

**Client Biography:  
Celebrating life and supporting a peaceful death through volunteer  
facilitated life stories**

**Names of authors:**

Francis Icasiano

Jenny Kearney

**Affiliations of authors:**

Eastern Palliative Care (EPC)  
Health Care Chaplaincy of Victoria (HCCVI)

Eastern Palliative Care (EPC)

**Contact for correspondence:**

Jenny Kearney  
Volunteer Coordinator  
Eastern Palliative Care  
PO Box 227  
Nunawading, Victoria 3131, Australia  
(03) 8804 0029  
1300 130 813  
[JKearney@epc.asn.au](mailto:JKearney@epc.asn.au)  
[francis.icasiano@consultant.com](mailto:francis.icasiano@consultant.com)

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## ABSTRACT

**Objectives:** To explore the client and family experience of volunteer-based biography and identify its potential benefits.

**Methods:** A mixed methods triangulation approach was undertaken. Self-report surveys for clients, family members, biographers and palliative care staff were summarised quantitatively, and qualitative open-ended responses were coded thematically.

**Results:** Clients, families and staff perceptions rated an overwhelmingly high level of satisfaction with the service. Thematic analysis presented over the dying process highlights the powerful benefits associated with life review and the benefits uniquely associated with this new volunteer-based service model.

**Significance of results:** Review of the relevant literature found that this unique service is a progressive extension of a formative model from New Zealand, is a practical application of life review and addresses fundamental concerns and limitations in life story work (eg. time and resources, professional power differential and ethical privacy considerations). For many clients and their families, biography represents something of profound value. The biography process itself supports personal growth - sustaining one's identity, personal meaning and purpose, and provides a venue for reconciliation of personal issues at end of life. Through leaving a tangible legacy for current and future generations Client Biography has potential to enhance critical relationships, enrich the time remaining, assisting in the process of "dying well" or "peacefully".

**Conclusions:** This sustainable volunteer-based model of Client Biography Service makes a unique and valuable contribution to palliative clients and families' experience of end of life. Enriching what is currently available in family, psychosocial and spiritual support, biography is a valuable person-centred complement to the suite of holistic palliative care services that can strengthen links with community.

**KEYWORDS:** biography, life review, life story work, palliative care, volunteer-based

## INTRODUCTION

Contemporary palliative care has its roots in hospice programs developed by local community groups with volunteer participation (Rumbold, 1998). In order to ensure service sustainability and improve client access, these programs were incorporated in the mainstream health system resulting in a shift to a model characterised by 'clinical dominance' and professional intervention (Kellehear, 2002). This led to a loosening of links with the community, with less reliance on volunteers and some areas in palliative care being underdeveloped - namely, social and spiritual domains, where outcomes are less easily quantified and framed in delivery terms (Rumbold, 1998).

Now, health promoting palliative care models recognise the unique and valuable role of community groups and volunteers in addressing these important domains and in rebuilding community capacity, social capital and resilience (Kellehear & Young, 2007; Salau, Rumbold & Young, 2007). Kellehear (1995) lists the fundamental components of a health promoting initiative including the creation of participatory relations – involving 'working *with* people rather than *on* them' through collaboration based on mutual interests.

Whilst there is a compelling need in palliative care to develop innovative interventions that assist in relieving end of life distress (Brietbart, 2001), there is also a great need to develop and support programs that:

- Are celebratory and build on strengths. If health is understood as more than the absence of disease (WHO, 2006) and if clinical interventions are primarily disease or problem focussed (Kellehear, 2002) then programs that are celebratory and quality of life *enhancing* are needed to address this imbalance.
- Promote mutual learning. If assessment frameworks are inherent in clinical approaches (Kellehear, 2002) where knowledge transfer is typically uni-directional, then participatory and collaborative approaches are needed to expand the flow of knowledge.
- Focus on the quality of relationships. If dying is a social and therefore interpersonal process (Rumbold, 2002), then programs that cultivate more intimate family and community relationships are needed in order to support the underlying social connections inherent in dying well or peacefully.

Developed at the community grass roots level, with support from the professional palliative care team that is vital, a new innovative volunteer-based service is described and explored here which:

- Exploits the power inherent in life stories
- Facilitates collaborative relationship based on the mutual interests of the dying person, their families and broader communities

## Volunteer-based Client Biography

Established in 2006, the Client Biography Service is offered freely among Eastern Palliative Care's (EPC) complementary community-based services as a way for dying clients to celebrate their unique lives through story, and pass on important information to their families and loved ones. At the service level, it includes formalised:

- Recruitment , screening and selection of appropriate members of the community to become volunteer biographers
- Extensive specialist training for biographers
- Ongoing professional supervision, training and editing support (EPC, 2008) for biographers
- Integration into the palliative care multidisciplinary team
- Biographer support systems, policies and guidelines including ethical guidelines around informed consent and levels of client-defined access to drafts and the published document

For the dying person, the process involves:

- Client referral from the family support team (professional assessment of suitability)
- Typically around 6-8 audio-recording sessions of the client's first person narrative facilitated by the biographer
- Manual transcription of audio recording by the biographer
- Ongoing editing of biography drafts with, and at the direction of the client
- Insertion of title, scanned photos, artworks, poetry, etc., at the direction of the client
- Binding of the final biography publication plus an electronic copy for the client

Although the biography product is seen as valuable, it is believed that the biography *process* is paramount, and should be first and foremost beneficial for the *client*. Importantly, the biography process is *not*: an interview, an exchange of ideas as in a conversation, nor is it a series of clinical counselling sessions. The biography service was created as a celebration of life, in and of itself.

Anecdotal evidence has attested to the great popularity of the Biography Service with extensive client waiting lists and great numbers of community members wanting training to become volunteer biographers. Current trends suggest there will be a greater increase in client demand, indicating that further growth of the service is needed to maintain adequate professional supervision of volunteers, which is imperative to maintain high levels of care.

As this service model is facilitated by volunteer members of the community, it is a progressive extension of a formative model from New Zealand (Lichter et al., 1993). Review of the published literature found volunteer-based Client Biography to be the first of it's kind in Australia and internationally, and a practical

application of life review that innovatively addresses the fundamental challenges associated with Life Story Work.

### **Life Review**

First described by Butler (1963), life review is essentially a personal and natural process of reflection over one's life and reorganisation of one's prior experiences. Although thought to be a naturally occurring process triggered by the keen awareness of one's mortality at end of life, it is a process that does not occur easily or automatically (Haight et al., 2000). It is thought that life review is essential to the final reorganisation and (re)integration of different aspects of the personality and for many, it is a final opportunity to resolve and come to understand personal conflicts in earlier life (Pickrel, 1989).

### **Life story work**

Contrary to Client Biography's roots in celebration, the value in biographical approaches has typically been identified in its ability to promote person-centred nursing care in the context of palliative assessment and intervention (Broadbent, 1999; Clarke, 2000; Clarke, Hanson & Ross, 2003; Heliker, 1999; Hirst, 1997; McKeown, 2006; Larson & Tobin, 2008).

In many cases, service models include the production of a life storybook and these have been applied across various populations including the learning disabled (Hewitt, 1998; Hewitt, 2000) and persons with dementia (Batson et al., 2002; Caron, Hepburn, 1999; Maher, 2002) as well as persons facing end of life (Lichter et al., 1993; Broadbent, 1999; Chochinov et al., 2005; Clarke, 2003; Elford et al., 2005; Guse et al., 2000; Jarvis, 1998).

The service frameworks, methodologies and approaches in these studies vary greatly. They include a developed therapeutic intervention (Chochinov et al., 2005), and various fledgling and one-off services - for example, solitary reminiscence writing (Elford et al., 2005) and visual collages (Jarvis, 1998). In most cases, the work is facilitated or administered by a person in a professional supportive role (eg. Clarke, 2003) – usually a nurse but in some cases a psychiatrist, psychologist or a nurse (Chochinov, 2005) or a research assistant (Guse, 2000).

Of note, an internet search identified several commercial ventures offering life story recording services charged at a significant cost to the individual (e.g. AU\$4,000-6,000) with a limited number (e.g. 2-3) of interview sessions. Although these services may be beneficial to some, it is thought that any benefits associated with these services are only accessible to the few in the community that can afford them. However, these commercial ventures, along with the popularity of online tribute websites do point to the great demand in the community for these types of services.

## **Challenges of life storybook work**

While methodological approaches vary within the life story book literature, several common challenges associated with this work have been identified.

### *Time and resources*

Story telling involves a one-to-one relationship between the storyteller and the listener and as such is a labour-intensive activity (Hirst, 1997). A number of studies have indicated that staffing limitations represent a significant barrier to implementing these types of programs in residential and other care settings owing to the time pressures on nursing and other hospice staff (e.g. Broadbent, 1999; Clark, 2003; Elford et al., 2005; Guse et al., 2000; Lichter 1993; Penna, 1995). Further, in a review of the literature on life story work, McKeown (2006) found that while some residents appreciated being listened to, they were aware of time restraints placed on staff, potentially restricting the breadth and depth of the story told. Hence, it has been suggested that professional staff may not be ideally placed to engage deeply in this type of work due to the investment in listening that is required (Hirst, 2001).

### *The professional – patient power differential*

The power differential between professional care staff and the storyteller is a concern in life story work (Elford et al., 2005) and can exist when the facilitator of the life story is seen as the 'expert', and is dominant and directive (Hirst, 1997; Hirst, 2001), as is often the case for the nurse (Sandelowski, 1991). Several factors may reinforce this power difference.

Firstly, when the language framework applied to the story telling process is incongruent to the story-teller's own subjective worldview (e.g. professional or inappropriately religious discourse) then this can potentially reinforce the power difference.

Secondly, professional care discourse is often objective, problem-focussed and disease-saturated (Caron, 1999) which can emphasise personal loss and weaknesses instead of affirming the dying person's strengths and supporting opportunities for personal growth. This can be the case for nursing documentation which is primarily concerned with scientific, objective knowledge instead of the subjective and personal, offering significant challenges for nurses moving between these cultures of discourse (Hirst, 1997). Further, Chochinov (2006) admits that psychiatric diagnoses themselves provide too narrow a framework to contain the broad range of distress at end of life and concedes that something outside the most sophisticated medicinal and technical modalities is at play.

Both the professional-patient power difference and the language used can limit the breadth and depth of the story, with potential to medicalise and devalue an individual's subjective lived experience (Caron, 1999) instead of normalising the dying process. Further, working within an inappropriate discourse framework that may be objective, disease saturated or inappropriately religious has the potential to limit or even negate the benefits that may be derived from the story-telling process.

### *Ethical privacy issues*

Managing the ethical issues around privacy of life stories and ownership of the final product is a dilemma identified in the life storybook work literature (Adams et al., 1996; 2005; Clarke, 2003; Elford et al., 2005; McKeown, 2006) but is also noticeably absent in some life story work frameworks (e.g. Chochinov, 2005). The process of making private memories potentially public needs to be handled sensitively and ethical issues of confidentiality, and ownership and access to the product should be dealt with formally at the outset (McKeown, 2006). Participants may be discouraged if they are not given a choice around who can access their life story (e.g. Elford et al. 2005) and these studies point to a great need and responsibility to work within explicit guidelines and give ultimate control over who accesses the recorded product to the storyteller.

Given the potential privacy issues encountered over the process of developing a life story book, there has been little mention in the published literature of processes around the editing of drafts leading up to the final production of the life story book. Owing to the potentially sensitive content of drafts, there is a strong need to develop explicit protocols around the editing process.

### *Training, supervision and support*

Sometimes evoking painful memories within complex emotional boundaries, there is a need for appropriate supervision and support for those facilitating life story work (McKeown, 2006; Trueman and Parker, 2006). In particular, key areas requiring supervision and support include the need to maintain appropriate boundaries, managing the disclosure of sensitive information and managing the potential distress from painful memories.

The limits to professional help in palliative care have been recognised (Kellehear, 2002), and the challenges described here lead to the single question of who is best placed to be facilitating life story work with the dying person. Life story approaches require a significant emotional investment from the facilitator to ensure that those telling their story are comfortable talking about their lives and a relationship of confidence, trust and equality is established (Clarke, 2003). Care *can* be a product of a more equal interaction as opposed to something delivered (Rumbold, 2002) and the challenges identified here point to the unique and powerful contributions that volunteer members of the community can make in supporting life review through a biographical approach at end of life.

The client biography service model utilises trained volunteers in the community who necessarily have an interest in people's stories and empathy for those facing loss and end of life. This model offers:

- A link with, and utilisation of a previously un-tapped human and social resource within the community.
- A more sustainable service long term

- A safeguard such that the story telling process occurs:
  - At a deeply human level outside the usual (imposed) discourse and language common to professional care settings or religious frameworks
  - Within a timeframe that adequately respects the breadth and depth of uniquely personal and rich stories that make up one's life

As this service model appears to be the first of its kind in the Australian and international literature there is a compelling need to evaluate the service and communicate these to the professional palliative care community. Essential to the success of this service is that it currently functions within a holistic care approach and is actively supported and resourced by the professional palliative care multidisciplinary team (Figure 1).

Debate continues on the relevance of evaluation criteria employed by studies (Higginson, 1993), however if it is the form and mode of delivery that is often just as important than the outcome of palliative care (Clarke, Neale & Heather, 1995) then it is important to explore the experience of biography for all involved within this context.



**Fig 1.** The multidisciplinary community-based palliative care team

## AIMS

The aims of this study were to explore the experience of biography for clients, their family members or carers, volunteer biographers and professional multidisciplinary staff and identify the potential benefits of Client Biography from the perspective of each of these groups.

## **METHODS**

Ethical approval for this study was gained from the Eastern Palliative Care Ethics Committee in 2008.

### **Participants**

Two sources for the present study were used: client surveys (version 1 & 2) from March 2006, and a series of in-depth self-report surveys (version 3) sent to four groups in January 2009. For this second source, participants included (1) palliative clients whose biography went to publication, (2) primary and secondary carers of clients whose biography was completed, (3) volunteer biographers and (4) multidisciplinary palliative care staff.

### **Approach**

The development of version 3 surveys for all groups is consistent with data triangulation methods using multiple information sources, and a mixed-methods approach was taken, incorporating qualitative open-ended questions as well as quantitative rating scales (Liamputtong and Ezzy, 2005). This methodological approach reflects the exploratory nature of this study that attempted to capture the depth of subjective human experience of biography in order to generate new insights for further research.

### **Measures**

Surveys version 1 and 2 were anonymous self-report surveys for the dying client and included basic demographics, Likert scales and open-ended questions about how biography may have helped. Survey version 3 was designed as a series of more in-depth anonymous self-report surveys for each of the four participant groups in order to explore the experience of client biography for clients, family, biographers and staff. Likert scales were included to measure overall satisfaction and favourability of client comments to staff. Tickboxes were included to identify the main reason to start biography and celebrations. Open-ended questions for clients, family and biographers included:

*“For me, biography means or has meant...”*

*“What did you enjoy most or least about biography?”*

Family and carers were asked:

*"If the biography has helped you, how?"*

Staff members were asked:

*"Generally, how would you describe the relationship that clients and/or families have with the completed biography?"*

If staff members indicated that they thought the service makes a unique contribution to the quality of life of clients, then they were asked to give their reason(s). All participant groups were asked:

*"Do you have any suggestions on how to improve the Biography Service?"*

*"Any further comments or reflections?"*

In this version of the survey, demographic questions were included for clients, family and biographers and for staff, employment details were asked. During development, version 3 surveys were reviewed by the researcher, multidisciplinary colleagues and an independent academic researcher for face and content validity. Finally, a Research Advisory Group comprising a cross-section of professional disciplines and leaders from various religious or spiritual denominations provided advice around theoretical and conceptual approaches.

### **Procedure**

Version 1 and 2 surveys were left with the client upon handover of the completed biography, to be completed and returned in a reply-paid envelope. Version 3 surveys were sent out to all four groups concurrently and respondents were given three weeks to return their completed survey. These surveys were sent to: (1) clients who were still alive and were not hospitalised, (2) primary and secondary carers where a postal address was available, (3) volunteer biographers who had an active status, and (3) all EPC staff in supportive care roles with clients. Recruitment lists for clients and carers were routinely checked against records for recent deaths and bereavements and no surveys or letters were sent if a death had occurred within two months.

### **Data analysis**

Quantitative survey responses were analysed using SPSS and percentages and means calculated. A thematic analysis of all qualitative open-ended responses was conducted with themes coded using nVIVO and the number of references for each thematic code considered to be a broad indication of how common a theme was. During the coding process and development of thematic concepts, a data-driven approach was taken drawing on multiple theoretical perspectives (nursing, pastoral care, psychology, etc.) to provide new insights (Liamputtong and Ezzy, 2005).

## RESULTS

### Participant demographics

Response rates were adequate to high (See Appendix 1). A response rate of 36% from clients was reasonable given their circumstances around facing end of life, illness, pain, treatment and hospitalisation; where possible, client data from older surveys (version 1 & 2) was used to augment the number of clients under study. Appendix 2 shows that the average age for clients, family members and biographers was 75, 59 and 64 years respectively. Most carers and biographers were female and most clients and biographers had a partner. Across the three groups, most had children, some indicated a religious or spiritual affiliation and most identified Australian as their cultural background. Most family members and carers in the present study were partners of the palliative or deceased client and most were female (See Appendix 3). For biographers, an average of 3.7 of their clients had gone to publication with one biographer having as many as eight clients published. Many biographies were started but not completed owing to client death or hospitalisation. Of the 23 biographers who indicated an occupation, seven (30%) had an administration background, five (22%) had a background in teaching and two had nursing backgrounds. Other occupational backgrounds included community work, healthcare, social work, psychologist, customer service, computer analyst, florist, labourer and publishing. Appendix 4 shows that palliative support staff were represented across the multidisciplinary roles and disciplines.

### Quantitative and qualitative findings

In order to exploit the strengths inherent in both quantitative and qualitative methods, both types of findings are presented together in a complementary fashion in order to clarify, confirm or explore both objective findings and subjective personal experiences.

#### ***Satisfaction with the biography process and product***

Of the 10 clients asked to rate their satisfaction, all rated that they were either satisfied or very satisfied with their completed biography. A total of 85 (95%) family members were either satisfied or very satisfied with the completed biography.

Unsolicited expressions of deep gratitude, thanks, or comments on the quality of the service were commonly found in survey responses. Among family and carers, 62 references were thematically coded as either an expression of thanks, gratitude, or value, or a comment on the high quality of service. Examples included:

*"I think this service is a wonderful idea. Please keep it going."*

*"Allow us to show our gratitude – it is a wonderful thing that you all do for humanity in a time of great stress."*

*"I think this is the most valuable service."*

*"Thank you.... It will never be forgotten."*

This high level of satisfaction is confirmed among staff. Of professional staff, 37 (93%) said their clients had commented on the biography service and of these comments, 100% were rated as either favourable or very favourable.

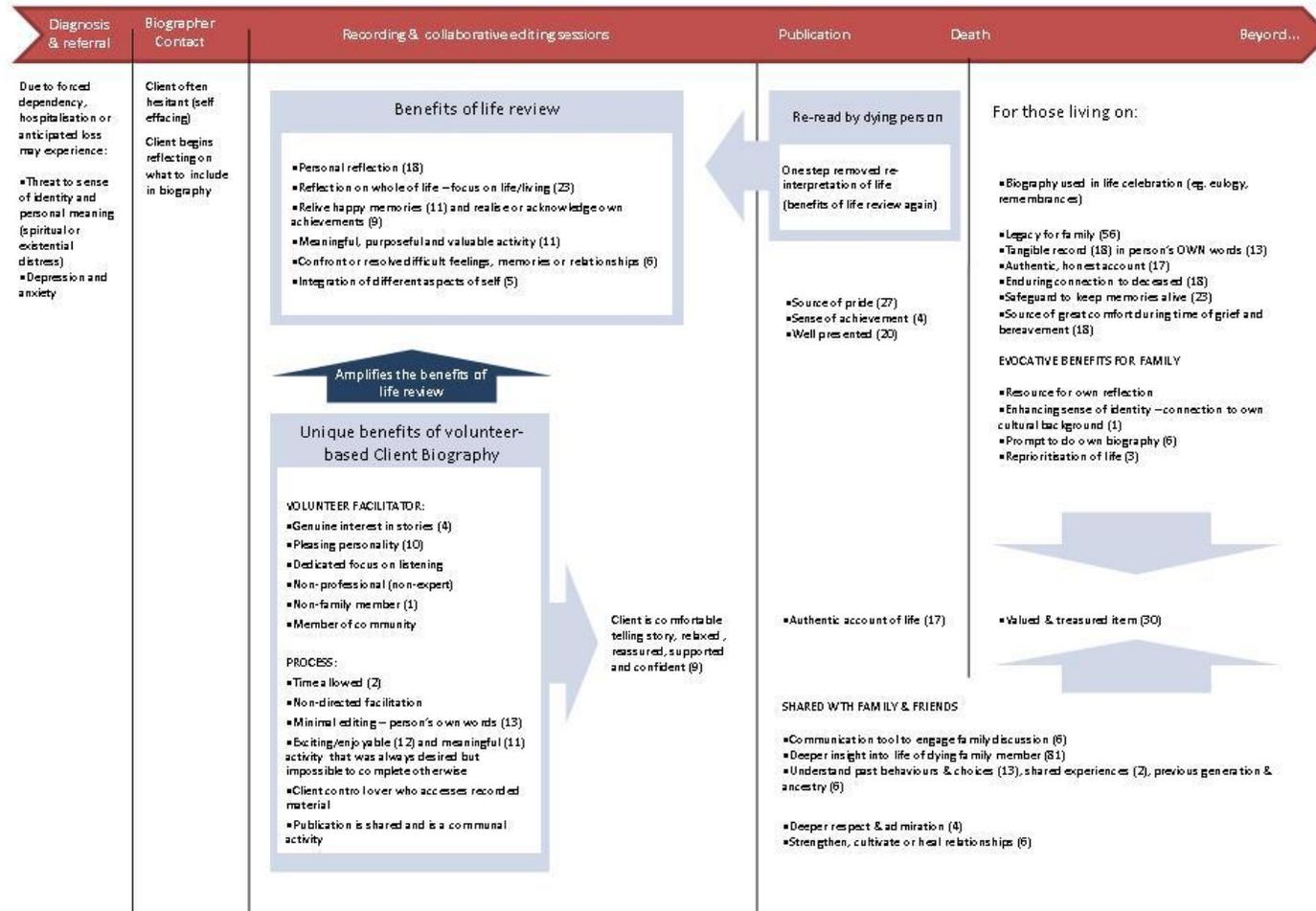
### ***Main reason to start biography***

Of the 74 family members who gave a reason, 35 (47.3%) chose 'Life story or historical record' as the one main reason their family member or friend chose to start their biography. Similarly, of the 34 staff members who gave a main reason for clients to decide to write their biography, 17 (50%) chose 'Life story or historical record'.

### **Benefits across the dying process and beyond**

Figure 2 is a visual guide to follow the potential benefits of Client Biography across the final stages of the developmental lifecycle and beyond. Numbers in parentheses indicate the total number of coding references to each theme for open-ended responses for all respondent groups and indicate how commonly a theme was identified.

**Fig 2. Client Biography at end of life**



### **Benefits associated with life review:**

During qualitative analysis it became evident that the process and product of biography yields many of the powerful benefits associated with life review. These are explored below with comments from surveys.

Biography can represent a valuable opportunity for reflection over one's life:

*"I have enjoyed the opportunity to reflect on life in much more detail than I would have done otherwise."*

*-Client*

This comes from the understanding that the process of storytelling requires reflection, which may lead to a new understanding of self and acceptance of the changes that life brings.

At a time when clients are undergoing tremendous loss to their independence and sense of identity (McGrath, 2003), the biography service can help clients identify with their entire self (not just their role as a 'sick person') and focus on their life as it has been lived. It can provide a history that predates their aging and disability, affirming strengths instead of emphasising loss.

*"Thank you for giving me my life back!"*

*-Client*

*"It is not about death/dying, but an affirmation of their lives and their contributions to the world."*

*-Staff*

*"It was exciting and gave him something positive to concentrate on."*

*-Brother*

*"Gave me other things to think about besides my illness."*

*-Client*

Clients appear to enjoy re-visiting periods in their life that were particularly happy, fulfilling or memorable. In the retelling, the person re-lives the past in the present, and for some they re-live the good times and come to terms with the bad.

*"It has brought back lots of memories and a few laughs for the family."*

*-Client*

*I enjoyed most ... "Talking about old times and forgotten memories, good and bad."*

*-Client*

*"I enjoyed watching my mum laugh while she was reliving very fond memories."*

*-Daughter*

Biography can be an opportunity to acknowledge or realise one's achievements:

*"It has been a format to look at my life and to see the many wonderful things I have achieved."*

-Client

*"It had the effect of taking Mum from thinking she had not done anything worth writing about to seeing her life as very full and worthwhile."*

-Daughter

*"I enjoyed that it helped the patient reflect on his life and realise that he had achieved a lot and lived a full life."*

-Carer

During times of great upheaval some literally forget what they have done and others may have never learnt to value their personal accomplishments and experience (Coleman, 1999). Reminiscing can serve to remind the person of past accomplishments and past successes at coping with life's stresses (Kovach, 1991) and then identify inner resources to cope with current distress.

Biography can represent a meaningful, purposeful and valuable activity:

*"It has been an introspective, challenging, meaningful and satisfying activity."*

-Client

*"The biography has helped me see a sense of purpose in my life."*

-Client

This client then later reported that biography 'unblocked' them, enabling them to finally clean out a room – a difficult but symbolic task leading to a sense of completion.

Biography can provide an opportunity to confront or resolve difficult feelings, memories or relationships:

*"The biography helped my sister a lot. An opportunity for her to tell aspects of her life, especially her relationship with mother that was difficult."*

-Carer

Quantitative analyses found that 13 (16%) of family members said that they found something in the process of biography that was painful or difficult. Of these, 9 (69%) said that the organisation supported them through these difficulties and the remainder mentioned that they chose not to seek support through the palliative care service.

Storytelling is a safe place in which to express difficult emotions (Heliker, 1999) and for many, biography can take on a cathartic quality, representing a chance to offload and get things off one's chest. In some cases during the editing phase, clients decide to omit difficult emotions or experiences from the draft document but nevertheless have attained great release in having voiced them in a comfortable and confidential setting. Still for others, it is valuable to have these difficult emotions or experiences affirmed or validated by their family or friends by communicating them through the published biography. It is believed that there is an ethical imperative here to give the client final say on what is included or omitted from their final life story.

For many others still, difficult experiences are dealt with indirectly in the narrative of their story as an 'inner story'. Hirst (2001) defines outer stories as those used to describe an experience and establish a relationship with the listener, whereas inner stories are those that reveal a depth of insight into feelings that may be too difficult to articulate or face explicitly. Often it is easier to tell an outer story than to articulate one's feelings and anecdotally, this is a common observation by biographers, especially among older male clients.

*"It helped him express some emotional pain he had experienced in his life."*  
-Carer

For many, the biography can be a personal exploration of their experiences in relation to regret, forgiveness and reconciliation.

*"To be able to talk about the bitterness and encourage forgiveness."*  
-Daughter

This is made all the more powerful when occurring within a venue that is non-threatening, without judgment where the person's own unique worldview, language or spiritual framework is valued and affirmed.

Biography, as in life review, can be a chance to explore new aspects of self, and reorganise or (re)integrate different experiences or aspects of one's personhood over one's lifetime:

*"I think the biography has helped me to look within myself to bring out different areas of myself that I didn't know were there."*  
-Client

*"An opportunity to draw together the strands of one's life."*  
-Staff

This has deep implications for how we think about healing, wellness and growth during the final stages of life. Coward and Reed (1996) distinguish healing (as originating from within) and curing (application of an external agent) and define healing as a sense of wellbeing derived from an intensified awareness of wholeness and integration among all dimensions of one's being. It is seen as a process of bringing together all the parts of oneself at deep levels of inner knowing to gain a sense of integration and balance (Dossey, 1988).

Debilitated by illness, a person's sense of self is clearly assaulted (e.g. vocation, future self) as death approaches, however some people emerge from the virtual disintegration of the person they once were to report a sense of wellness as they are dying (Byock, 1996). This is indicative that for many, the final stages of life represent the last stage for personal growth and self-determination, rather than withdrawal (Clarke, 2000) and the (re)integration of different parts of one's self may be the mechanism for that growth and healing. Coming to terms with loss involves recognising how we have been shaped by them (Rumbold, 1986) and storytelling through biography may help to integrate past roles lost and promote personal growth.

## **Benefits unique to a volunteer-based model of Client Biography:**

The model of volunteer-based biography presented here contains several unique characteristics (see Figure 2). That Client Biography makes a unique contribution to the life of palliative clients was supported quantitatively by staff, where 100% (35 respondents) indicated that the service does make a unique contribution to clients' quality of life. Guided by qualitative analyses, it is proposed here that the unique characteristics of the volunteer-based model of biography have the potential to:

1. Amplify the personal benefits associated with life review, and,
2. Lead to a higher level of comfort in the telling for the client, producing a more authentic account of the unique person's life and personhood.

Clients reported that they felt very comfortable in telling their story within the biography framework:

*"I appreciated the biographer's natural manner – she was easy to talk to."*  
-Carer

I enjoyed most ... *"The ease with which he was able to say what he wanted."*  
-Wife

*"I think initially it was a bit self-conscious to be talking to a stranger, but in the end it was easier."*  
-Daughter

This is confirmed in quantitative analyses with 93 (98.9%) of family members saying their relative or friend felt comfortable talking about themselves with the biographer.

It is proposed that it is the fundamental characteristics of volunteer-based Client Biography (see Figure 2) that creates a 'safe' and comfortable environment in which to tell one's story. This, in turn, leads to a more authentic and honest account of one's life:

*"I found it a very nice experience to talk to someone that I felt brought out the real me in me."*  
-Client

*"I feel that it has allowed myself to come through ... "*  
-Client

The following is an exploration of the key characteristics of volunteer-based biography involved in this dynamic.

### *Time spent – listening & attention*

The unique contribution of biography is ... *"Precious gift of time and attention given by Biographer in a way that paid staff cannot often justify. Paid staff don't have the luxury of this kind of commitment. Biographers often get to know the client better than anyone else – 'the whole person'."*  
-Staff

*"I am most appreciative of the devoted time the volunteer contributed to the project."*  
-Carer

Although listening to a person's life story is time- and labour-intensive, it is a powerful way of showing that they are valued as an individual and affirms the importance of those life experiences.

#### *A supportive presence and non-directed facilitation*

The time spent listening also highlights the added opportunity to be a larger supportive presence at end of life.

I enjoy most ... *"The privilege of being invited into someone's life and sharing it in such an intimate fashion."*  
-Biographer

*"Sharing a very private journey with others."*  
-Biographer

#### *Genuine interest in story and commitment to listening*

To bring together a person interested in hearing stories with a person who has stories to tell is a simple idea and introduces a level of humanity in the caring relationship.

*"It was relaxing and a real enjoyment in telling the story of my life to someone who seemed very interested in listening to me."*  
-Client

*"I felt happy that Mum was being supported and visited by someone who was truly interested and focused on her and the life she's living."*  
-Daughter

#### *Dedicated focus of telling and listening*

The luxury of a dedicated listener giving whole-hearted attention is usually a unique opportunity for many.

The unique contribution of biography is ... *"The process itself – the relationship of the biographer with the client, the dedicated focus ... "*  
-Staff

#### *An exciting, desirable but challenging activity*

Writing a biography is usually seen as an activity reserved for the rich and famous, and for many clients, this represents something exciting, highly desired but otherwise impossible to complete.

*"..... was so excited that there was going to be a book written about him."*  
-Brother

*"My mum's energy changed for the better when she was talking about herself – something she didn't do often."*

*-Daughter*

*"I felt positive that I have done something I always wanted to do."*

*-Client*

*"... without her help I would not have been able to write my own biography."*

*-Client*

*"I had initially started writing my biography... the assistance received from the biographer ensured a much better record..."*

*-Client*

Whatever the nature of the life, people find satisfaction in the telling and even more enjoyment in the sharing of their life in the form of a published book.

### **Enjoying the published biography before death**

If clients have the opportunity to enjoy their published biography before death, then there are many profound benefits for themselves and others.

#### *Life review with document*

Indicative of the high levels of client satisfaction with completed biographies, many re-read them with fascination and may derive even more benefit from this extended opportunity for life review.

*"Nice to have the story ...for my own reference"*

*-Client*

#### *Source of pride and accomplishment*

*"Usually very proud of their 'book' and keen to show it to everyone."*

*-Staff*

*"It made me happy to see my wife accomplishing something that she was always talking about."*

*-Carer*

*"She was very proud of it. As we are."*

*-Husband*

These expressions of pride were commonly found among clients and their families. This may represent both a sense of accomplishment in completing such a difficult task during illness as well as pride in what the biography represents – their life's accomplishments and in some cases, their unique self.

#### *Quality of the final product*

As many clients and families identify so much with the produced biography, it is very

important to safeguard against client and family disappointment at the quality of the published document.

*"It was put together sensitively, professionally, thoughtfully and with great detail."*

-Daughter

*"The biography was beautifully compiled. The photographs matched the story. Just excellent. Thank you."*

-Wife

This further highlights the need for not only specialist training of biographers but professional guidelines in the process of recording, transcription, editing and publication of biographies (EPC, 2009).

The writing up and publishing of one's reminiscence can have a power even greater than the telling (Bolton, 1999) and when (as is usually the case) the published biography is shared with family and friends the benefits can be even more deep, profound and enduring.

### **Deeper understanding leading to the cultivation, strengthening and healing of relationships**

Gaining a deeper insight into the life of the dying or deceased person was an overwhelmingly common theme in the responses from families and friends (Figure 2).

*"I have a better understanding of how Mum felt going through the war years and living overseas away from family..."*

-Daughter

*"I heard things I hadn't heard before, and it helped me to understand my Dad more."*

-Carer

*"We learnt things that Dad had not told us."*

-Daughter

*"I learned from it what was most important to my husband and how he felt about many things not often spoken about."*

-Wife

*"Heard about feelings and emotions not always shared with family."*

-Daughter

Revelations of subjective experience can clarify behaviour during ageing (Butler, 1963) and in fact behaviour, choices and values across the entire lifespan.

*I enjoyed most ... "Reading about my father's experiences as a child and having a better understanding as a result, of where his beliefs and values came from"*

-Son

*"Learning things about Mum that influenced her reactions and behaviour"*

-Daughter

For the family, a biography provides insights into their loved one's life and personality that may enable them to understand past behaviour and to empathise better with the dying person. From this deep level of understanding can come a deeper respect, admiration, appreciation or affection.

*"Contained a lot of things I did not know before, while at the same time marvelling at what was achieved through so much adversity."*

*-Daughter*

Biography means ... *"A link with her and a better understanding of who she was before I met her which in turn makes me appreciate her more."*

*-Husband*

Revelations of the past may free tongues (Butler, 1963) and if the client has the opportunity before death to share their biography with loved ones, communication can be enhanced.

*"It made Dad open up and tell us more of his stories. It allowed us to talk about life more, and to understand things better."*

*-Daughter*

*"We have developed a deeper intimacy through talking about my life and their life."*

*-Client*

*"It gave us more to talk about than just doctor's visits or treatment."*

*-Daughter*

The content of biographies themselves can vary greatly. For most, biographies are commenced with a view to developing a chronological record of life history, key milestones, experiences, interests and achievements. Still for others, it may represent a record of personal advice, philosophies, beliefs, values, ideas, creative expressions or all of the above. And lastly, for many others still, it can be the venue for the expression and lasting affirmation of personal intimacies or affections.

*"My husband's sincerity and love in his biography touched me deeply and I will treasure it forever."*

*-Carer*

### **For those living on**

When the palliative client dies, the published biography often takes on yet another dynamic, representing the deceased's identity as a tangible record of their memories. In a sense, those living on form a unique relationship towards the published biography.

Quantitative analyses found that all clients said they would consider celebrating the published biography by showing family and friends, and many would consider including it in remembrances such as eulogies. For family members, 74 (78%) would consider celebrating the biography by showing other family and friends, 35 (37%)

would consider using it in eulogies and 17 (18%) would consider including the biography in library archives and historical records. These findings suggest that for many, the biographies represent an opportunity to authentically celebrate the person's life:

*"The biographies are valued documents, helping with celebration of life ceremonies."*  
-Staff

*"I felt satisfaction on hearing the main eulogy included many passages from the biography."*  
-Biographer

Biography as a lasting legacy was a very common and major theme among families.

*"I feel I have some memories of my father locked away for eternity. My children will more intimately know their grandfather and thus understand me more."*  
-Son

*"There is something of Mum still here, not just memories, something more tangible and it will last for future generations, her grandchildren who may not remember her clearly as adults."*  
-Carer

*"Having a lasting memory of my mother's life – something I can show to future generations to help explain what an amazing person my Mum is."*  
-Daughter

Family members value the opportunity for their loved one to convey their life story in their own words. Client's commented on the authenticity and honesty of written biographies perhaps reflecting the light editing that occurs within this Biography Service model.

*"Gave my brother a chance to leave something special, that was in 'his own words.'"*  
-Sister

*"It was written in such a way it was easy to imagine him speaking the words."*  
-Carer

*"I am delighted that the biographer captured his thoughts and recorded them verbatim. It is almost as if he is talking to his family again."*  
-Wife

For the bereaved, published biographies are seen as an enduring connection with the deceased. Deeply profound comments were common:

Biography means ... *"We are still together"*  
-Husband

Biography means ... *"Keeping in touch with my husband."*

*"I have a permanent link with Dad. To reflect and feel close to him – to laugh and cry."*  
-Daughter

*"Something to pick up and read and feel a connection through the memories."*  
-Son

*"To have the biography now Tom is gone, I can read it and know he is still here in spirit."  
-Wife of 58 years' marriage*

Biography can safeguard against the loss of precious memories to keep the memory of the deceased alive:

*"I have my father's thoughts and feelings forever written on paper. When I feel like I can't remember him, I can revisit the biography to trigger memories"  
-Son*

*"Something I can keep as memories fade ... "  
-Husband*

*"My memory can be not so great in regard to the stories I heard. Now I have them in print.  
THANK GOODNESS."  
-Daughter*

To this end, published biographies can represent a source of great comfort during times of immense loss, grief and bereavement:

*"I wasn't up to reading it for a few months, but when I did it certainly helped with the grieving process."  
-Sister*

*"At a time when families are incapable of functioning normally, the structured external facilitation helped provide us with a written legacy which helps the grieving process."  
- Son*

*"Sense of personal loss diminished with re-reading as you refresh the memories."  
-Husband*

*"It helps me to still hear my friend's voice."  
-Close friend*

Biography ... *"helped with closure."*

It is apparent that biography can mean many things to people and the published biography becomes a highly valued and treasured item for families and friends.

*"This was an amazing gift for the family ... "  
-Carer*

*"An excellent biography, something that we will always treasure."  
-Son*

*"It is MINE to treasure."  
-Daughter*

Published biographies have the potential to evoke, inspire reflection and growth in the reader, enhancing values and identity:

*"The biography helps me reflect and remember our family and love."  
-Wife*

*"Has started me thinking about my values and beliefs and how important loved ones are."  
-Daughter*

*"I feel more connected to my culture and background. I take more pride in the way I am and why I am. I have become more involved in my father's church."  
-Son*

As active listeners of the dying person's story, volunteer biographers themselves identify an immense wealth of rewards and personal insight:

*"Sharing extraordinary stories, intimacies, sadness, pride, laughter of people's journeys. It is fascinating and such a privilege."*

*"Makes you realise your own humanity."*

*"I am uplifted by the hope and joy still in their lives right up to their death."*

*"It has enriched me in every way."*

"Rippling" has been described as the circles of influence that each individual creates that will be passed on to enlarge the life of others, often without conscious intent or knowledge (Yalom, 2008). These profound insights from biographers may in some way owe to the intimate observation of this effect and the underlying human connections that exist and persist beyond death.

The personal sense and meaning of the life cycle are more clearly unfolded by those who have nearly completed it (Butler, 1963) and those facing end of life offer a unique and arguably the most valuable perspective on what is truly important and precious in this life.

*"I find myself reflecting on the preciousness of experience and relationships. Maybe I'm tending less to 'do' and more to 'be'.  
-Biographer*

Stories are reflexive in nature, told in the present about the past but represent our hopes for the future (Moody, 1984). For those facing end of life their hopes for the future can often be carried forward as a legacy for those who live on, and biography can be a means for this to occur.

## DISCUSSION

Satisfaction with the Client Biography service was overwhelmingly high and this was found for both quantitative ratings from clients and families as well as observations of highly favourable comments from professional palliative care staff. The immense degree of delight, pleasure, excitement and overall satisfaction was illustrated in the overwhelming number of expressions of heartfelt gratitude and thanks from clients and their families and friends.

The main reason to start biography was seen to be practical – to create a life story and historical record. However, common themes indicate that clients and

families derive much more from the process of biography as well as the publication produced.

As this model of biography contains many aspects of life review, many of the benefits gained are common to this approach. Namely, this includes personal reflection on one's whole life, a focus on lived experiences instead of loss, reliving happy memories, confrontation of difficult experiences, reintegration of different aspects of self and the enhancement or (re)discovery of personal meaning.

Quantitative findings from professional palliative care staff confirmed that biography makes a unique contribution to the quality of life of palliative clients. This model of volunteer facilitated biography, as seen in Figure 2, contains several innovations built into the service framework. Qualitative findings highlighted these unique characteristics including:

#### *Time spent listening*

The greatest gift is given when one's life is heard and valued and listened to attentively – the acknowledgment of one's essential self and the freedom to continue to be oneself (Heliker, 1999). Listening to stories assigns value to memories (Hirst, 1997) and it imparts respect and sincerity, affirming that the person's life is of value (Lichter, 1993). Effective listening is the key; however, a significant amount of time must be invested (Hirst, 2001) if this is to be done well.

In a recent service evaluation of Client Biography (F. Icasiano, unpublished report, 2009) it was found that biographers spent an average of 30 hours working on a biography with one biography taking 150 hours to complete. Further, the number of sessions ranged to as high as 13 sessions with some published biographies being in excess of 20,000 words in length. It is proposed that the timeframe allowed within this model of Client Biography adequately respects the breadth and depth of uniquely personal and rich stories that make up one's life.

#### *A supportive presence and non-directed facilitation*

The time spent listening also highlights the added opportunity to be a larger supportive presence at end of life. The role of the palliative care volunteer has been described as less like an emotional attachment but more like accompanying another on a journey where the end is inevitable (Giurgis-Younger, 2008). Sometimes, simply being present can make a critical therapeutic difference (Byock, 1996) and the importance of simply providing a supportive presence at end of life cannot be discounted (Rousseau, 2003).

#### *Genuine interest in story and commitment to listening*

To bring together a person interested in hearing stories with a person who has stories to tell is a simple idea, yet has the great potential to draw out the client and develop a relationship based on mutual interest and equality. When one remains open to shared meanings in experiences, new possibilities of care emerge and the humanity of both is affirmed (Heliker, 2007).

### *An exciting, desirable but challenging activity*

The luxury of a dedicated and attentive listener is usually a unique opportunity for many of us. Further, the prospect of producing something usually reserved for the rich and famous represents something exciting, highly desired but otherwise impossible to complete.

These unique characteristics inherent in this volunteer-based model of biography address the limitations of life story work such as the time needed to engage in this type of work, the professional-patient power difference and ethical considerations. As it is facilitated by volunteers selected from the community, it ensures that the nature of the caring relationship occurs at a more human and equal level. Without imposing a language framework that may be incongruous to the person's own worldview (e.g. professional or religious discourse), the person's lived experience is affirmed and valued. Strengths can be promoted and a sense of normality maintained in the natural process of dying. While the process may have inherent therapeutic or spiritual benefits, it has broader applicability appealing to those who may not be comfortable entering a strictly therapeutic or pastoral relationship (eg. counselling or speaking to a spiritual leader such as a priest).

Qualitative findings suggest that the unique characteristics of this model have the potential to: (1) lead to a greater comfort in the dying person's telling of their story, (2) greatly amplify the benefits associated with life review and, (3) lead to an account of the person's life that is more authentic and honest.

Once published, the biography can represent a powerful personal resource at the end of life and beyond. If time permits for the dying client, they are able to enjoy the benefits of life review through re-reading the publication. It becomes a potent source of pride and is usually enthusiastically shared among family and friends, enhancing communication within families.

The most commonly identified theme from family members was biography's opportunity for them to gain a deeper insight and understanding into the life of their loved one. Stories themselves are essentially communicative. Story is the way we come to understand fully another's lived experience (Picard, 1991; Clarke, 2000) and elicit both common and personal meanings and allow new understandings among family and strangers alike (Heliker, 1999). There does seem to exist a deep human urgency to share stories with others, so that we may understand and be understood within our own context as well as the context of the group with whom we live everyday (Heliker, 1999).

For the family, a biography provides insights into their loved one's life and personality that may enable them to understand past behaviour and to empathise better with the dying. By using the storytelling process, hidden themes of great vintage may emerge and the listener can learn how an individual relates to the world, potentially changing the quality of even a lifelong relationship (Butler, 1963; Charmaz, 1999) and bonding can occur. Highly treasured before and after their loved one's death, the biography can impart a deeper respect or admiration for their loved one, with great potential to strengthen, cultivate and heal relationships.

For many, the biography is not only a historical life story but can be the venue for the expression and lasting affirmation of personal intimacies or affections.

Byock (1996) describes five key messages needed to be conveyed in order to feel complete in any close personal relationship: forgive me, I forgive you, thank you, I love you and goodbye. Client Biography can be the venue to help facilitate the communication of these, often leading to a sense of completion and a sense that there is nothing left unsaid.

For those living on, published biographies are used in life celebrations and families and friends value it as a tangible legacy. Through storytelling, knowledge is passed from one generation to another, and the physical record emphasizes the worth and value that others place upon the person - something that will endure and can be handed on.

Findings suggest that, biography can be a source of great comfort during grief and bereavement and represent a profoundly powerful and enduring connection to the deceased. Walter (1996) views the purpose of grief as to construct a durable biography that enables the living to integrate the memory of the deceased into their own ongoing lives. Indeed, it may be an inherent need in the natural bereavement process to construct a story that places the deceased in their lives – an enduring story (Walter, 1996). In this way, biography can safeguard against the loss of precious memories to keep the memory of the deceased alive.

Families can see both what they have lost and what they have found in the form of a recovered legacy - which may have been obscured by the disease-saturated narratives to which they have been accustomed (Caron, 1999). For families, discussing the biography after the patient's death, and sharing the story and talking about the person who has died may be a healing experience (Lichter et al., 1993).

Stories are evocative (Clarke, 2003), can affirm bonds and have the potential to transform both the storyteller and the listener or reader (Charmaz, 1999). Qualitative findings identify the great potential for biographies to inspire personal growth in the reader including family members and biographers alike.

## **Dying peacefully**

Over the course of the present study, it became clear that Client Biography has great potential to assist in the process of dying well or peacefully. Weisman (1972) considers four criteria for an 'appropriate death', but the same can be applied to notions of a 'peaceful death'. These are: (1) meaningful but limited goals should be set, (2) internal conflicts (e.g. fear) should be reduced, (3) sense of identity should be sustained, and (4) critical relationships should be enhanced. These are explored below with quotes relating to Client Biography.

### *Meaningful but limited goals*

*"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

For people who can no longer contribute to their families in accustomed ways, the effort to preserve and transmit their stories can provide a sense of tangible meaning (Byock, 1996). The biography process itself is oriented to achieving a meaningful

outcome and can create a sense of meaningful purpose right up to the end. Anecdotal evidence attests to a common sense of urgency in completing the finished story with some clients prioritising the biography over treatment.

### *Internal conflicts 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*

Dying well can be understood in terms of the subjective experience of personal growth and the sense of growing in the midst of dying (Byock, 1996). The biography process can help to reframe the dying experience in these terms and act as the venue to resolve or reconcile difficult experiences or emotions, arriving at a personal acceptance and healing - the ability to integrate the illness and gain positive insights about life and death.

### *Sustaining identity*

Biography is a personal and in most cases a public affirmation of one's identity when sense of self is threatened or disintegrated. For those where treatment, pain, illness and loss come to dominate one's sense of self, biography can help normalise the dying process and reconnect them with aspects of themselves that have given them meaning.

*"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*

Healing has been described as a sense of wellbeing derived from an intensified awareness of wholeness and integration among all dimensions of one's being (Coward and Reed, 1996). Cassell's (1982) typology of personhood lists features of the human condition that are universal. These are that: persons exist in time (with a past, present and future), are inherently social beings, experience self through their culture, relationships contribute to personhood, persons have beliefs and values, persons identify with actions in the past and future hopes, and persons have a transcendent dimension. This study suggests that Client Biography can be the venue to help attain a sense of coherence and continuity across all aspects of one's personhood.

### *Enhancing critical relationships*

Client Biography affirms the inherent social identity of individuals and can assist them to achieve a sense of connectedness to self, family and friends.

*"It helps me 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*

It has been asserted that maintaining an intimate connection with life through family, friends, leisure, home and work is just as important to individuals as transcendent meaning-making (McGrath, 2003). Dying is a social and therefore interpersonal process (Rumbold, 2002) and Client Biography can help attain a sense of affirmation and completion within the social and interpersonal domains.

### **Connections with community**

The current exploratory study has only touched the surface of biography's potential value for the communities that make up society as a whole.

"A 'good death' takes place within a community where people are known and cherished and valued for who they are" (Rumbold, 1986), but in turn, the broader community can in fact benefit from a good death through the creation of a tangible legacy as in Client Biography.

Firstly, stories are often representative of the experience of a particular community group based on common experience (e.g. migration), common gender, spiritual, or cultural background, and may offer insight into this experience (shared by the reader or otherwise) and what it means to belong to this group. Client Biography can represent a quality of generational story-telling that is perhaps no longer prevalent in modern culture and may support the human need to belong to a storied community.

Secondly, stories of those facing death can complement the existing rituals around the public celebration of life (e.g. eulogies, tributes and remembrances). In this way, the dying person's social identity and connectedness can be promoted, strengthening families and communities alike.

Coward and Reed (1996) describe self-transcendence as reaching a state where one reaches out beyond personal concerns (e.g. illness, loss of independence) to use what they have learnt to help others by being a role model and inspiration on how to live while dying. End of life can be a time of withdrawal (Clarke, 2000) and profound loneliness (Yalom, 2008) and Client Biography can help draw the dying person beyond their usual self into active engagement with others and the community. In Client Biography, not only does the dying person become a role model of how to live while dying, but they can also be a role model on how to live.

To learn how to 'die well' may be the key to learning how to live a full and enriched life. It is when we are pushed to the edge of life that we see life most clearly (Kubler-Ross & Kessler, 2000) and life stories of those facing death can represent a valuable insight into what is truly important and precious.

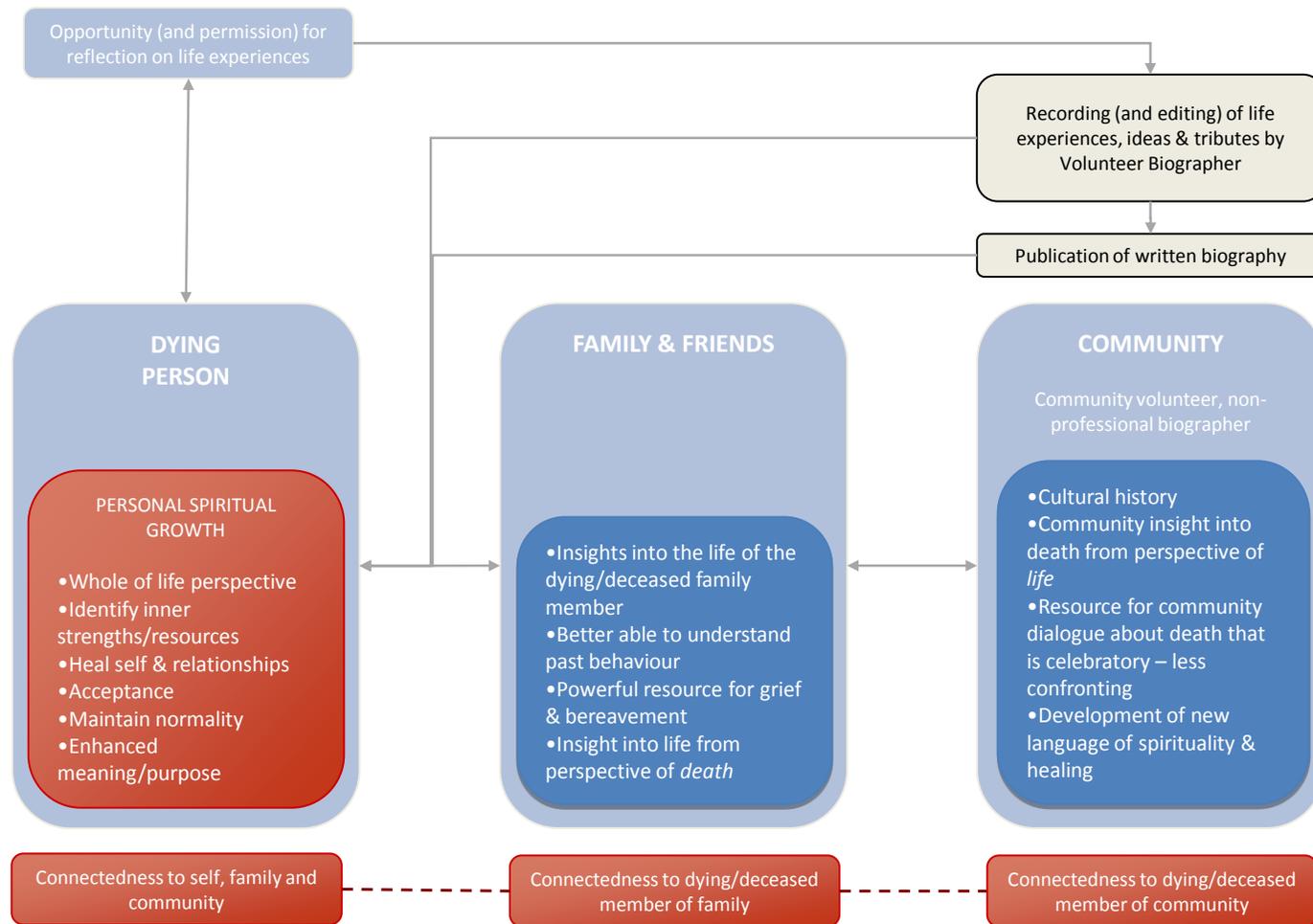
With the emphasis returned to celebrating the life lived, death is restored to its proper context – as secondary to, or the natural conclusion to the life celebrated. In this way, published biographies can help capture the imagination of the broader community and engaging others in a non-threatening dialogue about palliative care and end of life issues.

### **The educative role of biography and future research**

Storytelling has an educative function (Heiney, 1995). Every life *is* extraordinary and in the recording of dying persons' stories from their perspective lies unique

opportunities to study:

- Important cultural histories otherwise lost
- The final stage of the developmental lifecycle
- The opportunities for personal growth at end of life
- The enduring effects on bereavement and family identity long after the family member has died
- The powerful benefits for volunteer biographers themselves
- The potential for published biographies themselves to develop a language or concepts for spirituality and healing
- The applicability of this volunteer service model to other populations (e.g. aged care, dementia and indigenous populations)



**Fig 4.** Conceptual foundation for Client Biography – intra-personal, inter-personal and corporate relationships

## **CONCLUSIONS**

This present exploratory study indicates that this sustainable volunteer-based model of Client Biography Service can make a unique and valuable contribution to palliative clients and families' experience of end of life. It enriches what is currently available in family, psychosocial and spiritual support and can be a profoundly valuable person-centred complement to the suite of holistic palliative care services. The service can represent a powerful educative resource for communities and a wealth of research avenues have been identified.

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## APPENDICES

**Table A1.** Response rates for survey versions and respondent groups

	Version 3: January 2009			Version 1 & 2: June 2006 - December 2008		
		n	N		n	N
Clients	36%	10	(28)	48%	58	(122)
Family members and carers	42%	95	(225)			
Volunteer biographers	77%	27	(35)			
EPC Staff	57%	41	(71)			

**Table A2.** Demographics of clients, family members and biographers for version 3 surveys

	Clients (N= 10)		Family members and carers (N = 95)		Biographers (N = 35)		
		n	n	n	n	n	
Gender							
	Male	5	50%	24	25.3%	3	8.6%
	Female	4	40%	62	65.3%	22	62.9%
	Unknown	1	10%	9	9.4%	10	28.6%
Average age (range)		75 years		59 years		64 years	
Age range		65-88 years		24-90 years		46-79 years	
Partner or spouse							
	Yes	7	70%			22	62.9%
	No	2	20%			2	5.7%
	Unknown	1	10%			11	31.4%
Had children							
	Yes	8	80%	72	75.8%	21	60.0%
	No	1	10%	2	2.1%	4	11.4%
	Unknown	1	10%	21	22.1%	10	28.6%
Religious or spiritual affiliation							
	Yes	5	50%	35	36.8%	16	45.7%
	No	4	40%	26	27.4%	6	17.1%
	Unknown	1	10%	34	35.8%	13	37.1%
Cultural background							
	Australian	6	60%	56	58.9%	16	45.7%
	Other	1	10%	12	12.6%	4	11.4%
	Unknown	3	30%	27	28.4%	15	42.9%

**Table 3A. Carer's relationship to the palliative or deceased client**

Relationship to the client	TOTAL	%	Male	% within	Female	% within
Partner	43	51%	14	33%	29	67%
Child	34	40%	9	27%	25	73%
Sibling	5	6%	1	20%	4	80%
Other^	3	3%	0	0%	3	100%

^Includes mother, ex-wife, close friend

**Table 4A. Professional palliative care staff characteristics**

		EPC Staff (N = 41)	
		n	
Multidisciplinary role			
	Nurses	14	34.0%
	Family Support Workers	12	29.0%
	Complementary Therapists	7	17.0%
	Clinical Nurse Consultants	4	10.0%
	Family Support Consultants	3	7.0%
	Palliative Physician	1	2.0%
Employment Status			
	Permanent	37	90.2%
	Casual	4	4.4%
Discipline			
	Nursing or palliative medicine	19	46.3%
	Social Work	7	17.1%
	Pastoral Care	5	12.2%
	Massage Therapy	3	7.3%
	Music Therapy	3	7.3%
	Psychology	3	7.3%
	Art Therapy	1	2.4%