Beliefs, luck, and oppression associated with paediatric palliative care in South Korea: Implications for a model of anti-oppressive surrogate decision-making

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Outline

• Background of the Study and Aims
• Literature Review & Theoretical Framework
• Methods
• Results
• Conclusion
Background & Purpose

– Hidden moral dilemmas arise that lie between respect for autonomy and paternalism, while conducting surrogate decision making.

– This research aims to examine how social workers can identify the difficulties in the ethos of surrogate decision-making both children and young people with life-limiting conditions (LLCs).

– While identifying the difficulties, these imply for a model of anti-oppressive surrogate decision-making.
## Literature Review and Framework

### Shared decision-making?
- All types of patients? (Brundage et al., 2005; Deber et al., 2007; Edwards et al., 2005)
- To achieve in practice? (Berry, 2007; Towle et al., 2006)

### Oppression
- Young (1990) shows five faces of oppression: exploitation, marginalization, powerlessness, cultural Imperialism and violence.
- Dominelli (2002: 9) the exercise of power in social relationships primarily on the interpersonal level.
- Cudd (2006) defines violence as a force, economic forces and psychological harms

### Beliefs
- Michael Polanyi
  - Tacit dimension
  - Commitment and fiduciary – act in affirmation of truth
  - Conviviality
  - Power
- Pierre Bourdieu
  - Doxa
  - Habitus
  - Field-Social Class
  - Symbolic violence

### Luck
- Blind Luck – planning ahead
- Moral Luck – moral blame or praise for an unexpected action or consequences
- Epistemic Luck – conditions of knowledge and luck
Critical Ethnology

Observation site: Seoul, South Korea

To immerse myself in the same situations the ethnographic research will be conducted through at least 10 hours of weekly participant observation in the field and to live near the hospital in South Korea for 9 months.

Three main methods of data collection are observation, semi-structured interviews (in total, 112 interviews took place), field notes and document analysis.

The research underwent full ethical review by the School of Applied Social Science’s ethics committee at Durham University and the Institutional Review Boards in Korea gained full approval.
Research Place: Seoul, South Korea

Multi-level systems: Paediatric Palliative Care and Social Epidemiology

Fig. 2.1 Multi-level systems influencing experience of children receiving palliative or hospice care.

## Research Results: Palliative Care for Cancers Not Knowing Causes of Life-limiting illnesses

<table>
<thead>
<tr>
<th>Palliative Care for Cancers</th>
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<tbody>
<tr>
<td><strong>Institutional oppressors</strong></td>
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<tr>
<td>Multinational Companies &lt;-&gt; Government Disconnecting health care system Depending on Donation School</td>
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<td><strong>Targets of oppression</strong></td>
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<td>Children and Young people with LLC and their family members</td>
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<td><strong>Forms of resistance</strong></td>
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Research Results: Palliative Care for Non Cancers Not Knowing Causes of Life-limiting illnesses

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## Research Results: Palliative Care for Cancers Knowing Causes of Life-limiting illnesses

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<th>Death and Victims in Samsung Electronics Factories After Octavia Kim, 2007</th>
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<tr>
<td>Institutional oppressors</td>
<td>Multinational Companies, Government, Mass Media, the Court</td>
</tr>
<tr>
<td>Targets of oppression</td>
<td>Most poor female jobseekers living in rural areas</td>
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<tr>
<td>Forms of resistance</td>
<td>From 2007 to Now Acts of Civil, Disobedience, Conscious-Raising Forums, Social Media, Activism</td>
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**No More Death in SAMSUNG**
## Research Results: Palliative Care for Non Cancers Knowing Causes of Life-limiting illnesses

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<th>Death and Victims by Humidifier disinfectant as toxic chemicals' victims</th>
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Interactive dimensions of oppression

Personal oppression

Complex Interactive Negotiations around Oppression

Cultural oppression

Institutional oppression

**Holistic Intervention Chart For Empowering Anti-Oppressive Practice**

Oppression

1) Oppression in Place, Time and Ways of Communication
2) Oppression and Authority as Strong Paternalism: Medical Paternalism and Neo-confucianism
3) Oppression as Disagreement: Undervaluing the Best Interests of Children
4) Vicious Cycle: Oppressed Social Workers Oppress Service Users due to Neo-liberalism and Bureaucratic System
Beliefs: Doxa and Tacit Dimension

1) Authority in Belief - Doctor, Media, Government and Jaebal
   i. “We have no choice so we should follow what they say something from doctors.”
   ii. “The company will never do that”
   iii. “The government/ the media will at least protect the people but not the jaebal.”

2) Biased beliefs: hospice is giving up
   i. Parents- “My child does not know.”, "You should not tell the truth because my child will be shocked.”
   ii. “Why am I so unlucky?”, “Be careful what you wish for!”, “Rare diseases are infectious diseases.”, “This is what parents did wrong.”
   iii. “My child's disease must be recovered.”
   iv. “If a child dies before their parents, a funeral is not necessary because it is not filthy.”, “You should not go to a child funeral.”
Anti-oppressive surrogate decision-making
END - OF - LIFE DECISION MAKING (ELDM)
Anti-oppressive surrogate decision-making
oppression, beliefs and luck-blame/praise

Supportive Care, Palliative Care and Hospice Care
Conclusion

Anti-oppressive surrogate decision-making
oppression, beliefs and luck-blame/praise

The findings suggest the need to address oppression and luck in their cultural and social context, alongside children rights initiatives for pursuing effective anti-oppressive surrogate decision-making within a cross-agency approach.
Thank you for your attention!

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