

A voyage of grief and beauty: a phenomenological study of the experience of supporting a family member with an intellectual disability who is dying in a community setting

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Driving Forces

❖ Practice experiences

❖ Dearth of research



Societal
avoidance of the
“double taboo” of
disability and
death

WHY?

Todd, 2004

“Personal Tragedy
Model”
presenting death
as a “kind
release”

Institutionalisation rendering
people “socially dead” so their
physical deaths were not
considered to matter

“Death poses many uncomfortable, but important, questions. There are many good reasons to ask them, though, because they matter to individuals with learning disabilities, to the people who are bereaved by their deaths and to the providers of supported living services ... “

(Todd, 2004, p.12).

The Passing

I knew you were hovering on the edge of life

And was mindful

Of you and yours

What fear has death for one so pummelled by life?

Yet your preciousness has been revealed

Your beingness celebrated by all around

You found a place

A home

The cat found you and lived in your aura for days on end

And as sweet comfortable sorrow flowed down our cheeks

We stood with unity

Separate hearts

Silently honouring your glorious afterglow



Research Question

“What is it like to support a family member with an intellectual disability who is dying in a community setting?”



Research Aims

- 1. Release the voices of family members who have lived the experience**
- 2. Inform practice and service development**
- 3. Enhance the capacity for people who have an intellectual disability to experience an “ordinary death” at home**

Research Design

- ❖ Central Ethics Committee Approval
- ❖ Hermeneutic Phenomenological Methodology

**Reveals meanings
underlying a lived
experience –
through
interpretation**



The Research Participants

Pam Mother of Frances

Frances who had Down's syndrome died in hospital of acute myeloid leukaemia, 20 years earlier, aged 3 years.



“Grace” Mother of “Matthew”

“Matthew” who had phenylketonuria died in a hospice from renal cancer, 7 years earlier, aged 42 years.



“Dave and Alison” the Brother and Sister-in-law of “Maureen”

“Maureen” who had Down’s syndrome died at her group home of pneumonia secondary to advanced Alzheimer’s disease, 6 months earlier, aged 52 years.



“Sandra” the Mother of “Simon”

“Simon” had an undiagnosed syndrome which caused progressive physical disability and intellectual disability. Simon died at his group home of pneumonia secondary to influenza, 6 years earlier, aged 24 years.



Georgina the Mother of Endeavour

Endeavour who had Down's syndrome had died at her parent's home of acute myeloid leukaemia 3 years earlier, aged 3 years.



The Interviews

- ❖ All participants chose to be at home
- ❖ Range 59-86 minutes duration
- ❖ Field notes immediately post-interview
- ❖ Comments added to verbatim transcription



Thematic Analysis

**Concurrent
with data
collection**

**Reflexive
circular
movement**



Rigour and Trustworthiness

- ❖ “Phenomenological nod”
- ❖ Saturation
- ❖ Textual Rhetoric
- ❖ Independent Thematic Review
- ❖ Presupposition declaration



Research Findings

Metaphorically expressed as three groups of submerged boulders which had influenced the surface currents during

“A VOYAGE OF GRIEF AND BEAUTY”



“A VOYAGE OF GRIEF AND BEAUTY”

“... we felt devastated. I lay awake all night, thinking, ‘what am I going to do?’ And then I thought, ‘I’m going to have a party.’ So we ... rang up all Endeavour’s friends ... That was probably about three weeks before she died *[breaks down]* ... It was one of the best days of our lives.” (Georgina)



OVER ARCHING MEANING

A VOYAGE OF GRIEF AND BEAUTY

THEME ONE
Interlocked
Companionship

THEME TWO
Search for
New Balance

THEME THREE
Permeable
Interaction

Interlocked Companionship

Subthemes

❖ The extraordinary bond and being together

“with your child with an intellectual disability it is like you are right inside of them ...” (Georgina)



❖ Disenfranchised partnership

“It was awful when Matthew needed an enema ... he would trot off into the bedroom with the nurse looking all shrunken and frightened.” (Grace)



❖ Empathetic awareness and advocacy

“... she was acutely uncomfortable in hospital – she didn’t understand why she was there, why she felt so awful, that she didn’t know anybody, that she had these whirling machines...” (Alison)



❖ Gratitude for legacy

“ ... at the funeral people made donations, and the Wellington Down’s Association decided to set up awards which celebrate the achievements of people with Down’s syndrome, they are held annually and I still feel very moved.” (Pam)



❖ **Meaningful farewell**

“He loved Rod Stewart and ‘We Are Sailing’, so we played that. Everyone said what a lovely funeral it was, ... celebrating his life.”
(Sandra)



❖ **Unending relationship**

“We speak about her freely and often say Endeavour would have enjoyed this, or remember the time she did such and such.”
(Georgina)



❖ Careful positioning of the body

“... she’s still home I guess in that ... her ashes are in her bedroom, and I think one day - ... [breaks down] we’ll scatter her. At the moment we like her being here.”
(Georgina)



Search for New Balance Subthemes

❖ Resetting the compass

“So he was bewildered – he didn’t know why he was farewelled from work. ... he thought he’d been sacked or something. It was hard to explain to him, and then instead of being in the group home, he just came and lived at our home for a while ... ” (Grace)



❖ Accommodating flexibility

“ ... we had a flower for him [Maureen’s partner] to put on the coffin ... the other residents with their caregivers went up and James ... he didn’t want to go anywhere near the coffin.” (Alison)



Permeable Interaction Subthemes

❖ Appreciating pivotal people

“... Jenny [the paediatric oncology nurse] said, well would you like me to come home with you? But she sort of sensed how I was feeling and it really felt quite strange driving ... holding a dead child in your hands ... she probably got home about 2 in the morning. But, you know, I was really grateful for that.”
(Pam)



❖ **Watching out for others**

“...after she died the play centre children viewed her lying in her cot and gave her flowers and cards ... that was a really good healing process for them too.” (Pam)



❖ **Contributions of friends with intellectual disabilities**

“They wheeled his flat mates in ... like a normal day, ... they’d make noises ... as though they’re talking to Simon. [smiles] They tried to talk to him ...” (Sandra)



❖ Tailoring responses

“... the police got involved because Simon hadn’t seen his regular doctor. I was aware the policeman was watching my face very closely and it was just a horrible feeling ... so I thought maybe I’m not reacting well, I looked quickly at Simon and I gave a little smile and quickly looked away ...” (Sandra)



❖ Drifting away from services

*“So we hardly ever go to the house now. Went recently, invited to a celebration and the new manager said, you’re always welcome, but it’s just not the same.”
(Sandra)*



Research Recommendations

Service Delivery

Palliative Care - Hospital - Support Services

- ❖ **24 hour palliative care service to community settings, including for non-malignant terminal illnesses**
- ❖ **Networking and sharing of knowledge across the specialties**
- ❖ **Use of communication resources and adapted symptom assessment tools (actively seeking whanau input is vital)**

The Person

- ❖ **Consider their perception illness and death**
- ❖ **Avoid using words known to cause distress**
- ❖ **Only people who know them intimately should disclose sensitive information**
- ❖ **Ask do they have directives in place and empower them to “voice” their choices**

Whanau

- ❖ Offer palliative care education and support matching each situation and person
- ❖ Provide ethical support to whanau required to make proxy medical decisions
- ❖ Acknowledge the centrality of friends and partners with intellectual disabilities

- ❖ **Anticipate that those close to the person will feel the death acutely**
- ❖ **Recognise that optimal symptom control reduces post-bereavement distress**

To Each Participant

**Your trust and
generous sharing
of a deeply personal
story is the pulse beat
of this research project**



**And you spoke of being pulled deep deep deep
into the raggedness of humanity**

**The searching of innermost self and others and
that beyond**

And most of all that merged becomingness

With the jewel of your souls

That cradled one who will shine forever

Enlightening and whispering

And simply be there



Heartfelt Thanks Are Also Offered To

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as I ventured deeply inside the labyrinth**

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