¿Existen organizaciones o sitios web que puedan ayudarme cuando tenga más preguntas?

¿Puede decirme qué significan algunas de esas abreviaturas?

Acrónimos de organizaciones

AAA – Asociaciones de personas mayores–*Asociación de ancianos defensores que actúan en nombre de las asociaciones que reivindican servicios y recursos para las personas mayores y para las personas con discapacidad. Proporcionan un amplio abanico de opciones que permiten a las personas ancianas y a las personas con discapacidad a elegir el hogar, los servicios comunitarios y las condiciones de vivienda que mejor se adapten a ellos, estas asociaciones hacen posible que los ancianos puedan quedarse en sus casas o comunidades tanto tiempo como sea posible.– Asociación de ancianos defensores que actúan en nombre de las asociaciones que reivindican servicios y recursos para las personas mayores y para las personas con discapacidad. Proporcionan un amplio abanico de opciones que permiten a las personas ancianas y a las personas con discapacidad a elegir el hogar, los servicios comunitarios y las condiciones de vivienda que mejor se adapten a ellos, estas asociaciones hacen posible que los ancianos puedan quedarse en sus casas o comunidades tanto tiempo como sea posible*- www.n4a.org (aquí podrá buscar su oficina local)

AAIDD – Asociación americana de discapacidad intelectual o del desarrollo –*promueve políticas progresivas, investigaciones adecuadas, prácticas efectivas y el cumplimiento de los derechos humanos universales para personas con discapacidad intelectual o de desarrollo.*– www.aaidd.org

AIDD –Administración de discapacidad intelectual o de desarrollo – *dedicada a asegurar la participación y la contribución en todos los aspectos de la vida social en los Estados Unidos y sus territorios a personas con discapacidad de desarrollo y sus familias.*- www.acl.gov/programs/AIDD

APSE –Asociación de personas que apoyan el primer empleo – *defiende el empleo y la capacidad de tener autonomía económica para las personas con discapacidad a través de la defensa y la educación.* - www.apse.org

The Arc - (Antiguamente conocida como asociación de ciudadanos con retraso)–*promueve y protege los derechos humanos de las personas con discapacidad intelectual o de desarrollo y apoya de manera activa su total participación en la comunidad a lo largo de sus vidas. Su página web ofrece recursos de salud, planificación económica, opciones de viviendas entre otros.*-www.thearc.org

AUCD –*Asociación de los centros dedicados a discapacidades de la Universidad – red interdisciplinaria de centros que promueven políticas y prácticas para las personas con discapacidad de desarrollo o de otro tipo, sus familias y comunidades*. - www.aucd.org

DD Council –Comité de discapacidades de desarrollo (cada estado tiene el suyo propio) – *desarrolla y mantiene comunidades inclusivas, servicios individuales y ayudas a las personas con discapacidad de desarrollo.* -www.nacdd.org

DSAIA – Asociaciones Afiliadas al síndrome de Down en acción–*apoya el crecimiento y la posibilidad de dar servicios de las asociaciones de padres de síndrome de Down locales y regionales*.– www.dsaia.org

Acrónimos de organizaciones

EEOC –Comisión de igualdad en las oportunidades de empleo – *responsable de ejecutar leyes federales que consideran ilegal discriminar a los postulantes para una oferta de trabajo por su raza, color, religión, sexo (incluyéndose el embarazo), origen nacional, edad, discapacidad o información genética. Además, también establece como ilegal la discriminación contra una persona porque esta se haya quejado por haber sufrido discriminación, haya presentado una denuncia por discriminación, o haya participado en una investigación o un pleito contra la misma.*- www.eeoc.gov

HHS –Servicios humanos y de salud -– *es la principal agencia encargada de proteger la salud de todos los estadounidenses y de proporcionarles servicios humanos esenciales, especialmente a aquellos que no son capaces de valerse por sí mismos. De esta manera, proporciona a millones de niños, familias y ancianos un acceso a una sanidad de calidad, ayudas para encontrar trabajo, ayudas a los padres para cuidar a sus hijos, manteniendo los alimentos de los estadounidenses a salvo y en buenas condiciones y previniendo las enfermedades infecciosas.*- www.hhs.gov/iea/regional/index.html (aquí podrá encontrar su oficina local o estatal)también www.aspe.hhs.gov/office_specific/daltcp.cfm (para buscar información sobre el departamento de discapacidad, tercera edad y políticas de cuidado a largo plazo)

IMDSA – Asociación Internacional de Síndrome de Down Mosaico–*proporciona ayudas a cualquier familia o persona que tenga síndrome de Down mosaico. Estas ayudas consisten en incentivar oportunidades de investigación y incrementando la conciencia de existencia de esta discapacidad en contextos médicos, educativos y en comunidades de todo el mundo*. - www.imdsa.org

NARIC –Centro Nacional de Información sobre la Rehabilitación *–lleva a cabo programas de investigación muy exhaustivos y coordinados y actividades relacionadas con los mismos para aumentar la inclusión total, integración social, empleo y vida independiente de personas de todas las edades con discapacidades.* - www.naric.com

NDRN – Red Nacional de los Derechos de las personas con Discapacidad – *Organización sin ánimo de lucro en defensa de la protección y defensa exigida por el gobierno federal y de los sistemas y programas de asistencia a los clientes. De manera colectiva, ambos sistemas suponen el mayor proveedor de servicios de defensa legal para las personas con discapacidad en Estados Unidos.*– www.ndrn.org

NDSC –National Down Syndrome Congress o Congreso Nacional de Síndrome de Down – *proporciona información, defensa y ayuda a las personas con síndrome de Down en lo que respecta a todos los aspectos de su vida.* www.ndsccenter.org

NDSS –Sociedad Nacional del Síndrome de Down – *aboga por el valor, la aceptación y la inclusión de las personas con síndrome de Down.*- www.ndss.org

NIH – Instituto Nacional de Salud – *supone la mayor fuente de financiación de investigación médica en el mundo. NIH está formado por 27 centros e institutos, incluyendo el NICHD que lleva a cabo y apoya investigaciones en laboratorios, ensayos clínicos y estudios epidemiológicos en los que se exploran los procesos de salud, se examina el impacto de las discapacidades, enfermedades y variaciones en la vida de personas y financia programas de formación para científicos, personal sanitario e investigadores.* - www.nih.gov

Acrónimos de organizaciones

ODEP – Oficina de Políticas sobre empleo para personas con Discapacidad– *desarrolla y promueve políticas y prácticas que aumenten el número y la calidad de las oportunidades de empleo para las personas con discapacidad.*- www.dol.gov/odep

SLN – Red de Liderazgo del Hermano–*proporciona a los hermanos de personas con discapacidad información, apoyo y herramientas para ayudar a sus hermanos a solucionar problemas relacionados con ellos y con sus familias.*– www.siblingleadership.org

SSA –Administración del Seguro Social – *proporciona a las personas con discapacidad prestaciones sujetas a dos programas distintos SSI y SSDI*– www.ssa.gov

TASH–*Asociación internacional de defensa para las personas con discapacidad, los miembros de su familia y las personas que tienen algún empleo relacionado con las discapacidades.*– www.tash.org

Projecto del Estado en Discapacidades del Desarrollo – *administrado por la Universidad de Colorado y financiado en parte por la AIDD. Proporciona datos desde 1977 hasta 2011. Cada uno de los nuevos perfiles del estado presentan seis páginas de datos de gastos en I/DD, ingresos públicos y la tendencia de otros programas en cada estado. También tiene disponible información comparada y personalizada de cada estado actualizada en 2011.* - http://www.stateofthestates.org/

Acrónimos de discapacidades comunes

ABLE act –Conseguir una mejor vida (H.R. 647)

AD –Enfermedad del Alzheimer

ADA –Ley de los Estadounidenses con Discapacidad

ASD – Enfermedad del Espectro Autista

AT –Tecnología Asistencial

BD –Trastornos del Comportamiento

CBI –Instrucciones Basadas en la Comunidad

CM –Administrador de Casos

DD –Discapacidades del Desarrollo

DME –Equipo Médico Duradero

DS –Síndrome de Down

FERPA –Ley de Derechos educativos y de Privacidad en la Familia de 1974

HHA –Agencia de Salud en el Hogar

HSA –Agencia de Servicios en el Hogar

I/DD – Discapacidades Intelectuales o de Desarrollo

ICF –Centro de Cuidados Intermedio

IDEA –Ley de Educación para Personas con Discapacidad

IFSP –Plan Individualizado de Servicios para la Familia

IHP –Plan de Habilitación Individual

IL –Vida Independiente

ILC –Centro de Vida Independiente

ILP –Plan de Vida Integrado

IRWE –Gastos de Empleo debido a Discapacidad

ISP –Plan de Servicio Individual

LOC –Nivel de Cuidado

OT –Terapia o Terapista Ocupacional

PT –Terapia o Terapista Físico

PWD/PWDs –Personas con Discapacidad

RT –Terapeuta Recreativo

Sib – Hermano

SILP –Programa de Vida Semi-Independiente

SLP –Patólogo del Uso del Lenguaje

SLT –Terapeuta del Uso del Lenguaje

SMI –Seguro Médico Suplementario

SNT – Fideicomiso de Necesidades Especiales

SSDI - Seguro de la Seguridad Social por Discapacidad

SSI –Ingreso Suplementario de Seguridad

TANF –Asistencia Temporal a Familias Necesitadas

VR –Rehabilitación Vocacional

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PARA PADRES Y HERMANOS ADULTOS

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Los directores del Centro del Adulto con Síndrome de Down en Illinois comparten su experiencia al trabajar con más de 3.000 pacientes desde 1992. Este libroaborda trastornos y diagnósticos específicos, y ofrece alternativas de tratamiento para profesionales y cuidadores.

McGuire, Dennis y Brian Chicoine. *The Guide to Good Health forTeens & Adults with Down Syndrome* Bethesda, MD: WoodbineHouse.

En su segundo libro, los doctores afrontan algunas de las preocupaciones existentes sobre cuidados de salud específicos destinados las personas con síndrome de Down como individuos. Por lo que intentan profundizar en la relación entre el Síndrome de Down y el Alzheimer.

Pueschel, Siegfried M. (Ed)*Adults with Down Syndrome.* Baltimore: Brookes Publishing. 2006

Un completo libro que aborda diferentes cuestiones sociales, clínicas, legales y personales a las que se enfrentan los adultos con síndrome de Down. En el libro, se pueden encontrar tanto las contribuciones de profesionales que trabajan con adultos con síndrome de Down, como ensayos personales de las contribuciones de los profesionales que trabajan con adultos con síndrome de Down, junto con ensayos personales de autodefensores. Entre los temas se incluyen: la salud médica y mental, el empleo, la educación post-secundaria, las relaciones sociales y los acuerdos relacionados con el alojamiento.

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Bigby, Christine. *Moving on Without Parents*, Baltimore: Brookes Publishing. 2000.

Este libro proporciona recursos que facilitarán la transición que supone salir del seno familiar y prepararse para la fase de la vida en la que los padres dejan de ser los cuidadores de personas de adultos de mediana edad o mayores con discapacidades del desarrollo.

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Meyer, Donald y Patricia Vadasy. *Living with a Brother or Sister with Special Needs: A Book for Sibs.* Seattle: University of Washington Press. 1996.

Discute discapacidades específicas de una manera fácil de entender, así como las emociones tan intensas que son capaces de sentir los hermanos y hermanas.

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Una autobiografía en la que se narra las experiencias de la autora, que decide pasar un día a la semana durante todo el año junto a su hermana, quien tiene una discapacidad de desarrollo. Una experiencia reveladora en la que Simon se da cuenta de lo poco que sabía acerca de la vida de su hermana.

HEALTH ISSUES FOR ADULTS WITH DOWN SYNDROME

Brian Chicoine, MD

Dennis McGuire, PhD

Janet Bilodeau, CNP

Erin Dominiak, MD

Adult Down Syndrome Center of Lutheran General Hospital

www.advocatehealth.com/adultdown

Facebook: adultdownsyndromeclinic

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Health is more than the absence of disease. Health is a sense of physical, mental and spiritual well being. It is a process that involves health promotion, health monitoring, and early intervention for health problems. Understanding what is typical or in the normal range for a person with Down syndrome is essential for providing health care.

I. Understanding Normal/Typical

Adults with Down syndrome have a number of typical behavioral issues that are important to understand so as not to over-diagnose disease states.

A. Self-talk and imaginary friends
These appear to be developmental stage-appropriate behaviors that are used as coping strategies, defense mechanisms, and to alleviate boredom.

B. The Groove
People with Down syndrome often show a tendency towards needing sameness, repetition and order in their lives. It can be very functional.

C. Grief
A delayed response to grief is often seen and it may be demonstrated in alternative ways.

D. Pain Tolerance
People with Down syndrome may have an increased tolerance to pain. However, limited communication skills may also limit the ability to

express/convey pain that can lead to the pain being expressed in alternative ways.

E. Behavioral change as a potential communication device
Sometimes a behavioral change may be an attempt to communicate physical or psychological discomfort. A thorough medical evaluation is indicated when a person with DS presents with a behavioral change to assess for an underlying physical condition.

II. Health Promotion

A. Regular exercise. We have found that adults with Down syndrome are more likely to be closer to their ideal body weight if they have opportunities for recreational and social activities (not necessarily exercise). We generally recommend 20-30 minutes of exercise at least 3-5 times per week. In addition, (or alternatively) social activities like shopping, visiting museums, etc. that involve walking can be very beneficial. Increasing energy expenditure by parking a little farther away, taking the stairs, and working in the house and yard are all beneficial. Generally, turning off the television and being more active is beneficial.

B. Recreational Activities - As noted above, recreational activities can have a benefit for physical health. In addition, they are an important part of mental health as well as part of life's enjoyment. Sometimes as parents naturally slow down with age or the adult with Down syndrome ages out of the school system, fewer activities are available. That is a particularly important time to seek other reliable people who can assist in participation in recreational activities.

C. Nutrition – Obesity is the most common nutrition-related disorder. Attention to a healthy diet as well as regular activity and exercise are required to prevent and treat obesity.

D. Opportunities for Accomplishment and Sense of Worth – Adults with Down syndrome have the same need as others to feel a sense of accomplishment and worth. For some, that may be a repetitive job that fulfills their need for order and regimen. For others, it may be a particular sense of being needed achieved through doing for others. An assessment of what the individual would like to get from a job, as well what his skills are to do the job is encouraged.

E. Immunizations – (These recommendations assume all childhood immunizations were given appropriately.)

Diphtheria – Tetanus- Pertussis– recommended if no dT in 10 years, then resume dT every 10 years

Influenza – consider annually each fall especially if exposure to many people. Recommended annually for persons with certain other health problems.

Pneumonia – We recommend considering the pneumonia vaccine at age 50 for adults with Down syndrome. Recommended at a

younger age for persons with certain other health problems and then repeat at age 50.

Varicella (Chicken Pox) – recommended testing for immunity by blood tests if there is no history of having had chicken pox. Recommend the 2-shot series if not immune.

Hepatitis B – recommended for people living in group facilities. We also recommend it for persons working in a group setting (e.g. workshop) and considering it for all others. We recommend a blood test before administering the vaccine for adults with Down syndrome to see if they have immunity (thus, they do not need the vaccine). In addition, we recommend drawing a blood test (hepatitis B surface antibody) to document attaining immune status 4 to 6 weeks after the third shot.

F. Osteoporosis prevention-Osteoporosis is more common in adults with Down syndrome. Adequate calcium intake throughout life is essential. Recommend 1000 mg a day of calcium for men and non-menopausal females and 1500 mg a day for menopausal females (by diet or supplement). Recommend taking Calcium with vitamin D to promote absorption. Consider bone density scanning to screen for osteoporosis. Consider appropriate medical therapy for prevention or treatment of osteoporosis. Consider checking Vitamin D level (blood test).

III. Health monitoring

A. Health Screening – History and Physical exam recommended annually.

B. Some important aspects of the history:

- Decline in skills
- Memory impairment
- Swallowing difficulties, choking
- Change in gait, unsteadiness
- Incontinence of urine and/or stool
- Change in appetite
- Change in weight
- Behavioral issues
- Psychological concerns
  - Change in mood
  - Change in interest in life

C. Thyroid – Recommended annual thyroid blood testing.

D. Celiac Disease – Consider blood testing (anti tissue-transglutaminase antibody IgA).

E. Neck x-ray – consider every 10 years (lateral cervical spine xray in flexion, extension and neutral) to assess for cervical subluxation/atlanto-axial instability.

F. Cancer of the cervix – Recommend pap smear every 3 years (after two annual tests normal) if not sexually active and asymptomatic.

G. Breast cancer – Recommend discussing with your medical practitioner. Consider a mammogram annually after 40. Annual breast exam and teach/encourage breast self-exam (if possible).
H. Cancer of the testicle – Recommend annual testicular exam and teach self-exam (if possible).
I. Vision – Recommend exam every 1-2 years.
J. Hearing – Recommend audiogram every 1-2 years.
K. Sleep apnea- sleep apnea is common in people with DS. Annually review history of snoring, pauses in breathing, and restless sleeping. However, many people will have sleep apnea even when not observed by others. Sleep apnea can also cause mood changes, behavioral changes, and a decline or change in skills. Order sleep study if indicated by history.

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Health conditions associated with aging and end of life of adults with Down syndrome

Anna J. Esbensen, PhD
Cincinnati Children's Hospital Medical Center

Abstract

Expectations for the life course of individuals with Down syndrome (DS) have changed, with life expectancy estimates increasing from 12 in 1949 to nearly 60 years of age today (Bittles & Glasson, 2004; Penrose, 1949). Along with this longer life expectancy comes a larger population of adults with DS who display premature age-related changes in their health. There is thus a need to provide specialized health care to this aging population of adults with DS who are at high risk for some conditions and at lower risk for others. This review focuses on the rates and contributing factors to medical conditions that are common in adults with DS or that show changes with age. The review of medical conditions includes the increased risk for skin and hair changes, early onset menopause, visual and hearing impairments, adult onset seizure disorder, thyroid dysfunction, diabetes, obesity, sleep apnea and musculoskeletal problems. The different pattern of conditions associated with the mortality of adults with DS is also reviewed.

Keywords

Down syndrome; physical health; aging; mortality

A highly significant change in the survival of people with Down syndrome (DS) has occurred during the last two generations. In the 1940s, the average life expectancy for individuals with DS was 12 years (Penrose, 1949). With medical breakthroughs and improvements in services, individuals with DS now enjoy life expectancies into their 60s (Bittles & Glasson, 2004). As a result, we are now witness to the first generation of individuals with DS who have benefited from a revolution during their lifetime of better knowledge, health care, advocacy and services (Yang, Rasmussen & Friedman, 2002). Along with this longer life expectancy comes a larger population of adults with DS who display premature age-related changes in their health. There is thus a need to provide specialized health care to this aging population of adults with DS who are at high risk for some conditions and at lower risk for others. Adults with DS are at age-related increased risk for dementia, skin and hair changes, early onset menopause, visual and hearing impairments, adult onset seizure disorder, thyroid dysfunction, diabetes, obesity, sleep apnea and musculoskeletal problems. Along with these increased risks for some conditions comes a different pattern of conditions associated with the mortality of adults with DS. This review focuses on the rates and contributing factors to medical conditions that are common in adults with DS or that show changes with age.

Skin and hair changes

Adults with DS experience a number of dermatological and autoimmune symptoms characteristic of accelerated aging, including premature graying of the hair, hair loss and wrinkling of the skin (Lott, 1982). Significant differences in the skin and chronological age of the individual have been found in post-mortem examinations of the skin of adults with DS

(Edwards, 1978). Further, sun-exposure may have a greater effect on skin wrinkling for individuals with DS than for the general population, contributing to the appearance of premature skin aging in adults with DS (Brugge, Grove, Clopton, Grove & Piacquadio, 1993).

Alopecia areata (the loss of hair) is estimated to effect between 6% to 18.4% of adults with DS (duVivier & Munro, 1975; Prasher, 1994b). In comparison, only 0.1% of individuals with intellectual disability (ID) and 0.1- 0.2% of the general population are affected by alopecia areata (Safavi, Muller, Suman, Moshell & Melton, 1995; duVivier & Munro, 1975). It is posited that this elevated rate of alopecia areata in adults with DS may be related to immunological deficiency in thymus dependent function (Carter & Jegasothy, 1976).

Other skin conditions common in adults with DS include atopic dermatitis, fungal infections, seborrhoeic dermatitis, and xerosis, affecting 34% to 39% of adults (Kerins, Petrovic, Bruder & Gruman, 2008; Prasher, 1994b; Roizen & Patterson, 2003). These skin conditions are found in higher rates among older than younger adults with DS, and may be due in part to declines in self-care associated with memory loss and dementia that are common in the aging of adults with DS (Kerins et al., 2008).

Several theories have been proposed to account for the premature aging observed in adults with DS. The DNA damage theory of aging focuses on aging as a consequence of unrepaired DNA damage accumulation. The DNA damage theory is supported by lower levels of DNA repair enzymes being found in adults with DS (Madan, Williams & Lear, 2006). An alternate theory focuses on free-radical metabolism which involves a key enzyme, CuZn superoxide dismutase, which is located on chromosome 21 (Druzhyna, Nair, LeDoux & Wilson, 1998). Over-expression of this enzyme leads to the altered structure and function of tissue (Sinha, 2005).

Menopause

Women with DS are found to experience menopause starting at an earlier age than other women with ID and than women in the general population (Carr & Hollins, 1995; Cosgrave, Tyrrell, McCarron, Gill & Lawlor, 1999; Schupf, Zigman, Kapell, Lee, Kline & Levin, 1997). An early report found that 87% of women with DS and 69% of women with ID had stopped menstruating by age 46. All women with DS had stopped menstruating by the age of 51, and all of the women with ID by age 54. An estimate of the median age at menopause for women with DS of 47.1 is two years younger than the estimated median age for women with ID of 49.3 (Schupf et al., 1997). These estimates among women with DS and ID are potentially underestimates as the proportion of women who had never menstruated in the sample was unknown. A recent prospective study using multiple methods of analysis of the age at menopause for women with DS, all of whom had a history of menstruation, reported a median age of 45.8 to 47.1 (Seltzer, Schupf & Wu, 2001). No woman with DS older than 52 was menstruating. In comparison, the age at menopause in the general population is 51.3, with perimenopause starting at 47.5 (McKinlay, Brambilla & Posner, 1992), indicating that women with DS have a median age of menopause that is 4 to 6 years earlier than women in the general population.

The earlier onset of menopause in women with DS has implications for their health as menopause is a risk factor for heart disease, depression, osteoporosis, breast-cancer and dementia in the general population (Harlow & Ephross, 1995), and is associated with cognitive declines and dementia in women with DS (Patel, Seltzer, Wu & Schupf, 2001; Schupf et al., 2003). Some studies have found thyroid deficiency contributing to earlier onset of menopause (Carr & Hollins, 1995), whereas others have not replicated the findings in part due to appropriate thyroid treatment being available to the women sampled (Schupf

et al., 1997; Seltzer et al., 2001). As such, the contribution of thyroid conditions to earlier menopause is still uncertain.

Vision impairments

Visual impairments (44-71%) and eye abnormalities are common among aging adults with DS (Gardiner, 1967; Jacobson, 1988; McCarron, Gill, McCallion & Begley, 2005). The prevalence of visual impairments does not appear to be related to level of intellectual functioning among individuals with DS, and is greater than the prevalence (8-50%) observed in older adults with ID without DS (Gardiner, 1967; Haveman, Maaskant & Sturmans, 1989; Janicki & Jacobson, 1986; Moss, 1991). Comparable to visual acuity in the general population, visual impairment deteriorates among adults with DS, with the prevalence of severe visual impairment increasing from 18% among 30-39 year olds, to 28% among 40-49 year olds and to 45% among 50-59 year olds (Van Buggenhout et al., 1999). Of greater concern than the prevalence of visual impairment are reports of only 53% of cases of impairment being diagnosed, and only 50% of individuals with DS receiving correction for their visual impairment (Jacobson, 1988).

Cataracts (11-33%), strabismus (23-37%), refraction problems (30-34%) and keratoconus (15%) are common ophthalmological problems (Aitchison, Easty & Jancar, 1990; Prasher, 1994b; Van Allen, Fung & Jurenka, 1999; Van Buggenhout et al., 1999). A small study of 19 adults with DS over the age of 40 reported even higher rates of ophthalmological problems, with 55% suffering from strabismus and 75% from refraction problems (Hesmes, Sand & Fostad, 1991). The prevalence of cataracts is greater in adults than in children with DS and is comparable to or higher than the prevalence of 17% found in adults in the general population (Congdon et al., 2004). Higher rates of cataracts among adults with DS have been reported (30-68%), with few warranting surgery (Hesmes et al., 1991; Pueschel, 1990; Van Allen et al., 1999). Even when surgery is performed, visual problems and impairments may persist related to aphakia (absence of the lens of the eye) and to poor use of bifocals (Van Allen et al., 1999). Senile cataracts appear to develop earlier in adults with DS than in the general population and to increase in prevalence with age (Pueschel, 1990; Robb & Marchevsky, 1978; Van Allen et al., 1999). These senile cataracts, characterized by a gradual thickening of the lens, tends to occur at a younger age in DS compared to other individuals with ID, possibly due to the accelerated aging process present in individuals with DS and the increased amounts of free radical reactions (Ellis, 2002).

Keratoconus also increases in prevalence with age, from 11% in middle-age to 20% in the elderly (Van Allen et al., 1999). One small study reported that 37% of adults over the age of 40 had keratoconus (Hesmes et al., 1991).

Hearing Impairments

Age-related hearing loss is more common among adults with DS compared to the general population, and appears to have an earlier age of onset. High frequency sensorineural hearing impairments (such as presbycusis) in adults with DS onsets about 20 to 30 years earlier than in their peers with ID, and about 30 to 40 years earlier than in the general population (Buchanan, 1990). Rates of hearing loss among adults with DS range from 12 to 72% (Howells, 1989; Prasher, 1994b; Van Buggenhout et al., 1999), and may depend on the nature of the hearing assessment. Using detailed audiometric methods, Van Buggenhout and colleagues (1999) found 53% of adults with DS to have moderate hearing loss, 17% to have a severe hearing loss, and 2% to have a profound hearing loss. These rates of hearing loss were reported to increase with age and for the hearing loss to become more severe (Buchanan, 1990; Van Buggenhout et al., 1999). While the rate of hearing loss is not related

to level of ID, it has been found to be higher among adults with co-morbid dementia (McCarron et al., 2005).

Howells (1989) reported that 55% of adults over age 21 may have sensorineural hearing loss. For adults over 35 years of age, 68% of ears tested were reported to have cochlear hearing loss, with conductive hearing loss found in 5% of ears and mixed hearing loss found in 13% of ears (Evenhuis, Van Zanten, Procaar & Roerdinkholder, 1992). Van Buggenhout and colleagues (1999) similarly found a low rate of conductive hearing loss (10%) in their sample of adults with DS, and a comparable number with sensorineural and mixed hearing loss (45% and 44% respectively). However, Evenhuis et al. (1992) argues that we do not know how much the rate and degree of hearing impairment in adults with DS is related to previous middle ear pathology, such as otitis media. With the life expectancy of adults with DS growing longer, it is important to understand how medical conditions common early in the life course may influence the health of the individual later in life.

While hearing impairments are common among adults with DS, few are identified or treated. Of individuals identified with hearing impairments during research testing who did not use hearing devices, 80% of their care providers and general practitioners were unaware of the hearing loss (Van Buggenhout et al., 1999). Additionally, only 41% of individuals with hearing impairments identified during research testing were using hearing devices (Van Buggenhout et al., 1999). Half of this sample had severe to profound ID which may have contributed to a difficulty in using hearing devices.

Seizure disorder

The rate of seizures increases with age for individuals with DS, especially for individuals suffering from comborbid dementia. Early reports of the rate of seizures were significantly lower than more recent prevalence estimates. One early estimate of the rate of seizures was 12.2% for adults with DS over the age of 55 and 15.8% for adults over the age of 60 (Veall, 1974). However, early estimates were consistent with more recent estimates that abnormal readings reflective of seizure activity are high, with 71.4% of adults over 55 showing this abnormal activity (Tangye, 1979). Although these early reports underestimated current prevalence estimates, perhaps consistent with the shorter life expectancy of the time, these studies consistency reported a rise in the rate of seizures with age from adolescents to young adults to later adulthood. This increase in the rate of seizures across the lifespan is supported by other later research. Cohort differences show that 8% of adolescents or young adults with DS suffer from seizures as compared to 24-28% of seniors aged 50 and older (Johannsen, Christensen, Goldstein, Nielsen & Mai, 1996; McDermott, Moran, Platt, Wood, Isaac & Dasari, 2005). McVicker, Shanks and McClelland (1994) also supported a lower rate of seizures among younger individuals (7%) as compared to adults older than 50 (46%). A lifespan study of individuals with DS found that approximately 8% of individuals with DS suffer from seizures, and of these 40% experienced seizures after the age of 20 (Pueschel, Louis & McKnight, 1991). The higher rate of seizures observed in individuals with DS may be related to the gene for myoclonus epilepsy being mapped to chromosome 21, however this form of seizure is more commonly found in children and adolescents (Hattori et al., 2006). Older patients with DS typically have tonic-clonic (formerly known as grand mal), complex partial or simple partial seizures (Pueschel et al., 1991). Alternatively, structural abnormalities and biochemical aberrations of the CNS in adults with DS may in part be responsible for increased seizure frequency (Pueschel et al., 1991).

The increase in seizures related to age parallels the increase in the general population, although the rate of seizures is lower in the general population than among individual with DS (McDermott et al., 2005). However, it should be noted that the rate of seizure activity

among individuals with DS is lower than the reported rate among individuals with ID in general (McDermott et al., 2005). More recent estimates of the rate of seizures among adults with DS range from 9.4% to 26.5%, with a mean onset of seizures over the age of 30, around age 37 (Johannsen et al., 1996; McDermott et al., 2005; McVicker et al., 1994; Puri, Ho & Singh, 2001).

In addition to increasing with age, the rate of epilepsy and seizures is also related to the onset of dementia among adults with DS (Puri et al., 2001; Prasher & Corbett, 1993). In one study, 80% of the adults with seizures also presented with symptoms consistent with a clinical diagnosis of dementia (McVicker et al., 1994). In another study, 53% of individuals with dementia were reported to have seizures and the onset of seizures appeared to presage the onset of cognitive deterioration and symptoms of dementia (Lott & Lai, 1982). Indeed, the onset of seizures has been reported to occur at a younger age for individuals with DS who do not suffer from dementia (age 29) as compared to those who do (age 45). Dementia may be an important risk factor for late-onset seizures in adults with DS, but not for the high rate of seizures among all individuals with DS (Menéndez, 2005).

Thyroid dysfunction

Comparable to how the rate of seizures increases with age in adults with DS, the rate of individuals with DS at risk for thyroid disease also increases with age (Korsager, Chatham & Ostergaard-Kristensen, 1978), although some samples have indicated no increase with age (Murdoch, Ratcliffe, McLarty, Rodger & Ratcliffe, 1977; Šare, Ruvalcaba & Kelley, 1978). Approximately 35-40% of adults with DS are reported to have abnormal thyroid function, although only 7-8% had active hypothyroidism (Dinani & Carpenter, 1990; Prasher, 1994a; Prasher, 1994b). Also comparable to seizure findings, the rate of thyroid disease in adults with DS is greater than that found in the general population (Coleman, 1994).

The high rate of abnormal thyroid function highlights the need for consistent and routine monitoring of thyroid functioning for adults with DS. Routine monitoring is particularly important as some individuals tested with abnormal thyroid functioning were identified with thyroid disease and were receiving too much or too little medication to manage their disease (Prasher, 1994a).

Other Medical Conditions

Diabetes

There are a few reports of an increased risk of Type 1 diabetes among individuals with DS and of increased risk of mortality due to Type 1 diabetes as compared to the general population (Anwar, Walker & Frier, 1998; Hill et al., 2003). The age of onset of Type 1 diabetes appears to be increasing in individuals with DS. Earlier studies of Type 1 diabetes from the 1960s focused on children (Burch & Milunsky, 1969; Farquhar, 1962; Milunsky & Neurath, 1968) and reported that the age of onset peaked at 8 years of age for individuals with DS. However, the life expectancy of individuals with DS in the 1960s was 18 years (Collmann & Stoller, 1963). With increasing life expectancies for individuals with DS, more recent age of onset estimates of 22 years are comparable to the onset of type 1 diabetes in the general population (Anwar et al., 1998) and consistent with more individuals being diagnosed with adult-onset diabetes than juvenile diabetes. However, contrary reports suggest that adults with DS are at lower risk for mortality due to Type 1 diabetes than the general population and than adults with ID due to other causes (Haveman et al., 1989; Yang et al., 2002). Few reports are available regarding Type 2 diabetes in adults with DS, but the rate reported in a preliminary report appears to be lower than that in the general population

(Silverman, 2010). There is a need for more detailed population studies on the rate of Type 1 and Type 2 diabetes in individuals with DS to confirm these findings.

Obesity

A significant proportion of adults with DS are reported to be overweight or obese according to the body mass index (BMI). Between 45-79% of males and between 56-96% of females with DS are reported to be overweight (Bell & Bhate, 1992; Melville, Cooper, McGrother, Thorp & Collacott, 2005; Prasher, 1995; Rubin, Rimmer, Chicoine, Braddock & McGuire, 1998), while the prevalence in the general population that is overweight was reported to be approximately a third during the time period of these studies (Rubin et al., 1998). Contributing factors to the high rate of overweight and obese individuals with DS may include a combination of eating behavior, intake, metabolic rate, hypothyroidism and reduced exercise (Prasher, 1995).

BMIs are found to increase with age in the general population. Conversely, BMIs of cohorts of adults with DS are observed to be smaller with increasing age (Prasher, 1995; Rubin et al., 1998). Contributing factors to the lower BMIs found in older adults with DS are speculative, but may include residential setting, and healthier weights contributing to longevity (Rubin et al., 1998).

Sleep apnea

Obstructive sleep apnea (OSA) is present in approximately 30-55% of children with DS (de Miguel-Díez, Villa-Asensi & Álvarez-Sala, 2003; Stebbens, Dennis, Samuels, Croft & Southall, 1991). The known risk factors for OSA in children include facial (midfacial hypoplasia, mandibular hypoplasia) and other physical features (glossoptosis, an abnormally small upper airway, superficially positioned tonsils, relative tonsillar and adenoidal encroachment, hypotonia of upper airway) (Marcus, Keens, Bautista, von Pechmann & Ward, 1991; Roizen, 2003). Other risk factors have yet to be identified. Adults with DS are at increased risk for OSA as these risk factors observed in children continue into adulthood, and other risk factors become more prevalent. Obesity (reviewed previously) is a risk factor for OSA that put adults with DS at increased risk for developing this disorder. The rate of hypothyroidism (reviewed previously) increases with age in adults with DS, and is associated with OSA. The few studies that have examined the rate of OSA among adults with DS report that up to 94% of adults suffer from the disorder (Trois et al., 2009). Despite the increase in the number of risk factors predisposing adults with DS to OSA, increasing age is found to be the strongest risk factor, particularly when other risk factors are not present (Resta et al., 2003).

Musculoskeletal

Musculoskeletal problems often result from premature degenerative bone and joint disease (Dacre & Huskisson, 1988; Olive, Whitecloud & Bennet, 1988). Osteoporosis is common among adults with DS and adults are at greater risk as they age (Center, Beange & McElduff, 1998). There are several factors that may contribute to this increased risk for osteoporosis in adults with DS, including early menopause, deceased physical activity, low muscle tone and decreased strength. Degenerative osteoarthritis is also common among adults with DS, with osteoarthritis of the spine affecting 22% of middle-age adults and 40% of elderly adults (Van Allen et al., 1999). Typical symptoms include numbness, weakness and pain. It is often difficult to detect these symptoms in individuals with ID, and thus the rate of degenerative osteoarthritis may be underreported. Orthopedic problems, such as flat feet (a congenital condition), are the most common musculoskeletal abnormality observed in adults with DS, affecting approximately 70% of individuals (Prasher, 1994b).

Mitral valve prolapse

Mitral valve prolapse is common among adults with DS, occurring in between 46 to 57% of individuals (Barnhart & Connolly, 2007; Roizen & Patterson, 2003). Even though children with DS have a high risk of congenital heart disease, this previous cardiac pathology is not linked to the high rate of mitral valve prolapse later in life. Early signs of mitral valve prolapse are comparable to those observed in the general population and include fatigue, weight gain, and irritability (Barnhart & Connolly, 2007).

Mortality

Health problems present in adults, reviewed earlier in this chapter such as sensory handicaps, thyroid disorders, and degenerative spine disease, may contribute to the earlier mortality observed in adults with DS (Kapell, Nightingale, Rodriguez, Lee, Zigman & Schupf, 1998; Lantman-de Valk, Haveman, & Crebolder, 1996). However, their direct effect on mortality is not yet well documented. The life expectancy of adults with DS has a similar pattern until the age of 40 as compared to their age peers with other types of ID, and elevated mortality rates thereafter (Haveman, Maaskant & Sturmans, 1989; Maaskant, Gevers & Wierda, 2002; Strauss & Eyman, 1996).

The life expectancy of adults with DS is increasing and now averages around the mid- to late-50s. Still, this life expectancy is substantially below that of the general population and that of their peers with ID (Glasson, Sullivan, Hussain, Petterson, Montgomery & Bittles, 2002; Janicki, Dalton, Henderson & Davidson, 1999). Also, while women with DS are observed to have shorter life expectancies than men with DS, the opposite pattern is seen in the general population and among individuals with other types of ID (Carter & Jancar, 1983; Glasson et al., 2002; Glasson, Sullivan, Hussain, Petterson, Montgomery & Bittles, 2003; Tyrer, Smith & McGrother, 2007). A gender difference in mortality among individuals with DS is still speculative as other studies have not replicated this finding (Day, Strauss, Shavelle & Reynolds, 2005; Janicki et al., 1999). If valid, earlier menopause (discussed earlier) may be a contributing factor to earlier mortality in women with DS as compared to men with DS (Schupf, Zigman, Kapell, Lee, Kline & Levin, 1997).

The evidence is mixed regarding other risk factors found to predict mortality of adults with DS. Some studies have found that functional abilities predict mortality in adults with DS (Chaney & Eyman, 2000; Esbensen, Seltzer & Greenberg, 2007; Eyman, Call & White, 1991; Strauss & Zigman, 1996), comparable to findings in their peers with ID (Bittles, Petterson, Sullivan, Hussain, Glasson & Montgomery, 2002; Strauss & Eyman, 1996). Prior levels of functional abilities and declines in functional abilities were found to predict mortality in a sample of adults with and without DS (Esbensen et al., 2007). However, the relationship between functional abilities and mortality among adults with DS is not always supported (Glasson et al., 2002; Strauss & Eyman, 1996; Strauss & Zigman, 1996). Age has consistently been found to be a predictor of mortality for adults with DS (Esbensen et al., 2007; Eyman, Call & White, 1989; Hayden, 1998), and new research suggests that worsening of behavior problems is another predictor of mortality (Esbensen et al., 2007).

Common causes of death in this population include leukemia, respiratory illness, congenital circulatory defects, diseases of the digestive system, dementia and Alzheimer's disease, and are reported to vary with age (Day et al., 2005; Hermon, Alberman, Beral & Swerdlow, 2001; Hill et al., 2003; Thase, 1982). Although a common cause of death among children with DS is leukemia (behind respiratory illness and congenital heart defects), this risk is found to decrease with age (Hasle, Clemmensen & Mikkelsen, 2000; Yang et al., 2002). In contrast, the risk of mortality due to cancer in adults with DS is equal to or lower than that in the general population or among their peers with ID (Day et al., 2005; Hasle et al., 2000;

Patja, Eero & Iivanainen, 2001b; Sullivan, Hussain, Glasson & Bittles, 2007; Yang et al., 2002). In particular, the risk of mortality due to solid tumors among adults with DS is considerably lower than among their peers and the general population (Hasle et al., 2000; Hill et al., 2003; Sullivan, et al., 2007). In contrast, the risk for dementia was found to increase with age (Yang et al., 2002). Respiratory problems, congenital anomalies (other than congenital heart anomalies) and ischemic heart disease were also found to vary with age in their relation to mortality in individuals with DS. Among older adults with DS, respiratory problems and congenital anomalies are reported to be more common and ischemic heart disease less common than expected (Yang et al., 2002). That cardiovascular and circulatory defects are common causes of death among individuals with DS is not unexpected given the biological phenotype of this syndrome (Roizen, 1996). In comparison, the common causes of mortality found among individuals with ID include cardiovascular diseases, respiratory diseases, and cancers (Patja, Mölsä & Iivanainen, 2001a), and these have been found to be comparable to causes of mortality among a sample of only adults with DS (Esbensen et al., 2007).

Medical Conditions with Low Risk

While adults with DS are at risk for several medical conditions just described, they are also at low risk for other medical conditions. In a review of cancers among individuals with DS, malignant solid tumors were reported to be underrepresented (Satgé, Sommelet, Geneix, Nishi, Malet & Vekemans, 1998). In particular, common epithelial tumors were underrepresented in adults, as are breast, uterine, digestive, genital, skin, bronchial, ear/nose/throat or urinary tract cancers (Hasle, Clemmensen, Haunstrup & Margareta, 2000; Hill et al., 2003; Jancar & Jancar, 1976; Oster, Mikkelsen & Nielsen, 1975; Scholl, Stein & Hansen, 1982). However, a greater risk for testicular cancer has been reported among males with DS as compared to typically developing males (Dieckmann, Rube & Henke, 1997; Hasle et al., 2000).

Possible explanations for the decreased risk of some cancers among adults with DS are that accurate population morbidity studies are rare. It has also been proposed that individuals with DS may be less exposed to environmental contributors to cancer risk (Satgé et al., 1998). Decreased alcohol and tobacco use, early menopause and other lifestyle and environmental factors may contribute to lower cancer risk. However, obesity and the lack of physical activity common in adults with DS would contribute to an increased risk of cancers. The shorter life expectancy of individuals with DS has also been suggested to contribute to lower risk for cancer (Satgé et al., 1998). However, as the life expectancy of individuals with DS has increased dramatically over the last few decades, shorter life expectancy becomes a less probable explanation for the apparent lower risk of solid tumors. Several tumor-suppressor genes have been identified on chromosome 21, potentially contributing to the decreased risks for many solid tumors (Lee, T. Park, S. Park & J. Park, 2003). Copper-zinc superoxide dismutase, also located on chromosome 21, and its contribution to the metabolism of oxygen free radicals are further hypothesized to reduce the risk of carcinogens (de la Torre, Casado, Lopez-Fernández, Carrascosa, Ramirez & Saez, 1996).

While the rate of mitral valve prolapse is high, there is a lower risk for cardiovascular and cerebrovascular disease observed in adults with DS as compared to the general population (Marino & Pueschel, 1996) and lower rates of emphysema, fractures, hypercholesterolaemia and heart disease as compared to adults with ID due to other causes (Haveman et al., 1989; Kerins et al., 2008). Further, individuals with DS are found to have lower resting heart rates and lower blood pressure than the general population (Prasher, 1994b; Richards & Enver, 1979). The rise in blood pressure seen with age in the general population is not as great

among individuals with DS, and hypertension is an uncommon problem reported in adults with DS (Kerins et al., 2008; Prasher, 1994b).

While upper respiratory infections are common among adults with DS, significant respiratory problems are not common (Minihan & Dean, 1990; Prasher, 1994b; Wilson & Haire, 1990). Further, as mobility declines with age, recurrent pneumonia with incomplete recovery has been found to occur more often (Van Allen et al., 1999). This is particularly noteworthy as respiratory illness is a common cause of mortality in adults with DS. It may be that chronic respiratory problems contribute to mortality more so than acute respiratory problems.

Health Care

There are excellent guidelines for the health care of individuals with DS across the lifespan, including guidelines specific to adults (Cohen, 2002). They provide recommendations to health care professionals of what conditions to screen for and how frequently. However, little is known about the pattern of screening, health care use and access, or barriers to health care experienced by adults with DS specifically, although efforts are currently being made to explore these questions.

The literature on health care service use by adults with ID indicates that this population experiences significant health disparities in access to health care in comparison to the general population (Horwitz, Kerker, Owens & Zigler, 2000). As an example, few adults with ID receive care from specialists despite a high percentage of individuals, such as individuals with DS, having medical needs that require specialty care. An agenda has been set by the federal government for promoting the health of individuals with ID, improving their quality of and access to health care, and training health care providers to the specific needs of individuals with ID (US Public Health Service, 2001).

Conclusions

As individuals with DS continue to experience longer lives, the need to understand their aging and associated health conditions becomes more critical. The chronic disorders that onset in adults with DS, and the age-related change in other disorders, have important implications for health care management of this aging population. Health care providers need to be informed of the health conditions more common among adults with DS as they age, to be alert for declines earlier than expected in the general population, and the implication that early-life medical conditions may have in the later-life of the individual. For example, chronic and inadequately treated middle ear infections in childhood may have an impact on later hearing loss in adults with DS.

The different pattern of health conditions in aging adults with DS also has implications for family members and support providers. Over 60% of adults with ID co-reside with their families (Fujiura, 1998). As such, families and support providers of adults with DS need to be informed of what symptoms to be alert for in order to better communicate changes in health to medical providers, such as lethargy, irritability and fatigue. The health care provider is then responsible for determining whether these common symptoms are due to hypothyroidism, mitral valve prolapse, symptoms of menopause, pain, poor sleep, or to depression resulting from disorientation due to sensory impairments. Deteriorations in health can also be associated with an increase in behaviors, particularly if the individual with DS has communication difficulties in expressing problems or medical complaints. And finally, adults with DS should be provided with appropriate information to better understand, and counseling to cope with, changes in their own level of ability or health.

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