



**Belonging as an
important element of
QoL in persons with
PIMD**

Physicians' perception of QoL in
persons with
***P*rofound *I*ntellectual and *M*ultiple
*D*isabilities (PIMD)**

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November 2017
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PIMD: Profound Intellectual and Multiple Disabilities

- Physical *and*
- Intellectual disabilities *and*
- Sensory impairments *and*
- Medical problems



They cannot verbally express themselves



Project: Quality of life in persons with PIMD

Literature review

Interviews with Physicians

Interviews with primary care

Focus groups with parents

Development of a qualitative tool



QoL has major impact on health-decisions
such as major surgery, tube feeding and
withholding or sustaining life supportive
treatment

**How physicians determine QoL in
persons with PIMD is unknown**



Methods: In-depth interviews

3 pediatricians

4 intellectual
disability
physicians

Research question:

How do physicians describe good and poor QoL in persons with PIMD?

Results (1) Elements of QoL

Cluster	Good QoL	Poor QoL
Emotional	Happy, pleasure, enjoyment	Inconsolable crying, appears unhappy, no emotion, empty, shallow, suffering
Physical	Normalized muscle tone, no pain, no epilepsy or under control, can eat without choking and enjoys this, is able to breathe easily	Tense muscles, choking, short of breath, pain, major epilepsy, sick
Relational	Is able to make contact and has interaction. Good relationship with parents, parents/surroundings are able to cope, loving family, loving surroundings, safety	No contact. No parents, burden too great for parents /surroundings, no safety

Results (2) Balance

Important to physicians: balance between good and poor elements



Results (3)

Physicians appoint
mainly emotional
elements to
describe good
QoL

And physical
elements to
appoint poor QoL.

Results(4)

Physicians emphasize relational
context



*...these children cannot
make their own quality of
life...you need someone
who is fully committed to
the child..(1)*



For example, the child experiences safety. There is a very clear.. The child has a loving family around her. Or care providers, or whatever. With continuity. If that is missing, yes that does affect you.....What you want most for a child, is safety. That is what it is really about. A child has to feel safe somewhere. A child has to feel safe with certain individuals. Normally this involves the parents, but if there are very regular care providers, then as far as I am concerned, the same applies. But this is about safety and feeling safe.

(4)



Yes, that does define the lives of others. And yes, I do think that you never look at one life on its own And in this casethis category of individuals and children, it is so, you cannot focus on that child alone. You simply have to look at the whole picture.... (5)

Too great a burden on the family, they were simply unable to cope, they were caring for this girl literally day and night, she was also in pain, was unable to eat properly, was being bottle-fed and ultimately her surroundings – the sub-optimal environmental factors, the parents' inability to cope – also contributed to the fact that this girl died, because her family simply could not carry on (1)

Physicians perception on QoL in persons with PIMD

Relational context is essential



**belonging to their
relational
context is an important
element of QoL in
persons with PIMD.**

Next

Analyse interviews with Primary
care

Focus groups with parents

Development of a Qualitative tool



Questions?



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