disabilities and additional mental illness, 3. the article should include adults, and 4. the article should include any aspect of mental health nursing. There was one exclusion criterion: if the article focused only on behavioral problems not linked to mental illness.

Procedure

We combined three terms in the search for relevant articles: mental health nursing, intellectual disabilities, and mental illness. The following databases were searched: Cochrane Central Register of Controlled Trials, Medline, Psych-info and the nursing journal databases CINAHL. The search was conducted as follows: firstly we searched for articles including the term *intellectual disabilities*, with the synonyms learning disabilities/mental retardation/developmental disabilities. Next, we searched for articles mentioning mental illness with the synonym psychiatric disorder. Then we combined the two search results. Thirdly, we searched for articles including mental health nursing with the synonyms psychiatric nursing/milieu therapy. This search was combined with the first search. This search strategy was conducted for the four databases. An additional manual search was conducted through reference lists from retrieved articles, and from relevant web sites, for example the National Association for persons with Developmental Disabilities and mental health needs (NADD). Only publications available in English were included. Articles were selected for analysis through consensus between the authors, while the first author conducted the initial search.

The literature search gave 137 potentially relevant articles. Both authors screened these potentially relevant articles through titles, abstracts and method sections against the aim of the study. Sixteen articles were selected through consensus between both authors, 121 were rejected. Most articles were rejected because they were not empirical, referred to models, or the articles were opinion-based. Some articles were rejected because they did not refer to people with concomitant intellectual disabilities and mental illness; most articles in this group discussed mental health nursing of people with intellectual disabilities who did not have additional mental illness.

Analysis

The 16 articles were qualitatively analyzed according to the review aim. The breadth of the literature was a challenge. The spread of participants, methods, and topics made quantitative analyses inappropriate. Content analysis was the chosen method, as content analysis usually aims at a broad description of a phenomenon rather than investigating effect or prevalence (Elo & Kyngäs, 2008). Content analysis is a widely used method in nursing research (Elo & Kyngäs, 2007; Hsieh & Shannon, 2005). This method analyses texts for certain patterns or topics (Stemler, 2001). The analysis followed a three-step procedure:

1. Analyzing the articles for the variables study topic, design, participants, patient characteristics (level of intellectual disabilities and psychiatric diagnostic group), and contextual frame (Elo & Kyngäs, 2007).
2. Analyzing the articles in order to identify topics in each article. The topics were formulated consecutively as they appeared in the articles.
3. Analyzing the articles in order to identify adapted interventions related to each topic.

RESULTS

An overview of the studies included is presented alphabetically in Table 1; including the name of the first author and year of publication, study topic, adapted interventions, design, participants, patient characteristics, and contextual frame. All studies were published from 1994 or later, and they were from Europe (6), North America (7), and Australia/New Zealand (3).

The selected articles encompass both qualitative studies (7 articles), and quantitative studies (9 articles). The sixteen studies cover a breadth of topics, and a variety of samples. The small number of articles may reflect that mental illness among adults with intellectual disabilities is

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