

Social Networks of Youth with Hidden Disability: A Case Series Utilizing Personal Network Visualization & Analysis

Consuelo Kreider, MHS, OTR/L
Department of Occupational Therapy, University of Florida

PURPOSE

- Gain insight into the **quantitative and qualitative aspects of the social-environmental contexts of youth living with hidden disability such as high-functioning autism and learning disability.**
- Investigate structural and compositional sociometrics of youth with hidden impairments.
- Explore the extent to which youth with cognitive, attention, and/or perceptual impairments perceive the social structure surrounding them.
- Explore these youth's ability to handle the extensive level of cognitive inquiry necessary for sociometric assessment, the gold-standard methodology for measuring social structure.
- Explore the lived perceptions of the sociometrics for youth with hidden impairment.
- Identify potential social network targets of intervention.**



BACKGROUND

The social environment serves as a crucial arena in which to advance competence necessary for participation, social engagement and overall development.

- Few studies investigate **social network** effects in chronically **impaired pediatric populations.**
- Personal (egocentric) network studies **focus on the social relationships of those surrounding** the individual and the influence that network members have on the respondent's attitudes, behaviors, and actions.
- Graph-based structural metrics such as network density, centrality, and components ascertained from personal network data have been shown to be meaningful to respondents in the assessment of their individual social environment (McCarty, 2002).
- Network analysis enables the capturing of **quantitative contextual** data not otherwise obtained by less structured or detailed methods of inquiry (McCarty, Molina, Aguilar, & Rota, 2007).
- Still needing to be understood are the mechanisms by which a disabled child's social network impacts engagement in everyday life activities and overall well-being.
- Qualitative features of the context of disabled childhood participation, such as aspects of enjoyment and with whom, are only beginning to be investigated (King et al., 2004).

METHOD

Subjects

- 5 boys with chronic hidden cognitive impairment
- Ages 10-13 years (mean = 11.2 ± 1.3)

Methods & Instruments

- Personal (egocentric) network analysis**
 - Name generator:** "Everyone hang-out' or do things with"
 - Alter attributes:** gender, age, kin, social-developmental roles
- Structured interview**
 - What's your network like?
 - Who are important people in your network?
 - Does your network help you? In what ways?
- PedsQL™**
 - Self-report or proxy measure, ages 2-18 years old
 - Physical, Social, Emotional & School functioning
 - 23 items; sum scoring

Analysis

- Case Series
- Personal (egocentric) Network Analysis (UCInet 6 & NetDraw 4.14)
- Descriptive Statistics

GROUP RESULTS:

Network Closeness Centrality: Mean = 34.4 ± 15.9

- Degree of inequality of social power resulting from the social power gained from being close to others in the network

Network Betweenness Centrality: Mean = 28.4 ± 17.0

- Degree of inequality of social power resulting from the social power gained from intermediary positioning between others in the network

Network Cohesion: Factions Mean = 6.7 ± 2.6

- Number of fully connected sub-groups in the network

Network Attributes:

- Size:** Mean = 28.6 ± 5.1
- Adults:** Mean = 34.9% ± 16.8
- Kin:** Mean = 52.2% ± 21.4

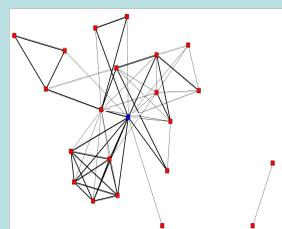
Perceived Functioning:

- Overall Functioning:** Mean = 29.83 ± 19.22 / 92 max. possible 0-4 point scale; 0 = no problems; 92 = highest possible score/worst functioning
 - Physical, emotional, social, school functioning

Qualitative Analysis of Interview Data:

- Themes of isolation, rejection, and maltreatment from both classmates and peers who were self-identified as "friends".
- Themes of social protection and resultant social naivety.

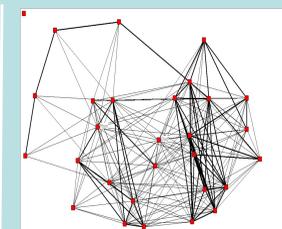
CASE RESULTS



11 year old

22 network members; 7 factions; 2 components, 0 isolates, 1 cut-point
77% kin; 55% adult; 46% same gender
73% hang-out; 46% horse around; 73% do things-play; 14% share feelings; 18% takes care of you; 14% you take care of; 14% frienemy
Highest closeness centrality = mom (7/7 roles)
Closeness centralization network index = 54%
Highest betweenness centrality = mom
Betweenness centralization network index = 35%

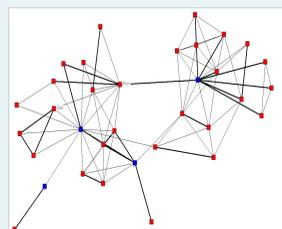
"...To tell you the truth, I've been lonely..."
"...My friendliness [sets me apart from other kids] 'cause everyone else is just plain mean."
✓ themes of physical aggression from peers
✓ themes of isolation, loneliness, & solitary play
✓ themes of friction and lack of social support from friends
✓ reports no peer socialization outside of school



12 year old

29 network members; 4 factions; 2 components, 1 isolate, 0 cut-points
45% kin; 45% adult; 45% same gender
14% hang-out; 3% horse around; 48% do things-play; 0% share feelings; 52% takes care of you; 3% you take care of; 7% frienemy
Highest close. centrality = adult assist (1/7 roles)
Closeness centralization network index = 19%
Highest betwn. centrality = adult sister (1/7 roles)
Betweenness centralization network index = 6%

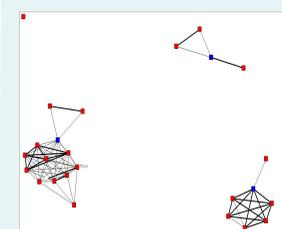
"...[network member] hits me and...spits on me"
"She (mom) wants to try to keep me away from everybody..."
✓ themes of physical aggression & name-calling from peers
✓ themes of desire to be part of social groups despite mother's protectiveness and peer hazing
✓ reports that favorite friend makes him feel good



10 year old

34 network members; 11 factions; 1 component, 0 isolates, 4 cut-points
24% kin; 26% adult; 65% same gender
56% hang-out; 32% horse around; 65% do things-play; 27% share feelings; 52% takes care of you; 3% you take care of; 7% frienemy
Highest closeness centrality = teacher 1 (3/7 roles)
Closeness centralization network index = 48%
Highest betwn. centrality = teacher 1 (3/7 roles)
Betweenness centralization network index = 44%

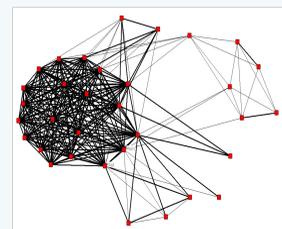
"...Everybody in my network is kind..."
"They're all very nice and kind and jokeular and are all pretty very smart."
✓ themes of social support from network
✓ perceives a large, well-connected, homogenous network
✓ perceives mother as central person in network
✓ identifies classmates & teachers who are "important" or "valuable" to know based on social connections



13 year old

25 network members; 7 factions; 4 components, 1 isolate, 3 cut-point
45% kin; 24% adult; 72% same gender
100% hang-out; 80% horse around; 84% do things-play; 4% share feelings; 20% takes care of you; 20% you take care of; 4% frienemy
Highest close. centrality = adult sister (3/7 roles)
Closeness centralization network index = 7%
Highest betwn. centrality = brother (5/7 roles)
Betweenness centralization network index = 42%

"I don't get to see everybody that much"
✓ themes of solitary or family-based play
✓ unsure of his own level of group acceptance
✓ identifies self as having only one social group



10 year old

33 network members; 7 factions; 1 component, 0 isolates, 0 cut-points
70% kin; 49% adult; 70% same gender
85% hang-out; 42% horse around; 27% do things-play; 0% share feelings; 55% takes care of you; 27% you take care of; 9% frienemy
Highest closeness centrality = brother (5/7 roles)
Closeness centralization network index = 15%
Highest betwn. centrality = brother (5/7 roles)
Betweenness centralization network index = 15%

"...I feel like they (classmates) want me to go to another school..."
"...They'll usually ... laugh at me...yell at me."
"...[friend] used to, to intimidate me...he would like bully me or like pick on me..."
This friend perceived as central in network.
✓ themes of peer rejection & kids picking on him
✓ themes of orchestrated "play-dates" w/ classmates & cousins outside of school
✓ perceives a small network

CONCLUSIONS

- Methods of personal network analysis can be used with neurologically immature respondents. This group of children living with cognitive, attention and/or perceptual impairments, successfully handled the level of sustained cognitive interview needed for utilization of personal (egocentric) network analysis methods. The neurologically immature youth required varying levels of assistance from parent or other knowledgeable informant. The investigator must be prepared to accommodate for shortened attention and reduced cognitive and/or communicative endurance when using a personal network analysis approach.
- Personal network analysis yielded unique information not obtained via in-depth qualitative interview alone.**
- Identified incongruence between perceived and measured social network structure and attributes are **potential targets of intervention** for facilitation of social competence and overall functioning to be pursued in subsequent research.
 - Misperceived network size
 - Incorrectly perceived network structure
 - Misperceived centrality/social power of network members
 - Misidentification of structurally key network members
 - Inconsistent and mis-identification of network sources of peer social support
- This study provides important insights for those seeking to mold the social environments surrounding youth growing up with chronic hidden cognitive impairment.** Findings from this preliminary investigation begin to shed light on the complexity of the disabled youth's contextual circumstances enveloping childhood activity and overall functioning.

REFERENCES

- King, G., Law, M., King, S., Hurler, P., Rosenbaum, P., Hanna, S., Kertoy, M., & Young, N. (2004). *Children's assessment of participation and enjoyment & preferences for activities of children manual*. San Antonio, TX: Harcourt Assessment, Inc.
- McCarty, C. (2002). Structure in personal networks. *Journal of Social Structure*, 3(1). Retrieved July 31, 2008, from <http://www.cmu.edu/joss/content/articles/volume3/McCarty.html>
- McCarty, C., Molina, J. L., Aguilar, C., & Rota, L. (2007). A comparison of social network mapping and personal network visualization. *Field Methods*, 19, 145-162.
- Varni, J. W., Seid, M., & Rode, C. A. (1998). The PedsQL™: Measurement model for the Pediatric Quality of Life Inventory. *Medical Care*, 37(2), 126-139.

ACKNOWLEDGEMENTS: Special thanks to Drs. Mary L. Hennessey, Christopher McCarty and Roxanna Bendixen for their mentorship and assistance.