



Adults with Intellectual or Developmental Disability

Intellectual/Developmental Disability and Complex Care Needs

Individuals with IDD and co-occurring mental illness, medical illness and/or challenging behavior

Aging and Physical Decline/Loss of Functioning Vicki Kijewski, MD

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Objectives

List the most common physical symptoms experienced by individuals with intellectual disability as they age

Describe the most common medical comorbid medical conditions

Become familiar with the differences in medical comorbidity based upon

- 1. Severity of intellectual disability
- 2. Presence or absence of Down Syndrome
- 3. Presence or absence of Autism Spectrum Disorder
- 4. Gender differences
- 5. Institutionalization

Introduction

People with
intellectual
disability ~ 1% of
global population

Health
Inequalities

Barriers to
effective
healthcare

More likely to die
prematurely

Inadequate
recognition of
health needs

Evidence of
psychiatric
conditions is
extensive

Higher prevalence
of physical
conditions

Less likely to have
solid cancers

Most Common Physical Symptoms with Aging in those with Intellectual Disabilities

Sensory Impairments

- Vision Loss
- Hearing Loss

Seizure Disorders

Constipation

Obesity

Mobility and Gait Disorders

Incontinence

Thyroid Disorders

Chronic Pain

Overall Pattern

Earlier Onset

High Prevalence of
Multiple Chronic Physical
Symptoms

Need for Comprehensive
Multidisciplinary
Management

Sensory Deficits

Hearing Loss

Vision Loss

Highly Prevalent

Tend to worsen
with age

Epilepsy

Common

Especially in those with
severe or profound
intellectual and motor
disabilities

Prevalence rates up to 70%
in some cohorts

Bowel/Bladder

Constipation

Urinary
Incontinence

Urinary Retention

Obesity

Hyperlipidemia

Hyperglycemia/Diabetes

Sleep Apnea

Hypothyroidism

Pain

Chronic Pain

Arthritis

Dental Pain

Headaches

Abdominal pain

Back pain

Mobility Problems

Ataxic gait (lack of voluntary coordination of muscle movements)

- Irregular, jerky, unsteady walking

Antalgic gait (type of walking pattern that develops to avoid pain)

- For example, a limp

Bone degeneration

Loss of physical strength

All contribute to functional decline

Sleep
Disturbances

Insomnia

Obstructive
Sleep Apnea

Gastrointestinal Symptoms

Chronic Diarrhea

Chronic
Constipation

GERD

Diabetes

Occurs at
higher rates

Often at a
younger age

Cardiovascular Disease

Heart Failure

Hypertension

Adults with both autism and
intellectual disability have
elevated rates of heart disease

What about
institutionalized
older adults?

Higher prevalence of
comorbid medical
problems

Earlier onset

Multimorbidity > 70%

Why?

Greater severity
of intellectual
disability

Limited access to
preventative care

Higher exposure
to unhealthy
lifestyle factors

Metabolic effects
of medications

Often poorer
management of
long-term
conditions

Higher healthcare
utilization

Ways to Improve



**Targeted
proactive
prevention**



**Management
strategies**



**Annual or
regular health
checks**



**Screening
tools and
protocols
should be
adapted for
the ID
population**



**For example,
National Task
Group
recommends:**

Specialized
cognitive
assessment
instruments and
tracking changes



**Early
intervention
and health
promotion
programs**

Physical activity
Nutrition
Health education
Social inclusion

Dementia Screening

Challenging due to
baseline cognitive
deficits

Atypical
presentations

Lack of validation for
standard screening
tools (MOCA, SLUMS,
Mini-Mental)

Recommend annual
screening starting at
age 40

Informant-based
assessment (DSQIID,
CAMDEX-DS)

Functional evaluation

Baseline

Repeated screenings

Increased risk for
early-onset dementia

Often present with
atypical symptoms

High rates of
multimorbidity

Pharmacological Interventions for Dementia

Cholinesterase Inhibitors

- donepezil, rivastigmine, galantamine
- Most commonly used
- Generally well tolerated
- Do not consistently improve cognition or function
- GI upset, insomnia, muscle cramps, bradycardia

NMDA receptor antagonists

- Memantine
- Generally well tolerated, similar to placebo in terms of adverse events
- Dizziness, headache, confusion, constipation
- Limited and inconsistent efficacy

Adverse effects more common

Monitoring for side effects challenging

Long term outcomes unclear

Non-pharmacologic Interventions for Dementia

As effective or more effective than pharmacological treatments

Recommended as first line

Physical-cognitive rehabilitation

Music therapy

Reminiscence therapy

Caregiver-focused strategies

Adaptation for ID population

- Simplified tasks
- Higher staff ratios
- Alternative communication

Condition Specific Screening



Hypothyroidism

Screening every 1-2 years

TSH, free T4

Be vigilant for atypical presentations



Regular assessments for

Constipation

Urinary incontinence

Obesity

Sensory impairments

Cardiovascular Disorders
(Hypertension, Heart Failure)

Metabolic disorders (glucose,
cholesterol)

Adults with Down Syndrome

Early Cataracts

Keratoconus

Atlantoaxial
Instability

Celiac Disease

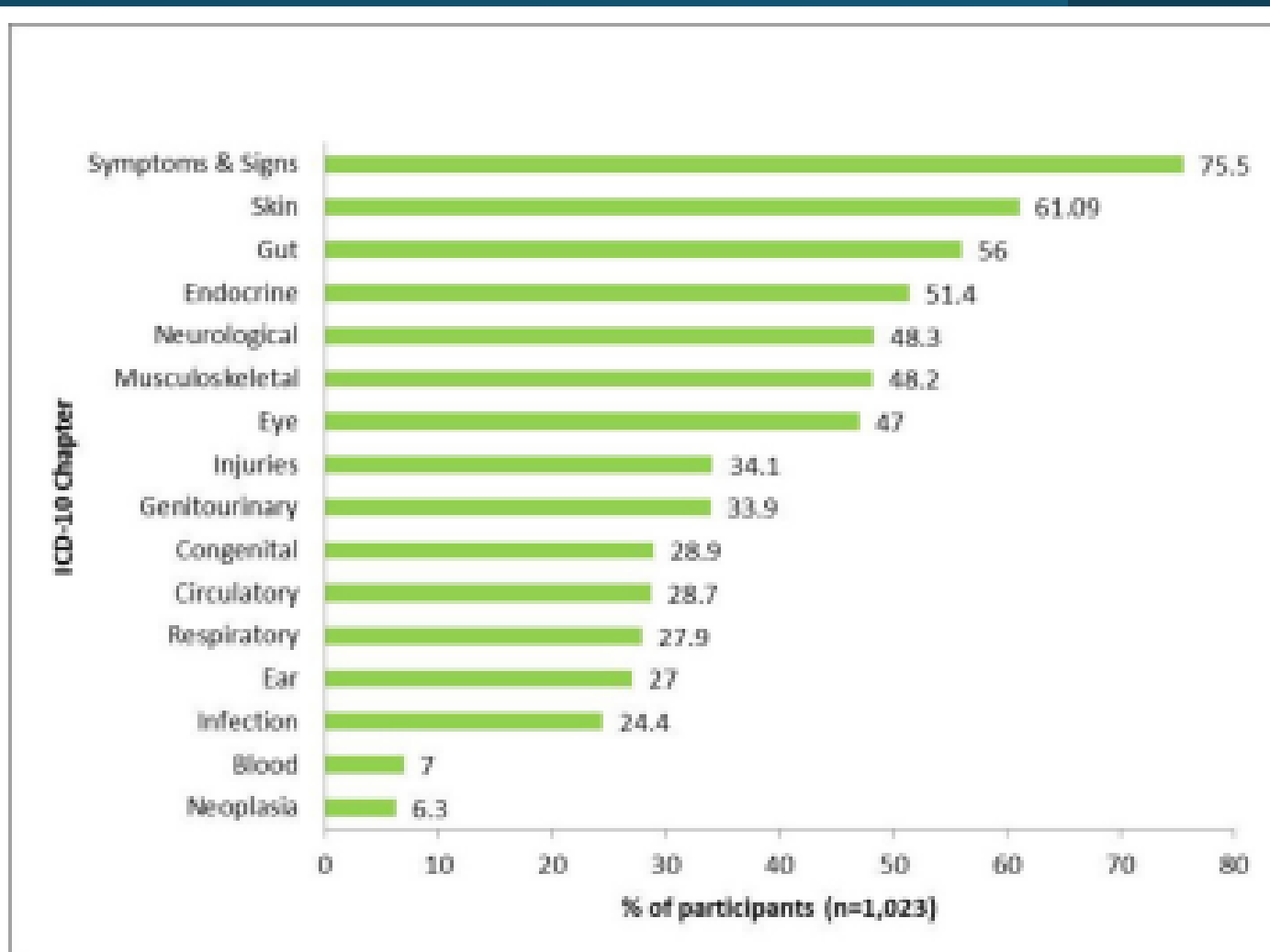


Figure 5 Prevalence (%) of physical ill health by ICD-10 chapter. ICD-10, International Statistical Classification of Diseases, 10th revision.

Table 2 Prevalence of physical health conditions for adults with and without Down syndrome across all ICD-10 chapters

	Physical health condition	Whole cohort (n=1023) n	Whole cohort %	Down syndrome (n=186) (n (%))	Without down syndrome (n=837) (n (%))
1	Visual impairment	481	47	90 (48.4)	391 (46.7)
2	Obesity	415	40.6	105 (56.5)	310 (37)
3	Epilepsy	349	34.1	24 (13)	325 (38.8)
4	Constipation	346	33.8	45 (24.1)	301 (36)
5	Ataxic/gait disorders	306	29.9	30 (16.1)	276 (33)
6	Hearing impairment	276	26.9	73 (39.2)	203 (24.2)
7	Nail disorder (eg, ingrowing nail)	238	23.3	50 (26.9)	188 (22.5)
8	Epidermal thickening/xerosis	217	21.2	69 (37.1)	148 (17.7)
9	Cerebral palsy and other paralytic syndromes	191	18.7	8 (4.3)	183 (21.9)
10	Osteoporosis	189	18.5	11 (5.9)	178 (21.3)
11	Fungal infection	167	16.3	42 (22.5)	125 (14.9)
12	Hypertension	158	15.4	8 (4.3)	150 (17.9)
13	Bone deformity	155	15.1	27 (14.5)	128 (15.3)
14	Musculoskeletal pain/dorsalgia	152	14.9	32 (17.2)	120 (14.3)
15	Eczema/dermatitis	149	14.6	38 (20.4)	111 (13.3)
16	Gastro-oesophageal reflux disorder	148	14.5	26 (14)	122 (14.6)
17	Dysphagia	147	14.4	24 (12.9)	123 (14.7)
18	Lower respiratory tract infection	134	13	34 (18.3)	100 (11.9)
19	Dyspnoea/wheezing	131	12.8	27 (14.5)	104 (12.4)
20	Dental/oral	130	12.7	28 (15)	102 (12.2)

ICD-10, International Statistical Classification of Diseases, 10th revision.

Multimorbidity

Epilepsy

Mental Health Disorders

Thyroid Dysfunction

Diabetes

Cardiovascular Disease

Chronic Respiratory Disease (Asthma, COPD)

Obesity

Constipation

Urinary Incontinence

Hearing/Vision Loss

Arthritis

Dysphagia

Tooth pain/Oral pain

Recommendations

Multi-disciplinary approach

Encourage information sharing to optimize care

Multimorbidity leads to polypharmacy

Carefully evaluate need for medications

Lowest effective dose of medications

Preventative Health Care

Encourage an open dialogue