

Evaluation of Client Biography Service

eastern palliative care



Rationale & Aims

- Rationale
 - To qualify anecdotal evidence & its popularity
- Aims
 - To explore the experience of biography for clients, family, biographers & staff
 - To identify the impacts of biography

Literature review

- Life Review
- Limitations of Life Story Book Work:
 - Time & resources
 - Professional power differential
 - Training, support & supervision
 - Ethical privacy issues

Methods & Analyses

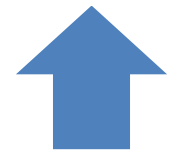
- Self report surveys:
 1. Client
 2. Family/Carer
 3. Biographer
 4. EPC Staff
- Mixed Methods: Qualitative (nVIVO) & Quantitative rating scales
- Response rates were adequate

Quantitative Findings

- Satisfied/Very Satisfied: All 10 clients & 95% family/carers
- 62 references to gratitude & thanks
- 99% carers said their relative felt comfortable
- Celebrations: 74% show family/friends, 37% eulogies, 17% library archives
- 100% client comments to staff were favourable/very favourable
- 100% staff said Biography DOES make a unique contribution to QoL

Qualitative Findings

The Lifespan



Diagnosis

Referral

Biographer Contact

- Distress (Spiritual, existential, anxiety, depression)

- Client is often hesitant (4)
- Client begins thinking about what to include in biography

Biography recording & editing sessions

- Volunteer facilitated, provides opportunity for Life Review:
 - Personal reflection (18)
 - Reflection of whole of life - Focus on life/living (23)
 - Re-live happy memories (11)
 - Realise achievements (9)
 - Meaningful, purposeful & valuable activity (11)
 - To confront or resolve difficult feelings, memories or relationships (6)
 - Integration of different aspects of self (5)

Biography recording & editing sessions

- Benefits of Life Review are amplified due to *unique* components of the Biography Service:

PROCESS

- TIME allowed (2)
- More meaningful (11), enjoyable/exciting experience (12)
- Editing process –minimal, person's own words (13)
- No language imposed (professional or religious)
- Client control over sharing the published record
- Publication sharing is a more 'communal' activity

FACILITATOR

- Genuine interest in story (3)
- Personality, empathy & listening skills (10)
- Non-Family member (1)
- Volunteer member of community (non-professional)
- Supportive presence & non-directed facilitation

Client
comfort
in telling
story (9)

Authentic,
honest
account of
life (17)



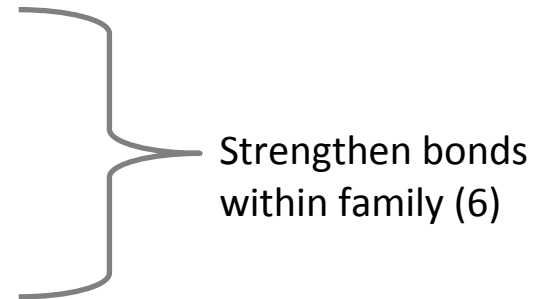
Biography used in eulogy (2)

Re-read by client:

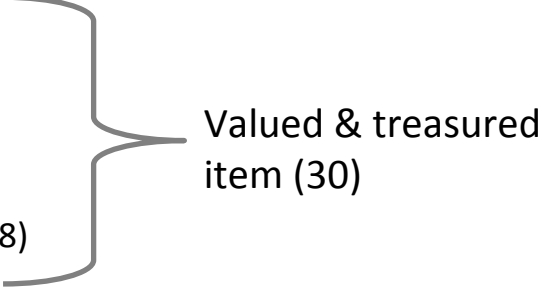
- Benefits of Life Review AGAIN (1)
- Source of pride (27) & accomplishment (4)
- Well presented (20)

Shared with family & friends:

- Deeper insight into life of dying family member (81)
- Understand better: past behaviours & choices (13), shared experience (2), previous generation & ancestry(6)
- Deeper respect & admiration (4)
- Communication tool to engage family discussion (6)



Strengthen bonds within family (6)

- Tangible (18) legacy (56) in person’s **own** words (13)
 - Enduring connection to deceased (18)
 - Keep memories alive (23)
 - Source of great comfort during time of grief & bereavement (18)
 - Reflexive benefits for readers:
 - Resource for own reflection (13)
 - Enhancing sense of identity
 - Connection to cultural background (1)
 - Reprioritisation of life (3)
- 
- Valued & treasured item (30)

Criteria for “Dying well” or “Peacefully”

1. Meaningful but limited goals set
2. Internal conflicts (eg. fear) reduced
3. Sense of identity sustained
4. Critical relationships enhanced

1. Meaningful but limited goals set

“It has provided me with an outcome that I have been able to complete despite illness pressures (when I have been able to complete little else!) ... I am proud of the outcome.”

-Client

2. Internal conflict reduced

“Let more patients know of this wonderful service. It certainly has made my walk towards death a much more interesting walk and driven away my FEAR.”

-Client

3. Sense of identity sustained

“Great benefit is being able to identify with all that they are/have been, not just what their life has been reduced to because of illness, treatment and impending death.”

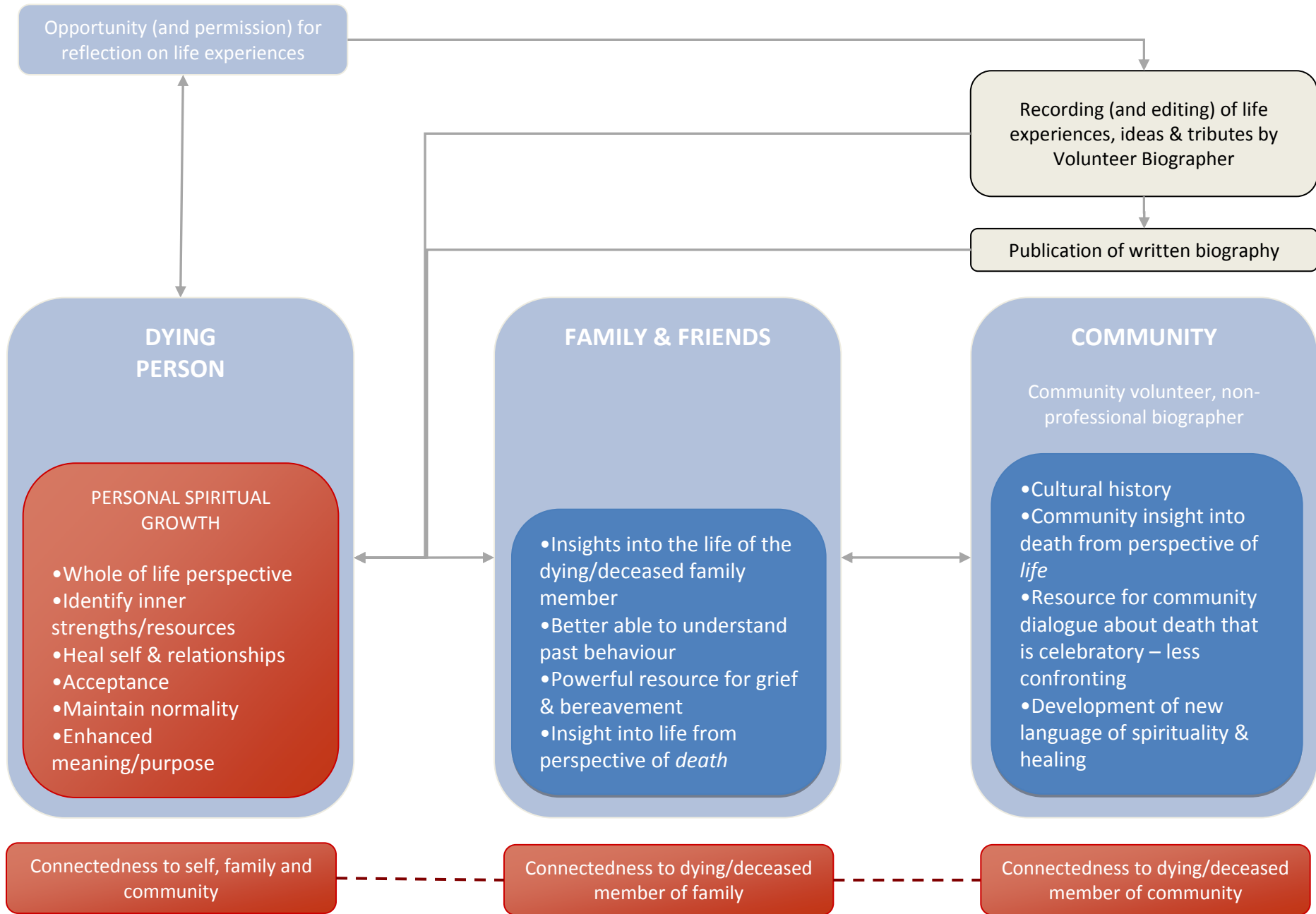
-Staff

4. Critical relationships enhanced

“It helps to know who my Mum is more completely. To understand her is to love her more deeply and feel a part of her and so inspired by her life journey.”

-Daughter

Intra-, Inter-personal & Community Relationships



SUMMARY

- The Biography Service Model:
 - Innovatively addresses concerns in Life Story Work
 - Supports a “peaceful death”
 - Makes a unique and valuable contribution to client and family experience
 - Enriches and enhances what is currently available in family, psychosocial & spiritual end of life support
 - Is a valuable complement to suite of palliative care services

FURTHER RESEARCH

- Cultural histories
- LT effects on bereavement
- Benefits for Biographers
- Final stage of development/personal growth
- Non-religious language of spirituality
- Application to other populations (aged care, dementia, indigenous)

ACKNOWLEDGEMENTS

- Health Chaplaincy Council of Victoria (HCCVI)
- Eastern Palliative Care (EPC)
- Research Advisory Group
- Clients, family, volunteer biographers & EPC staff for sharing their insights & stories

able about account **all** already am **an** appreciate appreciated appreciative
biographer biographers **biography** can care caring clients community
dad do doing done dying effort **epc** excellent fantastic **good**

great had has have help helped her his hope how **i** idea illness its job

just keep kindness life like made make many me more most much

mum **my** offer opportunity our palliative part **people** person process

provide provided providing recommend say **service**

services she should **so** support tell **thank** thanks them thing

think time up us use valuable **very** volunteer we well when

who **wonderful** work worth worthwhile would **you**
your