

# Promoting children's access to health care: Nurses' perceptions and practices when obtaining consent from children

Yolanda Havenga RN, D.Cur



#### **DISCLOSURE**

#### **Authors**

Bester, M; Havenga, Y & Lightelm, Z

#### Learner objectives:

- 1. Describe nurses' perceptions and practices when obtaining consent from children.
- 2. Critically reflect on how these perceptions and practices influence children's access to health care.

#### **Conflict of interest**

The authors declare that there is no conflict of interest

#### **Funding support**

This work is based on the research supported in part by the National Research Foundation of South Africa for the grant, Unique Grant No. 84260



# **OUTLINE**

- Background
- Problem statement
- Aim and objectives
- Research design
- Methods
- Findings
- Conclusions
- Acknowledgments
- List of references

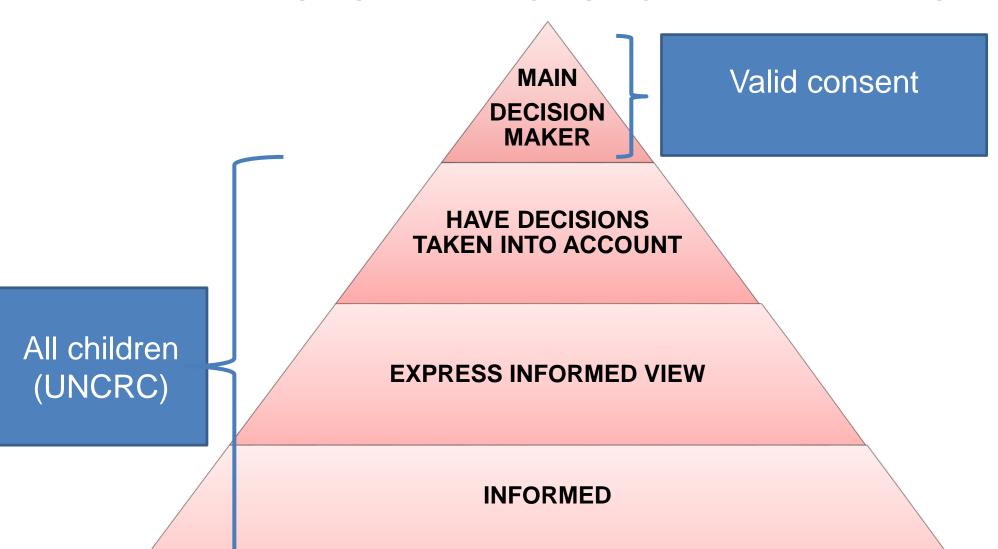


## **BACKGROUND**

- Children should not be deprived of their right to access health services.
  - The ability to consent promotes children's access to health services.
- Children have the right to express their views in all matters that affect them and have their views be given weight.
  - Enhances involvement in decision-making.

Department name: Adelaide Tambo School of Nursing Science

# LEVELS OF DECISION-MAKING





## **BACKGROUND**

- In South African legislation, valid consent is:
  - Given by a person capable in law to do so.
  - Informed, unambiguous, comprehensive and voluntary.
- Capable person:
  - Age threshold
  - Mental capacity Decisional capacity



## **AGE LIMITS**

Full decisional capacity in South Africa is 18 years

Medical treatment

Surgery

**HIV Testing** 

Contraceptives

Termination of Pregnancy

Children's Act (2005) & Choice on Termination of Pregnancy Act (1996)



#### **BACKGROUND**

Mental capacity is the ability to:

**Understand Appreciate** Choice Reason

Appelbaum, 2007



## **BACKGROUND**

Factors that influence mental capacity:

- Parent
- Child
- Procedure
- Health care provider
  - Attitude & competency:
    - share information
    - respect for children's views and perspectives
    - assess mental capacity



## PROBLEM STATEMENT

- No clear guidelines for capacity assessment.
- Limited trained to do cognitive and mental health assessments.
- No single test available.
- Intuition used in assessments.
- A guide needs to be developed.
- First step is to determine what the current practice and perceptions are of nurses who have to enact the laws.



## **OBJECTIVES**

The **objective** of the study is to determine nurses' perceptions and practices in obtaining consent from children to treatment.



## RESEARCH DESIGN

Explorative and descriptive qualitative design.

# **SETTING**

- Tshwane, Gauteng South Africa.
- Administrative capital.



www.un.org/Depts/Cartographic/**map**/profile/southafr.pdf



#### RESEARCH METHODS

#### Sampling

- Purposive
- 19
   Professional nurses
- A hospital, primary health care clinics

#### **Data collection**

- Semistructured interviews
- English
- 30-60 minutes
- Audio recorded

#### **Data-analysis**

- Verbatim transcription
- Descriptive qualitative content analysis

#### **Ethics**

- Ethical approval
- Informed consent
- Anonymity & confidentiality
- No harm



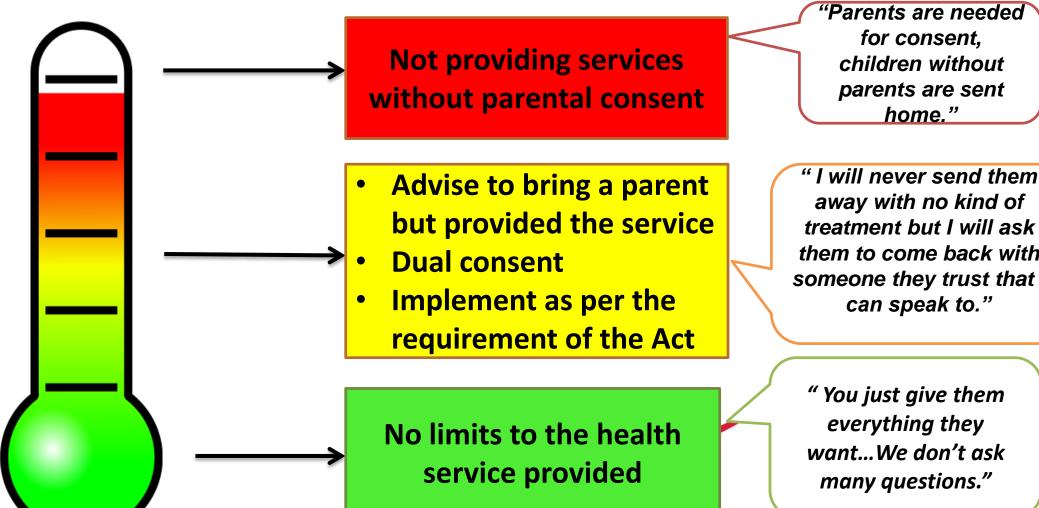
| Category                                     | Subcategory                                  | Unit of meaning   |
|--|--|---|
| Inconsistent implementation of               | Degrees of implementation                    |   |
| consent laws                                 | Factors related to degrees of implementation | Limited knowledge and misinformation Perceptions and personal frame of reference Obligation to protect Practical barriers |
| Practices in determining capacity to consent | Establish trust and rapport                  |   |
|  | Health Information                           | Appropriate levels Peer groups  |
|  | Assessment                                   | History and social circumstances Understanding Use of different yardsticks  |



| Category                                     | Subcategory                                  | Unit of meaning   |
|--|--|---|
| Inconsistent implementation of consent laws  | Degrees of implementation                    |   |
|  | Factors related to degrees of implementation | Limited knowledge and misinformation Perceptions and personal frame of reference Obligation to protect Practical barriers |
| Practices in determining capacity to consent | Establish trust and rapport                  |   |
|  | Health Information                           | Appropriate levels Peer groups  |
|  | Assessment                                   | History and social circumstances Understanding Use of different yardsticks  |



# DEGREES OF IMPLEMENTATION OF **CONSENT LAWS**



them to come back with someone they trust that I



| Category                                     | Subcategory                                  | Unit of meaning  |
|--|--|--|
| Inconsistent implementation of               | Degrees of implementation                    |  |
| consent laws                                 | Factors related to degrees of implementation | Limited knowledge and misinformation Perceptions and personal frame of reference Obligation to protect |
|  |  | Practical barriers   |
| Practices in determining capacity to consent | Establish trust and rapport                  |  |
|  | Health Information                           | Appropriate levels Peer groups   |
|  | Assessment                                   | History and social circumstances Understanding Use of different yardsticks                             |



# CONTRIBUTING FACTORS Knowledge limitations

| Unit of meaning      | Quotes   |
|----------------------|--|
| Limited of knowledge | First you need to know what the Law says, which I myself have very little knowledge about.  South Africa is 14[years], certain is 16 [years], stuff like that, so I get confused sometimes [about] what actually is the right age. |
| Misinformation       | I have been trained in child legislation, in South Africa it is 14 and 16"  I was under the impression a 14 year old can never consent on their own.   |



| Category                                     | Subcategory                                  | Unit of meaning   |
|--|--|---|
| Inconsistent implementation of               | Degrees of implementation                    |   |
| consent laws                                 | Factors related to degrees of implementation | Limited knowledge and misinformation  Perceptions and personal frame  of reference  Obligation to protect  Practical barriers |
| Practices in determining capacity to consent | Establish trust and rapport                  |   |
|  | Health Information                           | Appropriate levels Peer groups  |
|  | Assessment                                   | History and social circumstances Understanding Use of different yardsticks  |



# CONTRIBUTING FACTORS Perceptions & personal frame of reference

| Unit of meaning             | Quotes   |
|-----------------------------|--|
| Perceptions                 | There is a thin line between what the law says I should do and my personal opinion. As a HCP I don't think children are able to consent.  [An] eleven year old does not understand anything other than schoolwork according to me.   |
| Personal frame of reference | I know in this new South African law that children can consent to HIV [tests] and they can come and look for contraception at that age, it is a difficult one, because I think when it comes to that I am biased as well.  You start turning the things to you, what if this was your child? |



| Category                                     | Subcategory                                  | Unit of meaning   |
|--|--|---|
| Inconsistent implementation of consent laws  | Degrees of implementation                    |   |
|  | Factors related to degrees of implementation | Limited knowledge and misinformation Perceptions and personal frame of reference Obligation to protect Practical barriers |
| Practices in determining capacity to consent | Establish trust and rapport                  |   |
|  | Health Information                           | Appropriate levels Peer groups  |
|  | Assessment                                   | History and social circumstances Understanding Use of different yardsticks  |



# CONTRIBUTING FACTORS Obligation to protect

| Unit of meaning                           | Quotes   |
|---|--|
| Feel obligated to protect children        | I just speak to her as a mother protect her  |
|   | They don't really know what they are doing to their bodies, they need to be protected.         |
| Feel obligated to protect parental rights | I think a parent has a right to know what is happening with their child. I would want to know. |
|   | I think the parents must be called and be informed and be involved, they must know.            |



| Category                                     | Subcategory                                  | Unit of meaning   |
|--|--|---|
| Inconsistent implementation of consent laws  | Degrees of implementation                    |   |
|  | Factors related to degrees of implementation | Limited knowledge and misinformation Perceptions and personal frame of reference Obligation to protect Practical barriers |
| Practices in determining capacity to consent | Establish trust and rapport                  |   |
|  | Health Information                           | Appropriate levels Peer groups  |
|  | Assessment                                   | History and social circumstances Understanding Use of different yardsticks  |



# CONTRIBUTING FACTORS Practical barriers

| Unit of meaning                                   | Quotes  |
|---|---|
| Limited time                                      | We do not have enough time, there are queues, and queues and queues. I don't have enough time with a child.  You look at the queue outside and this child is here, you smile            |
| A need for multi-<br>professional team<br>support | [A child] who is going to need prolonged treatment or rehabilitationthat is the time when I would like to have support from other professionals, like social workers and psychologists. |
| Lack of guidelines                                | A standard operating procedure can be used by everyone, so that it can be uniformthat would guide us and that would protect us.   |



| Category                                     | Subcategory                   | Unit of meaning                      |
|--|-------------------------------|--------------------------------------|
| Inconsistent                                 | Degrees of implementation     |                                      |
| implementation of                            |                               |                                      |
| consent laws                                 | Factors related to degrees of | Limited knowledge and misinformation |
|  | implementation                | Perceptions and personal frame       |
|  |                               | of reference                         |
|  |                               | Obligation to protect                |
|  |                               | Practical barriers                   |
| Practices in determining capacity to consent | Establish trust and rapport   |                                      |
|  | Health Information            | Appropriate levels                   |
|  |                               | Peer groups                          |
|  |                               |                                      |
|  | Assessment                    | History and social circumstances     |
|  |                               | Understanding                        |
|  |                               | Use of different yardsticks          |



# ESTABLISHING TRUST AND RAPPORT

- Time
- Interpersonal qualities
- Confidentiality and privacy

"If you talk in a very formal way, above their heads, ...they won't, feel that we care about them, they will consent without really understanding all the implications, but if they learn to trust you, then they will ask all the questions to know exactly what is going on with their bodies."



| Category                                     | Subcategory                   | Unit of meaning                      |
|--|-------------------------------|--------------------------------------|
| Inconsistent                                 | Degrees of implementation     |                                      |
| implementation of                            |                               |                                      |
| consent laws                                 | Factors related to degrees of | Limited knowledge and misinformation |
|  | implementation                | Perceptions and personal frame       |
|  |                               | of reference                         |
|  |                               | Obligation to protect                |
|  |                               | Practical barriers                   |
| Practices in determining capacity to consent | Establish trust and rapport   |                                      |
|  | <b>Health Information</b>     | Appropriate levels                   |
|  |                               | Peer groups                          |
|  | Assessment                    | History and social circumstances     |
|  |                               | Understanding                        |
|  |                               | Use of different yardsticks          |



# **HEALTH INFORMATION**

| Unit of meaning   | Quotes  |
|-------------------|---|
| Appropriate level | Use the language they use [on] the street so that they [connect] with you. Don't use those sophisticated medical terms even your English must be simple.  |
| Peer group        | They normally come in groups; you find they are 3 or 4.  Children tend to come to facilities in groups and healthcare providers were happy to talk to them together or provide education or information in a group. |
|                   |   |



| Category                                     | Subcategory                                  | Unit of meaning   |
|--|--|---|
| Inconsistent implementation of consent laws  | Degrees of implementation                    |   |
|  | Factors related to degrees of implementation | Limited knowledge and misinformation Perceptions and personal frame of reference Obligation to protect Practical barriers |
| Practices in determining capacity to consent | Establish trust and rapport                  |   |
|  | Health Information                           | Appropriate levels Peer groups  |
|  | Assessment                                   | History and social circumstance Understanding Use of different yardsticks   |



# **ASSESSMENT**

| Unit of meaning                  | Quotes   |
|----------------------------------|--|
| History and social circumstances | If the child is less than 12 years but he is matured he comes here and she tells you that 'my mother or my parent [is] dead because of HIV' then you can see that this child [has] knowledge about HIV . |
| Understanding                    | The fact that this child came to the clinic and asked help, says to me that this child <b>understands</b> when she comes here alone not with a parent.   |
|                                  | If you probe and they give back, what the procedure holds, why it is necessary and what is the <b>reason for the future.</b>   |



| Category                                     | Subcategory                   | Unit of meaning                      |
|--|-------------------------------|--------------------------------------|
| Inconsistent                                 | Degrees of implementation     |                                      |
| implementation of                            |                               |                                      |
| consent laws                                 | Factors related to degrees of | Limited knowledge and misinformation |
|  | implementation                | Perceptions and personal frame       |
|  |                               | of reference                         |
|  |                               | Obligation to protect                |
|  |                               | Practical barriers                   |
| Practices in determining capacity to consent | Establish trust and rapport   |                                      |
|  | Health Information            | Appropriate levels                   |
|  |                               | Peer groups                          |
|  |                               |                                      |
|  | Assessment                    | History and social circumstances     |
|  |                               | Understanding                        |
|  |                               | Use of different yardsticks          |
|  |                               |                                      |



# **DIFFERENT YARDSTICKS**

| Unit of meaning            | Quotes   |
|----------------------------|--|
| Age                        | Cannot consent if you are not 16 years old.  |
| Experience and background  | You cannot do it in age, it is impossible.   |
|                            | Children's development depend on background and understanding and stimulation at home.             |
| Understanding of the topic | Assesses knowledge on a specific topic. Any misinformation indicates lack of capacity.             |
| Future<br>consequences     | The moment they can see the bigger picture, they are mature enough to make decisions on their own. |



#### CONCLUSION

# Inconsistent practice in this context by health care providers

- Refusal of services
  - Impedes access health services.
  - Violates right to participate and be listened too.
- Providing any service regardless of maturity and mental capacity:
  - Children not mature: Burdened with responsibilities.
  - Invalid consent.



#### CONCLUSION

Nurses competence influence children's capacity to consent.

Guidelines, education and support are required.

"Children's competence greatly depends on adults' competence to be supportive, generous, courageous and 'big enough' to respect them"



#### **ACKNOWLEDGEMENT**

This work is based on the research supported in part by the National Research Foundation" of South Africa for the grant, Unique Grant No. 84260





## LIST OF REFERENCES

**ACTS see SOUTH AFRICA** 

ALDERSON, P. 2007. Competent children? Minors' consent to health care treatment and research. *Social Science and Medicine, 65,* 2272 - 2283

APPELBAUM, P.S. 2007. Assessment of patients' competence to consent to consent to treatment. *The New England Journal of Medicine*, 457 (18), 1835 – 1840.

HEIN, I.M., TROOST, P.W., LINDEBOOM, R., DE VRIES, M.C., ZWAAN, C.M. & LINDAUER, R.J.L. 2012. Assessing children's competence to consent in research by a standardized tool: a validity study, *Biomedical Central Pediatrics*, 12:156 doi:10.1186/1471-2431-12-156.

JAMIESON, L., & LAKE, L. 2013. A guide to the Children's Act for health professionals. 5th ed. Children's Institute: University of Cape Town.

LARCHER, V. & HUTCHINSON, A. 2009. How should Paediatricians assess Gillick competence? *Archives of Disease in Childhood*, 95(4):307-11.

Medical Protection Society (MPS). 2010. Booklet: Consent to medical treatment in South Africa. An MPS Guide. Medical Protection Society. Available from:

www.medicalprotection.org/southafrica/factsheets. Accessed on 1 April 2013.



## LIST OF REFERENCES

MILLER, V.A., DROTAR D., KODISH E. 2004 Children's competence for assent and consent: a review of empirical findings. *Ethics and Behaviour*,14(3): 255–95. http://dx.doi.org/10.1207/s15327019eb1403\_3

REPUBLIC OF SOUTH AFRICA. 2005. Children's Act 38. Available from: <a href="http://www.justice.gov.za/legislation/acts/2005-038%20childrensact.pdf">http://www.justice.gov.za/legislation/acts/2005-038%20childrensact.pdf</a>. Accessed on 12 March 2014.

REPUBLIC OF SOUTH AFRICA. 1996. Choice on Termination of Pregnancy Act 92. Available from: <a href="http://www.info.gov.za/acts/1996/a92-96.pdf">http://www.info.gov.za/acts/1996/a92-96.pdf</a>. Accessed on 12 March 2014.

REPUBLIC OF SOUTH AFRICA. 2003. The National Health Act 61. Available from: <a href="http://www.info.gov.za/view/DownloadFileAction?id=68039">http://www.info.gov.za/view/DownloadFileAction?id=68039</a>. Accessed on: 29 October 2013.

UNITED NATIONS. UNITED NATIONS CONVENTION ON THE RIGHTS OF THE CHILD. 1989. Geneva: United Nations. Available from: <a href="http://www.ohchr.org/en/professionalinterest/pages/crc.aspx">http://www.ohchr.org/en/professionalinterest/pages/crc.aspx</a> Accessed on: 2014 August 7.

UNITED NATIONS. 2007. Department of Peacekeeping Operations. Cartographic Section. Available from: <a href="https://www.un.org/Depts/Cartographic/map/profile/southafr.pdf">www.un.org/Depts/Cartographic/map/profile/southafr.pdf</a>. Accessed on: 23 June 2015