End-of-life Care for Persons with Intellectual Disability: Are we prepared for it?

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13th Hong Kong Palliative Care Symposium (Oct 22, 2016)

Persons with Intellectual Disabilities (PIDs) in Hong Kong

• Number: 71,000-101,000
• Prevalence: 1.0% - 1.4%

Persons with Intellectual Disabilities
Special Topics Report No. 62
Prepared by: Social Welfare Department

Persons with Intellectual Disabilities and their Families

(Census and Statistics Department, 2014, p.250)

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PIDs in Hong Kong

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(Census and Statistics Department, 2014, p. 233 & 241)

Increase Longevity of PIDs

- (Coppus, 2013, p. 12)
**PIDs with poorer health outcomes**

- Unrelated to the causes of their cognitive impairment
- Failings within the healthcare systems
- Negative attitudes and assumptions about quality of life of PID

*(Tuffrey-Wijne, 2016)*

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**PIDs with poorer health outcomes**

- “... less likely to have access to specialist palliative care services and received less opioid analgesia in their final illness. Their deaths were sometimes described as not being planned for, uncoordinated and poorly managed.”

*(Confidential Inquiry into Premature Deaths of PID, as stated in Tuffrey-Wijne, 2016)*

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**Challenges of PWIDs in End-of-Life (EoL) Situation**

- **Delayed diagnosis because of**
  - Lack of health screening
  - Communication problems:
    - Give accurate medical history
    - Describe symptoms
  - Diagnostic overshadowing:
    - Behavioral manifestation of discomfort misinterpreted as challenging behaviors
    - Trivialize complaints

*(Tuffrey-Wijne, 2016)*

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**Challenges of PWIDs in End-of-Life (EoL) Situation**

- **Communicating about illness and death**
  - Myths about
    - “They don’t understand”
    - “The truth is too upsetting”
  - Informed Consent
    - Ability to understand
    - Who is the proxy
- **Availability of support services**
- **Family dynamics**

*(Tuffrey-Wijne, 2016)*
PIDs in Hong Kong

<table>
<thead>
<tr>
<th>Intellectual disability</th>
<th>No. of persons</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Total population</td>
<td>25,400</td>
<td>100</td>
</tr>
<tr>
<td>Institutional residents</td>
<td>25,000</td>
<td>100</td>
</tr>
<tr>
<td>Non-institutional residents</td>
<td>400</td>
<td>1.6</td>
</tr>
</tbody>
</table>

(Census and Statistics Department, 2014, p. 234 & 242)

Challenges of PWIDs in EoL Situation

- Communication
- Symptom assessment and management
- Decision making
- Additional Time required for the formation of trusting relationships between person with intellectual disability and palliative care staff
- Continuity of place and carers
- Ongoing needs related to the presence of complex physical and/or sensory disabilities

(Ryan et al., 2010)

How are different countries addressing the needs of PWIDs?

European Association for Palliative Care (EAPC)

- Taskforce on Intellectual disabilities established in 2012
- Report published in 2015
- Developed and examined consensus norm
European Association for Palliative Care (EAPC)

- 13 Consensus Norms:
  1. Equity of access
  2. Communication
  3. Recognizing the need for palliative care
  4. Assessment of total needs
  5. Symptom management
  6. End of life decision making
  7. Involving those who matter: families, friends and carers

(EAPC, 2015)
2. Communication

- Assessment of pain and symptoms
- Communications about illness and diagnosis
- Consent to care and treatment

* (EAPC, 2015)

2. Communication

- May need more time to understand information
- Cannot manage too much information
- Need repetition of information
- Combination of verbal and written (or diagrammatic) information
- Tailor-made information
- Dosage as decided by the PIDs

* (EAPC, 2015)

6. End of Life Decision Making

- End of life decision making is complex
- PIDs should be assumed to have capacity to make decision around their care and treatment, unless it is demonstrated otherwise

* (EAPC, 2015)
6. End of Life Decision Making

- Medico-legal interface

**Consent to Medical and Dental Treatment**

If you are a “mentally incapacitated person” or his / her carer / family member or appointed guardian, you need to read this leaflet. There is a law dealing with medical and dental treatment of “mentally incapacitated persons” – Part 2A of the Mental Health Ordinance (Cap. 132) of Hong Kong. A “mentally incapacitated person” is an adult of or over 18 with a mental illness, dementia, mental handicap or a disability of mind, such as an acquired brain injury due to an accident or stroke. This leaflet discusses both medical and dental treatment, but for the sake of space we will usually discuss medical treatment.


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**England and Wales**

- *We’re Living Well but Dying Matters*

- [http://dyingmatters.org](http://dyingmatters.org)

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**USA**

**Advance Directives and Advance Care Planning for People with Intellectual and Physical Disabilities**

[Link to website]

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11. Bereavement Support

- PIDs experience loss and grief
- PIDs are at a higher risk of complicated grief

(EAPC, 2015)

Assessment of Grief

- Disenfranchised grief: person’s loss is not recognized or validated
- Not giving the opportunity to talk about what has happened
- Maybe expressed in non-conventional way
- “the handicapped smile” to hide the feelings to meet others’ expectation

(EAPC, 2015)

United States

- California, USA
- Coalition for Compassionate Care of California
- Thinking Ahead: My Life at the End
- (http://www.coalitionccc.org/thinking-ahead.php)

United Kingdom

- Making a Different Together: a Health Toolkit (Keele University, 2014)
12. Education and Training

- Staff Training
- Death Education for PIDs

(EAPC, 2015)

13. Developing and Managing Services

- Policy makers should
  - Prioritise equitable PC for PIDs
  - Commit adequate resources
- Organizations
  - Plan for the provision
  - Plan for the inclusion of PIDs

(EAPC, 2015)

United Kingdom

- The Palliative Care for People with Learning Disabilities Network (PCPLD)

United Kingdom

- National Health Services (NHS)
Experiences in Hong Kong

Research on PIDs in Hong Kong
- Launched from Sept, 2011 to Dec, 2012
- 4 Stages of Studies

Do PWIDs understand Death?

Australia
- The Disability Residential Services Palliative Care guide
Comprehension of Death

- Universality
- Irreversibility/Finality
- Non-functionality
- Causality
- Inevitability

(Speece and Brent, 1992)

(McEvoy et al., 2012)

Findings: Understanding of death (n=104)

<table>
<thead>
<tr>
<th>Concept of Death</th>
<th>University</th>
<th>Non-Functionality</th>
<th>Universality</th>
<th>Inevitability</th>
<th>Multiple Causes of death</th>
</tr>
</thead>
<tbody>
<tr>
<td>Finality</td>
<td>70 (67.3%)</td>
<td>26 (25.0%)</td>
<td>34 (32.7%)</td>
<td>50 (48.1%)</td>
<td>68 (65.4%)</td>
</tr>
<tr>
<td>Finality</td>
<td>35 (33.7%)</td>
<td>19 (18.3%)</td>
<td>19 (18.3%)</td>
<td>19 (18.3%)</td>
<td>19 (18.3%)</td>
</tr>
<tr>
<td>Universality</td>
<td>27 (26.0%)</td>
<td>9 (8.7%)</td>
<td>9 (8.7%)</td>
<td>9 (8.7%)</td>
<td>9 (8.7%)</td>
</tr>
<tr>
<td>Inevitability</td>
<td>33 (31.7%)</td>
<td>22 (21.2%)</td>
<td>22 (21.2%)</td>
<td>22 (21.2%)</td>
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</tr>
</tbody>
</table>

Findings: Comparison with Ireland

- Guilt Driven Culture: I am not good thus he died (Causality)?
- Death as a taboo: My family members and other will NOT die (Universality)?
- Death as a taboo: I will NOT die (Inevitability)?

(Chow et al., in press)
Findings: Correlates with Concept of Death

- Irreversibility (Finality)
- Non-Functionality
- Universality
- Inevitability
- Multiple Causality

Gender, Age, Community skill, ID Level, and self care ability do not correlate with conceptualization of death.

Communication skill: -0.300** -0.331** -0.327** -0.340**

Community skill: 0.214* 0.264** 0.255** 0.316**

Experience of Bereavement

* p<.05; ** p<.01;

Bereavement experience correlates with the conceptualization of death.

Delphi Study in Hong Kong

Area | Item | 1st round of survey | 2nd round of survey | 1st round of survey | 2nd round of survey | Mean score in 1st round of survey | Mean score in 2nd round of survey | Mean score in 1st round of survey | Mean score in 2nd round of survey |
---|---|---|---|---|---|---|---|---|---|
PWID's needs when they are seriously sick or dying | Gathering with family members | 9.33 | 9.45 | 9.33 | 9.45 |
| Quality of Life | 9.45 | 9.45 |
| Accompany and visit by family members and friends | 9.19 | 9.05 |
| Cope with loneliness and sense of strangeness | 9.1 | 8.9 |
| Fulfilling their wishes | 8.86 | 8.85 |
| Cope with fear regarding medical procedures | 8.8 | 8.85 |
| Assist them in completing the medical treatment | 8.62 | 8.55 |
| Cope with fear of death | 8.46 | 8.45 |
| Help them to understand their conditions step by step | 8.29 | 8.15 |
| Decide their own care plans | 8.19 | 8.15 |
| Decide their medical treatment | 7.95 | 7.95 |
| Educate them the meaning of death | 7.71 | 7.5 |

(Chow et al., in press)

Area | Item | 1st round of survey | 2nd round of survey | 1st round of survey | 2nd round of survey | Mean score in 1st round of survey | Mean score in 2nd round of survey | Mean score in 1st round of survey | Mean score in 2nd round of survey |
---|---|---|---|---|---|---|---|---|---|
Family members' needs when PWID are seriously sick or dying | Agony of separation | 9.48 | 9.4 |
| Knowing PWID patient's illness condition | 9.33 | 9.3 |
| Balance between safety and quality of life | 9.38 | 9.25 |
| Physical and psychological burnt out caused by taking care of PWID patient | 9.29 | 9.25 |
| Feeling of helplessness when facing PWID patient's suffering | 9.29 | 9.15 |
| Deal with sudden death of PWID patient | 9.1 | 9.15 |
| Visiting the PWID patient | 9.05 | 9.15 |
| Concrete daily life assistance | 9 |
| Evaluate PWID patient's decision on their own medical treatment | 8.81 | 8.9 |

(Chow et al., in preparation)
Staff Training

Experiences in Hong Kong
- Training on communications with parents and PIDs
  - Mental Health Association
  - Tung Wah Group of Hospitals
- Emotional Competence, Knowledge Competence and Practice Competence

Life and Death Education

Experiences in Hong Kong
Bereavement Measurements

Assessment of Grief

- Complicated Grief Questionnaire for People with Intellectual Disabilities, CGQ-ID (Guerin, Dodd, Tyrell, McEvoy, Buckley, & Hillery, 2009)

Assessment of Grief

- Bereavement Reactions of Persons with Intellectual Disability Scale (BRPIDS) (Chow et al, 2013)
Criterion Validity: Concurrent Validity

<table>
<thead>
<tr>
<th>Complicated Grief Questionnaire for People with Intellectual Disabilities (CGQ-ID)</th>
<th>23-item whole scale</th>
<th>15-item revised scale</th>
<th>Traumatic grief (5 items)</th>
<th>Separation distress (items)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Bereavement Reactions of Persons with Intellectual Disability Scale (BRPIDS)</td>
<td>.874**</td>
<td>.907**</td>
<td>.761**</td>
<td>.864**</td>
</tr>
</tbody>
</table>

** p < .01

Are we prepared?

Visions

1. Collaboration between Health and Social Care Providers
2. Collaboration between practitioners and researchers
   - Profile of end-of-life decisions and process
   - Communication strategies
   - Measurements
3. Collaboration between international groups

Visions

4. Tripartite Collaboration

- Health Care
- Social Care
- Patient & Family
- Person-Centred Palliative Care
Asia Pacific Hospice and Palliative Care Conference 2017 in Singapore

www.aphc2017.org

謝謝！