Physical Activity

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Introduction

The benefits of physical activity are well documented[1-4] and include lower rates of heart disease, depression, type II diabetes, and stroke.[5] It has been suggested that physical activity should be used as a vital sign [6] because it is a leading indicator of health and lowers mortality and morbidity.[5] Unfortunately the majority of Americans fail to meet the recommended guidelines for physical activity.[7] Additionally, it is recognized that both children and adults with Spina Bifida, as well as groups of individuals with other disabilities, are even less active when compared to the general population.[8-10]

Increasing physical activity for individuals with Spina Bifida may be critical since a loss of strength or fitness may lead to less independence and function in carrying out activities of daily living.[11] In addition to physical and functional benefits of physical activity, there are many mental health benefits such as perceived improvement in activities of daily living[12] higher athletic competence, better perceived physical appearance, greater self-worth, and higher quality of life.[13]

The National Physical Activity Guidelines are for everybody.[14] These guidelines are incorporated into the Spina Bifida Guidelines for Physical Activity and should be followed as closely as possible by children and adults with Spina Bifida unless deemed medically unsafe by a health care provider. Physical activity is the key to health and wellness. Endorsement rather than caution is recommended for the vast majority of individuals with Spina Bifida.

The physical activity guidelines for children ages 6-17 state:[15]

- Children should engage in 60 minutes or more of physical activity each day.
- Aerobic activity should make up most of the youth's activity each day; vigorous intensity aerobic activity should be done at least 3 days/week.
- Muscle strengthening activities should be done at least 3 days/week as part of the 60 or more minutes.
- Bone-strengthening activities should be done at least 3 days/week as part of the 60 or more minutes.

The physical activity guidelines for adults state:[15]

- Adults should avoid inactivity. Some physical activity is better than none, and adults who participate in any amount of physical activity gain some health benefits.
- For substantial health benefits, adults should do at least 150 minutes (2 hours and 30 minutes) a week of moderate-intensity, or 75 minutes (1 hour and 15 minutes) a week of vigorous-intensity aerobic physical activity, or an equivalent combination of moderate- and vigorous-intensity aerobic activity. Aerobic activity should be performed in episodes of at least 10 minutes, and preferably, it should be spread throughout the week.
- For additional and more extensive health benefits, adults should increase their aerobic physical activity to 300 minutes (5 hours) a week of moderate-intensity, or 150 minutes a week of vigorous-intensity aerobic physical activity, or an equivalent

combination of moderate- and vigorous-intensity activity. Additional health benefits are gained by engaging in physical activity beyond this amount.
- Adults should also include muscle-strengthening activities that involve all major muscle groups on two or more days a week.

Please see Appendix for physical activity and disability resources.

Outcomes

Primary

1. Increase (or maintain) the minutes per day of daily physical activity at the different age levels as established by the National Physical Activity Guidelines.

Secondary

1. Increase knowledge and awareness of physical activity (i.e., benefits, safety, what/how to do it).

Tertiary

1. Improve health outcomes through physical activity participation across the lifespan (holistically, to maintain function, prevent secondary conditions, and for mental health and wellness).

0-11 months

Clinical Questions

1. Is there evidence that early motor skill intervention increases physical activity across the lifespan?
2. How early should doctors and therapists talk to parents/caregivers about physical activity for infants with Spina Bifida?
3. Are physical activity goals included in the Individual Family Service Plan (IFSP) for children beyond physical and occupational therapy?

Guidelines

1. Conduct infant motor development assessment to evaluate motor function in children with Spina Bifida to identify the most appropriate therapeutic intervention to enhance motor development outcomes.[16] (Mobility Guidelines)
2. Provide guidance to parents and caregivers and include physical therapists in discussions about how to encourage movement and activity in their child.[17] (Health Promotion and Preventive Health Care Service Guidelines)
3. Inform parents and caregivers of their child's right to early intervention services that include adapted physical education/activity (Appendix: Early Intervention Services, Individualized Educational Plans (IEP) and 504 Plans). Encourage parents/caregivers to request that physical activity goals be added to the IFSP, if eligible for IFSP.[18]

1-2 years 11 months

Clinical Questions

1. What strategies work to educate parents/caregivers about the importance of physical activity and ways to get their child involved?
2. How early should parent/caregiver education about physical activity start? What resources are available?
3. What is the most successful way to encourage parents/caregivers to invest time and money in physical activities for their child with Spina Bifida?

Guidelines

1. Discuss with parents and caregivers the benefits of involving their child with Spina Bifida in recreation, physical activity, and social programs and services, and provide information and/or resources about adapted and inclusive activities.[15] (Health Promotion and Preventive Health Care Services Guidelines)
2. Collaborate with parents/caregivers to identify physical activities they can do in everyday life to model the importance of physical activity as part of a healthy lifestyle. (clinical consensus)
3. Use motivational interviewing techniques with parents/caregivers to talk about physical activity goals for their child with Spina Bifida and work through barriers.[19]
4. Inform parents/caregivers of the rights of their child to adapted physical education/activity and encourage parents/caregivers to advocate for physical activity goals to be added to their IFSP* or Section 504 plan (if they are eligible for an IFSP or Section 504 plan) (Appendix: Early Intervention Services, Individualized Educational Plans (IEP) and 504 Plans).[18]

3-5 years 11 months

Clinical Questions

1. Given that some children with Spina Bifida will be limited in their physical function, what activities should they be exposed to, and when? Typically, children start playing baseball, soccer and other team sports at age 4 or 5. Should children with Spina Bifida start similar activities at the same age?
2. What training will coaches need to welcome children to meaningful play?
3. How does proper/improper mobility equipment affect the child's ability to participate in physical activity (e.g., a wheelchair that fits properly, proper seating and back setup, ankle foot orthotics, crutches, etc.)?
4. Who can parents and caregivers and doctors consult when they have questions related to physical activity and exercises that help maintain upper and lower body function (e.g., physical therapists (PTs), occupational therapists (OTs), recreation therapists, fitness staff, the National Center on Health, Physical Activity and Disability)?

Guidelines

1. Discuss with parents and caregivers the importance of involving the child in recreation, physical activity, limiting sedentary behaviors and engaging in social programs/services where they can be actively engaged with peers who have and those who don't have a disability.[20] Also, give parents/caregivers information about the life-long benefits of physical activity (e.g. active adults with Spina Bifida report more functional independence and a higher quality of life compared to those with Spina Bifida who are inactive).[11] (Health Promotion and Preventive Health Care Services Guidelines)
2. Discuss strategies with parents/caregivers that balance parental involvement in their child's physical activities and the child's need for autonomy to increase independence.[21]
3. Identify and provide additional support and information on precautions that children with shunts and ambulatory limitations should take when being physically active.[22]
4. Use a team approach and include PTs/OTs to work with parents/caregivers to ensure children have proper fitting mobility equipment to maximize participation in physical activity. (clinical consensus)
5. Educate parents/caregivers of their child's right to adapted physical education/activity in preschool and encourage parents/caregivers to advocate for physical activity goals

to be added to their Individualized Education Plan (IEP) or Section 504 plan (if eligible for IEP or Section 504 plan).[18,23]

6-12 years 11 months

Clinical Questions

1. What are some strategies to continue physical activity or physical education while in the hospital or after a long hospital stay (e.g., exercise band/tubing stretches or increasing knowledge of physical activity through reading/lecture- style learning if no physical activity is allowed)?
2. Is there evidence about the benefits/effects on the physical activity levels of children with Spina Bifida who advocate for themselves on their physical education goals in their IEP meetings?
3. Does the evidence support the least restrictive environment? Is this support related to health, socialization, something else, or a combination of factors?
4. What training do schools need to include children with Spina Bifida in meaningful play throughout the day (at recess, physical education class, on-site after-school programs)?
5. What are some ways that physical education teachers can be more inclusive of children with Spina Bifida? How do we start this process as early as possible?
6. Does getting children engaged in sports at a young age improve the likelihood that they will remain engaged in activity throughout their lifespan?

Guidelines

1. Discuss the benefits of participating in physical activity, recreation, and sports with children with Spina Bifida.[24,29] Discuss with parents/caregivers the importance of limiting sedentary behaviors[20]. Encourage parents to give their child choices about where they can be actively engaged with peers who have and those who don't have a disability.[25] (Health Promotion and Preventive Health Care Services Guidelines)
2. Recommend that parents/caregivers follow the National Physical Activity Guidelines for their child with Spina Bifida as closely as possible unless a health care provider advises that they are medically unsafe. (clinical consensus)
   - Engage in 60 minutes of physical activity or more each day.[15]
   - Aerobic activity should make up most of the child's activity each day; vigorous intensity aerobic activity should be done at least 3 days/week.
   - Muscle strengthening activities should be done at least 3 days/week as part of the 60 or more minutes.
   - Bone strengthening activities should be done at least 3 days/week as part of the 60 or more minutes.
3. Use health care encounters and follow-up meetings to develop physical activity goals and monitor progress (e.g. minutes of physical activity per day). Use motivational interviewing techniques with the child and parents/caregivers to talk about physical activity goals and work through barriers.[19] Support parents/caregivers to develop an action plan with strategies to support their child's participation in physical activity in their community and school.[28] Prescribe, using a prescription pad, physical activity based on goals identified by the child.[14] (clinical consensus)
4. Perform pre-participation evaluations for children with Spina Bifida in collaboration with the child and family, pediatric specialists, therapists, coaches, and others to identify medical risks and modifications that can be made to ensure participation.[24]
5. Identify strategies to minimize risk of illness and injury related to participation through activity adaptations and safety precautions.[24] Identify and provide additional support and information for parents/caregivers on precautions to take when children with

shunts and ambulatory limitations are being active.[22] Discuss strategies that balance the parents'/caregivers' involvement with their child's need for independence when they participate in physical activity.[21]

6. Use a team approach and include PTs/OTs to work with parents/caregivers to ensure their child has proper fitting mobility equipment to maximize physical activity participation. (clinical consensus)
7. Work with children with Spina Bifida and their family to address personal barriers such as bowel/bladder care, medical events, assistive devices, as well as environmental factors that may affect participation.[30]
8. Advocate for and address barriers to participation of children with Spina Bifida in physical activity, recreation, and sports.[24]
9. Inform parents/caregivers of their child's right to adapted physical education/activity and encourage parents/caregivers to advocate for physical activity goals to be added to their child's IEP or Section 504 plan (if eligible for IEP or Section 504 plan).[18,23]
10. Advocate for the participation of children with Spina Bifida in both unified and adapted sports, recreation, and physical activity programs.[24]
11. Provide families with a local/regional therapeutic recreation and adapted sport resource guide.[22]

13-17 years 11 months

Clinical Questions

1. Do adapted physical education programs in schools adequately prepare (via a transition plan) children with Spina Bifida to lead physically active lifestyles?
2. What are the physical activity contraindications for children with Spina Bifida?
3. What are the types of physical activities used or recommended in the literature specific to children with Spina Bifida (resistance, cardio, incidental activity vs. planned physical activity/exercise)?
4. In what setting are children the most comfortable and likely to continue participation in a physical activity (e.g., in a group, at home, etc.)?
5. What are the doses of physical activity used or recommended in the literature for children with Spina Bifida? Are they effective for health changes?
6. Is physical activity included in the Individualized Transition Plan for children? (Transition Guidelines)

Guidelines

1. Discuss with children the benefits of participating in physical activity, recreation, and sports.[24,29] Discuss with children and parents/caregivers the importance of limiting sedentary behaviors.[20] Encourage children and parents/caregivers to consider choices about where they can be actively engaged with peers who have and those who don't have a disability.[25] (Health Promotion and Preventive Health Care Services Guidelines)
2. Recommend that children and parents/caregivers follow the National Physical Activity Guidelines as closely as possible, unless a health care provider advises that they are medically unsafe. (clinical consensus)
   - Engage in 60 minutes of physical activity or more each day.[15]
   - Aerobic activity should make up most of the child's activity each day; vigorous intensity aerobic activity should be done at least 3 days/week.
   - Muscle strengthening activities should be done at least 3 days/week as part of the 60 or more minutes.
   - Bone strengthening activities should be done at least 3 days/week as part of the 60 or more minutes.

3. Use health care encounters and follow-up meetings to develop physical activity goals and monitor progress (e.g. minutes of physical activity per day). Use motivational interviewing techniques with children and parents/caregivers to talk about physical activity goals and work through barriers.[19] Support children and parents/caregivers to develop an action plan with strategies to support the participation of children age 13-17 years in physical activity in their community and school.[28] Prescribe, using a prescription pad, physical activity based on goals identified by children with Spina Bifida.[14] (clinical consensus)
4. Perform pre-participation evaluations for children with Spina Bifida in collaboration with parent/caregivers, pediatric specialists, therapists, coaches, and others to identify medical risks and modifications that can be made to ensure participation.[24]
5. Identify strategies to minimize risks of illness and injury related to participation through activity adaptations and safety precautions.[24] Identify and provide additional support and information for children age and parents/caregivers on precautions to take when children with shunts and ambulatory limitations are being active.[22] Discuss strategies that balance the parents'/caregivers' involvement with their child's need for independence when they participate in physical activity.[21]
5. Use a team approach and include PTs/OTs to work with parents/caregivers to ensure their child has proper fitting mobility equipment to maximize physical activity participation. (clinical consensus)
6. Work with children with Spina Bifida and their family to address personal barriers such as bowel/bladder care, medical events, assistive devices, as well as environmental factors that may affect participation.[30]
7. Advocate for and address barriers to participation of children with Spina Bifida in physical activity, recreation, and sports.[24]
8. Inform parents/caregivers of their child's rights to adapted physical education/activity and encourage children and parents/caregivers to advocate for physical activity goals to be added to their IEP or Section 504 plan (if eligible for IEP or Section 504 plan).[18,23]
9. Assist students who are considering post-secondary education to assess supports for physical activity in the educational institutions they are considering and include these in their individual transition plans.
10. Advocate for the participation of children with Spina Bifida in both unified and adapted sports, recreation, and physical activity programs.[24]
11. Provide families with a local/regional therapeutic recreation and adapted sport resource guide.[22]
12. Discuss with children where they feel most comfortable being physically active and about their options (e.g., in the community, at school, with peers with/without disabilities).[25]
13. Highlight that ages 13-17 years is a critical period to build physical activity into a daily routine that will preserve overall lifelong satisfaction and community participation among persons with Spina Bifida.[29]

18+ years

Clinical Questions

1. What are the physical activity contraindications for adults with Spina Bifida?
2. What are the types of physical activities used or recommended in the literature specific to adults with Spina Bifida (resistance, cardio, incidental activity vs. planned physical activity/exercise)?

3. What is the best setting for physical activity for adults (e.g., in a group, at home, etc.)? Where are they most comfortable and likely to continue participation?
4. What are the doses of physical activity used or recommended in the literature for adults with Spina Bifida? Are they effective for health changes?

Guidelines

1. Discuss the National Physical Activity Guidelines with adults with Spina Bifida.[15] (Health Promotion and Preventive Health Care Services Guidelines)
2. Follow the guidelines for adults with Spina Bifida as closely as possible, unless a health care provider advises that they are medically unsafe. (clinical consensus)
3. For substantial health benefits, it is recommended that adults should do at least 150 minutes (2 hours and 30 minutes) a week of moderate-intensity, or 75 minutes (1 hour and 15 minutes) a week of vigorous-intensity aerobic physical activity, or an equivalent combination of moderate- and vigorous-intensity aerobic activity. It is recommended that aerobic activity should be performed in episodes of at least 10 minutes, and preferably, it should be spread throughout the week. (clinical consensus)
4. For additional and more extensive health benefits, it is recommended that adults should increase their physical activity to 300 minutes (5 hours) a week of moderate-intensity aerobic exercise, or 150 minutes (2 hours and 30 minutes) a week of vigorous-intensity aerobic physical activity, or an equivalent combination of moderate- and vigorous-intensity activity. Additional health benefits are gained by engaging in physical activity beyond this amount. (clinical consensus)
5. It is recommended that adults should include muscle-strengthening activities that involve all major muscle groups on 2 or more days a week. (clinical consensus)
6. It is recommended that all adults should avoid inactivity. Some physical activity is better than none, and adults who participate in any amount of physical activity gain some health benefits. (clinical consensus)
7. Identify and provide additional support and information on physical activity precautions for adults with shunts and ambulatory limitations.[22]
8. Use health care encounters and follow-up meetings to develop physical activity goals and monitor progress (e.g. minutes of physical activity per day). Employ motivational interviewing techniques to discuss and set physical activity goals and strategies to overcome barriers to achieving those goals.[19] Discuss the importance of physical activity and physical activity options with adults with Spina Bifida.[11]
9. Prescribe, using a prescription pad, physical activity based off on goals discussed with adults with Spina Bifida.[27]
10. Assist students who are considering post-secondary education to assess supports for physical activity in the educational institutions they are considering.
11. Use a team approach and include PTs/OTs to work with the adult with Spina Bifida to make sure that their mobility equipment fits properly in order to maximize their participation in physical activities. (clinical consensus)
12. Emphasize that any movement is beneficial.[15]

Research Gaps

1. What are the strategies/solutions needed to intrinsically motivate individuals with Spina Bifida to be physically active at different ages across the lifespan (e.g., peer support, increased knowledge, self-efficacy, and other approaches)?
2. How can we best educate and train parents and individuals with Spina Bifida to be advocates for their inclusion in physical activity in their communities at large?

3. What physical activity resources are available for doctors nationwide? Locally? What resources need to be created?
4. Is there evidence that physical activity prevents secondary conditions? If so, how strong is this evidence?
5. What are the social/health benefits of participating in physical activity for individuals with Spina Bifida at different ages across the lifespan?
6. What are some strategies to continue physical activity or physical education while in the hospital or after a long hospital stay (e.g., exercise band/tubing stretches or increasing knowledge of physical activity through reading/lecture- style learning if no physical activity is allowed)?
7. Is there evidence that the early motor skill intervention increases physical activity across the lifespan?
8. What strategies work to educate parents/caregivers about the importance of physical activity and ways to get their child involved?
9. How early should parent/caregiver education about physical activity start? What resources are available?
10. What is the most successful way to encourage parents/caregivers to invest time and money in physical activities for their child with Spina Bifida?
11. Given that some children with Spina Bifida will be limited in their physical function, what activities should they be exposed to, and when? Typically, kids start playing baseball, soccer and other team sports at age 4-5 years. Should children with Spina Bifida start similar activities at the same age?
12. What training will coaches need to welcome children to meaningful play?
13. How does proper/improper mobility equipment affect the child's ability to participate in physical activity (e.g., a wheelchair that fits properly, proper seating and back set up, ankle foot orthotics, crutches, etc.)?
14. Who can parents/caregivers and doctors consult when they have questions related to physical activity/exercises that help maintain upper and lower body function (e.g., physical therapists (PTs), occupational therapists (OTs), recreation therapists, fitness staff, National Center on Health, Physical Activity and Disability)?
15. Is there evidence about the benefits/effects on the physical activity levels of children with Spina Bifida who advocate for themselves on their physical education goals in their IEP meetings?
16. Does the evidence support the least restrictive environment? Is this support related to health, socialization, something else, or a combination of factors?
17. What training do schools need to include children with Spina Bifida in meaningful play throughout the day (at recess, physical education class, on-site after-school programs)?
18. What are some ways that physical education teachers can be more inclusive of children with Spina Bifida? How do we start this process as early as possible?
19. Does getting children engaged in sports at a young age improve the likelihood that they will remain engaged in activity throughout their lifespan?
20. What is the best setting for physical activity for adults (e.g., in a group, at home, etc.)? Where are they most comfortable and likely to continue participation?
21. What are the doses of physical activity used or recommended in the literature for adults with Spina Bifida? Are they effective for health changes?

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Appendix

1. National Physical Activity Guidelines (can be read online, or downloaded as a PDF):

https://health.gov/paguidelines/guidelines/

2. The Centers for Disease Control and Prevention's disability & physical activity resources for doctors and other health professionals: https://www.cdc.gov/ncbddd/disabilityandhealth/pa.html
3. The National Center on Health, Physical Activity, and Disability (NCHPAD): http://www.nchpad.org/
4. NCHPAD's health professionals resources (includes DocTalk and other videos for doctors and other health professionals): http://www.nchpad.org/Health~Care~Providers
5. NCHPAD's Physician's Toolkit: http://www.nchpad.org/1195/5822/Physician~s~Toolkit
6. Foundation for PM&R RX for Exercise (resources for doctors to prescribe exercise): http://foundationforpmr.org/rx-for-exercise/