



# Differences in meaning of Quality of Life and Inner Strength in families with and without adolescents and young adults with spina bifida

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# Differences in meaning of Quality of Life and Inner Strength in families with and without adolescents and young adults with spina bifida

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## Objectives

**The learner will be able to**

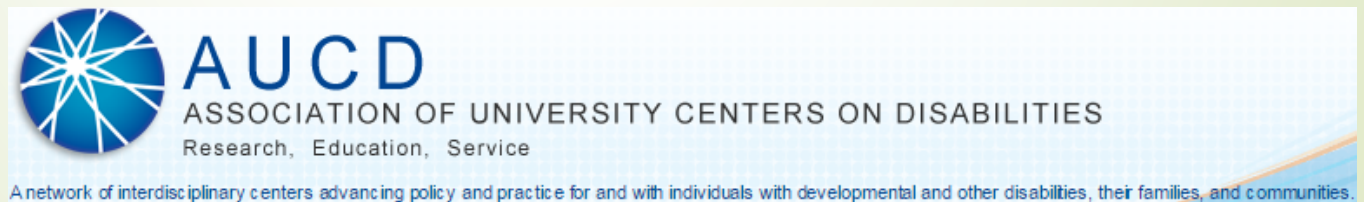
- understand differences in meaning of QOL between family members who have an AYA with and without SB.
- identify clinical strategies to assist families in building inner strength and maintain good QOL when living with an AYA with a neurological condition.

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# Background

The purpose of this study was to explore the concepts of Quality of Life (QOL) and Inner Strength in adolescents/young adults (AYA) with spina bifida (SB) and their parents.

Research is a component of large mixed method, multi-site study in US on factors associated with secondary conditions and adaptation in adolescents with spina bifida (SB).


# QOL and Inner Strength

QOL is defined as “an individual’s perception of their position in life in the context of the culture and value systems in which they live, and in relation to their goals, expectations, and concerns”<sup>1</sup>

Family Quality of Life (FQOL) is defined as “an overall appraisal of the domains of life important to the family”<sup>2</sup>

Inner Strength is defined as the human response when an individual is confronted with a difficult and challenging life circumstance characterized by:

(1) anguish & searching; (2) connectedness; (3) engagement; (4) movement; The process results in the outcome “living a new normal”<sup>3</sup>



# Why We Were Interested in this Study

Program of research for team members:

Previous studies conducted and publications in this field of participants living with spina bifida.

Ecological Model of Secondary Conditions and Adaptation developed by Sawin et al. 2003.

Middle range theory of Inner Strength in Women with Chronic Health Conditions developed by Roux & Dingley, 2002.





# Spina Bifida

Congenital chronic health condition caused by neural tube malformation during early stage of fetal development.

Prevalence 3.1 per 10,000<sup>4</sup>

Secondary conditions include physical mobility impairment, neuropsychological deficits, bladder and bowel dysfunction, and social competency difficulties.



# Aims of the Study

## Primary aim:

Explore perceptions of the meaning of QOL for the parent and AYA.

What are the perceptions of the meaning of QOL for the parent and AYA?

Do the perceptions differ by parents of AYA with and without condition?

## Exploratory aim:

Determine if there is evidence of the protective process of “inner strength” in the participants’ description of QOL.





# Interview questions

Parent

What do you think quality of life means for your son/daughter (what goes into making a good “quality of life” for him/her)?

What does quality of life mean for you and your family?

What goes into making a good quality of life for you and your family?

AYA

What do you think quality of life means for you (what goes into making a good “quality of life”)?

What does quality of life mean for your parent and your family?

What goes into making a good “quality of life” for you and your family?

# Method – Content Analysis

## Detection of substantive content

Differentiation of responses by participants (parent and AYA) about AYA, parent, & family

## Categorization with descriptive data

Frequency of terms to discern common concepts

Coded with concepts

## Classification of categories

Text for each concept was clustered

Categories (themes) derived descriptive of whole.



# Participants

198 families (parent and AYA) living in Midwest & Eastern U.S.

## Recruitment -

- Group with SB (54%) from 4 children's hospital spina bifida programs.
- Group without SB (46%) by referral from SB families in study, advertisement in each hospital and referral from primary care providers.

## PARENT

%

Gender (Female)	94%
Level of education $\geq$ high school	93%
Married	74%
Mean Age	43 (27 – 67)
Race/Ethnicity	
Caucasian	86%
Black	11%
Other	3%
Hispanic	3%
Family income*	
< \$20,000	12%
\$20, 000 – \$50,000	27%
> \$50,000	60%

## AYA

%

Gender (Female)	54%
Mean Age	15 (12 – 25)

## AYA with SB

%

requires wheelchair	50%
functional motor level	
high lumbar	19%
mid lumbar	33%
low lumbar	35%
sacral	8%
with shunt	84%

\* For family of 4, 18% of group with SB and 4 % of comparison were at poverty level (<\$20K) About 50% of group with SB were < 200% poverty level (earning < \$50K)

# Thematic Results: Meaning of QOL

Importance of  
friendship

by parents & AYA about **AYA QOL**

Time for  
togetherness

by parents & AYA about **family QOL**

Connectedness

by parents & AYA about **parent & family QOL**

Financial stability

by parents about **parent & family QOL**, *not* AYA QOL

Meaningful  
Activities

by parents & AYA about **AYA, parent & family QOL**



# What were meaningful activities?

- *Being able to do things you want to do*
- *Opportunities, exploring new things, trips, seeing beyond her neighborhood, pursuit of dance, not having to work, volunteer activities*
- *Opportunities socially, activities, sports, able to travel*
- *Finding family activities that include teen with SB that she is able to do*
- *Participate in meaningful activities*





# Parent perspective of meaning of QOL

## AYA/Parent QOL

- Being active
- Participation in activities
- Importance of friendship

## Family QOL

- Time for togetherness
- Connectedness of family
- Financial stability

*Both individual and family activity were important from the parent perspective.*

# AYA perspective of meaning of QOL

## AYA/Parent QOL

- Friends
- Being happy
- Healthy

## Family QOL

- Connectedness

*AYA did not differentiate between individual and family meaning. Many said it was the same or they did not know.*

# Parent perspective of differences in meaning of QOL by group

## SB

- Being happy
- Independence

## Without SB

- Importance of friends

*While “happiness” was important in both groups it was mentioned more frequently in the group with SB (28) than without SB (8).*

*Friends were more often mentioned in group without SB (32) than with SB (18).*

*Independence was mentioned more explicitly in group with SB (14) than without SB (4).*

# AYA perspective of differences in meaning of QOL by group

## SB

- Happiness

## Without SB

- Happiness
- Friendship
- Getting along

*While “happiness” was important in both groups it was mentioned more frequently in the group without SB (30) than with SB (16).*

*Friends were more often mentioned in group without SB (20) than with SB (8).*

*Getting along was mentioned more explicitly in group without SB (12) than with SB (1).*

# Evidence of Inner strength

## Inner strength

- Connectedness (relationships with friends & family)
- Movement (activity)

## QOL

- Importance of friendship
- Time for togetherness
- Connectedness
- Financial stability
- Meaningful activities

*Data only collected for QOL. Dimensions of Inner Strength were identified in these data.*



# Discussion

Study results can assist providers to focus support on enhancing components of QOL important to parents and AYA.

- Connectedness with family and friends is a critical component of QOL.
- “Being happy and healthy” are characteristic of what QOL means to the AYA from their perspective, not explicitly expressed by parents.
- Parents and AYA think being active and participation in meaningful activities is characteristic of QOL.





# Limitations



- 37% of AYA with SB either did not respond or stated they did not know when asked to describe their meaning of QOL. This is a methodological limitation in the interview of adolescents, particularly adolescents with neurological conditions.
- Themes that emerged from this analysis may be influenced by the interview questions.
- Limited geographic, ethnic, and family diversity.



# Implications for Practice

**The findings emphasize the need for comprehensive interprofessional teams to**

- Promote independence of the AYA in families with AYA with SB
- Promote enjoyable meaningful activities for AYA and parents
- Provide families with strategies to enhance connectedness with friends and family



# Implications for Future Research

Explore relationship of inner strength and QOL in families of AYA with SB.

Develop and test intervention strategies for the health and QOL of families with adolescents living with neurological conditions.



# Future steps

- Currently working on publication for dissemination of findings. Plan to submit to *Quality of Life Research (QURE)*.
- The findings of this research and quantitative findings from the *Global Family Quality of Life Scale (G-FQOLS)* will support development of a family-centered self-management intervention.

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# Questions | Comments

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