

**EXPLORING COMMUNITY VOLUNTEERS' USE OF THE
MEMORY BOX MAKING TECHNIQUE TO SUPPORT
COPING WITH HIV AND AIDS.**

by

Ancois Swanepoel

Submitted in partial fulfilment of the requirements for the degree

**MAGISTER EDUCATIONIS
(EDUCATIONAL PSYCHOLOGY)**

in the

Department of Educational Psychology
Faculty of Education
University of Pretoria

SUPERVISOR:

Doctor Liesel Ebersöhn

CO-SUPERVISOR:

Professor Irma Eloff

PRETORIA

DEDICATION

**I DEDICATED MY WORK TO MY BELOVED BROTHER
WHO LOST HIS LIFE DUE TO A TERMINAL ILLNESS,
LEUKAEMIA:**

“We love you Jacques, thank you for leaving us with such precious memories of you. You will forever remain part of our hearts”

DECLARATIONS

I, Ancois Swanepoel (99044910), hereby declare that all the resources that were consulted are included in the reference list and that this study is my original work.

.....

A Swanepoel

October 2005



I, Rika Opper, hereby declare that I undertook the editing of the grammatical and language aspects of this dissertation.

.....

R Opper

Tel: (042) 298 0330

October 2005

ACKNOWLEDGEMENTS

I would like to express my grandest appreciation and thanks to the following individuals for their contributions:

Academici and related:

Educational Training and Development Sector Education Training Authority
(ETDP SETA) for funding and financial assistance

Doctor Liesel Ebersöhn (Supervisor)

Professor Irma Eloff (Co-Supervisor)

Rika Opper (Language Editing)

Mr Benedict Sedibe (Organiser in Acornhoek)

Other:

Our Lord Jesus Christ

Björn Opper (Partner)

Koos and Elize Swanepoel (Parents)

Family, friends and colleagues

Their support and encouragement guided me through the tough times, and remains an unforgettable memory

SUMMARY

EXPLORING COMMUNITY VOLUNTEERS' USE OF THE MEMORY BOX MAKING TECHNIQUE TO SUPPORT COPING WITH HIV AND AIDS

By
Ancois Swanepoel

Supervisor : Doctor Liesel Ebersöhn
Co-Supervisor: Professor Irma Eloff
Institution : University of Pretoria, Department of Educational Psychology
Degree : M.Ed (Educational Psychology)

The HIV and AIDS pandemic have already impacted considerably on the South African society. Volunteers play a pivotal role in mitigating the impact of HIV and AIDS in three spheres, namely prevention, care and support. The aim of the study was to explore community volunteers' use of the Memory Box Making technique to support coping with HIV and AIDS. Research was done by using an interpretive paradigm through means of qualitative research. Data was primarily collected through interviews with the community volunteers who acted as participants in the study. Findings of the study suggest that volunteers were able to acquire, apply and adapt the Memory Box Making technique in both their personal and professional lives.

KEYWORDS

- Community volunteers
- Memory Box Making technique
- Memory box
- HIV and AIDS
- Coping with HIV and AIDS
- Support in HIV and AIDS
- Grief/bereavement
- Explore
- Describe
- Application/apply

TABLE OF CONTENTS

	Page
CHAPTER 1	
Overview and Rationale	
1.1 INTRODUCTION	1
1.2 RATIONALE	1
1.3 THE PURPOSE OF THE STUDY	3
1.4 PARADIGMATIC PERSPECTIVE	4
1.5 RESEARCH DESIGN AND DATA COLLECTION METHODS	4
1.6 ETHICAL STRATEGIES	6
1.7 QUALITY CRITERIA	6
1.8 CONCEPTUAL FRAMEWORK	6
1.9 CLARIFICATION OF CONCEPTS	9
1.10 OUTLINE OF CHAPTERS	11
1.11 CONCLUSION	12

CHAPTER 2

Literature Review

2.1	INTRODUCTION	13
2.2	DEATH, BEREAVEMENT AND COPING IN THE CONTEXT OF HIV AND AIDS	13
2.2.1	THE EXTENT OF THE AIDS EPIDEMIC	13
2.2.2	CHALLENGES FACED BY INDIVIDUALS LIVING WITH HIV AND AIDS	15
2.2.3	COPING WITH HIV AND AIDS	16
2.2.4	AIDS-RELATED GRIEF AND COPING WITH LOSS	18
2.3	THE MEMORY BOX-MAKING TECHNIQUE	21
2.3.1	WHAT IS MEMORY BOX MAKING?	21
2.3.2	USING THE MEMORY BOX-MAKING TECHNIQUE AS A TOOL FOR DEALING WITH BEREAVEMENT	23
2.3.3	USING THE MEMORY BOX-MAKING TECHNIQUE AS A FORM OF FUNCTIONAL SUPPORT	24
	2.3.3.1 Exclusive items	24
	2.3.3.2 Important documents	25
	2.3.3.3 Personal Information	26
2.4	COMMUNITY VOLUNTEERS	26
2.4.1	DEFINITION OF THE TERM <i>COMMUNITY VOLUNTEERS</i>	26
2.4.2	COMMUNITY LEVEL HOME-BASED CARE	27
2.4.3	PROVISION OF SUPPORT BY COMMUNITY VOLUNTEERS	29
2.5	CONCLUSION	32

CHAPTER 3

Research Design

3.1	INTRODUCTION	33
3.2	BACKGROUND TO THE PROJECT	33
3.3	PARADIGMATIC PERSPECTIVE	34
3.4	RESEARCH DESIGN	36
3.4.1	DESIGN	37
3.4.2	METHODOLOGY	39
	3.4.2.1 Selection of case	39
	3.4.2.2 Selection of participants	40
	3.4.2.3 Data gathering	43
3.5	DATA ANALYSIS	52
3.6	ETHICAL CONSIDERATIONS	54
3.6.1	INFORMED CONSENT	54
3.6.2	PRIVACY	55
3.6.3	ETHICAL STATEMENT	55
3.7	VALIDATION OF RESEARCH	55
3.7.1	Trustworthiness	55
	3.7.1.1 Credibility	55
	3.7.1.2 Transferability	56
	3.7.1.3 Dependability	56
	3.7.1.4 Confirmability	56
3.8	CONCLUSION	56

CHAPTER 4

Results and Literature Control

SECTION A – Results	58
4.1 INTRODUCTION	58
4.2 CONTEXT AND PROCESS	58
4.2.1 CONTEXT WHERE UNDERSTANDING EMERGED	58
4.2.2 GETTING STARTED	60
4.2.3 THE TWO-DAY WORKSHOP	60
4.2.4 THE RETURN VISIT	62
4.2.5 DATA ANALYSIS PHASE	62
4.3 RESULTING THEMES	63
4.3.1 THEME 1: JOB-RELATED APPLICATION OF THE MEMORY BOX-MAKING TECHNIQUE BY VOLUNTEERS	65
4.3.2 THEME 2: THE IMPACT OF THE MEMORY BOX MAKING PROCESS ON THE PERSONAL LIVES OF THE VOLUNTEERS	69
4.3.3 THEME 3: BARRIERS IN USING THE MEMORY BOX	71
4.3.4 THEME 4: ADVANTAGES OF USING A MEMORY BOX	73
4.4 CONCLUSION	78

4.6.4.2	<i>Sub-theme 4.2: 'Commemorate the past'</i>	88
4.6.4.3	<i>Sub-theme 4.3: 'That thing [the memory box] it can help the orphans to know their future'</i>	89
4.6.4.4	<i>Sub-theme 4.4: Experience of application</i>	90

4.7 CONCLUSION

94

CHAPTER 5

Conclusions, limitations and recommendations

5.1	INTRODUCTION	95
5.2	OVERVIEW OF CHAPTERS	95
5.3	PURPOSE AND RESEARCH QUESTIONS	96
5.4	FINDINGS	97
5.5	LIMITATIONS OF THE STUDY	100
5.5.1	LIMITED SCALE OF PARTICIPANTS	100
5.5.2	LIMITED GENERALIZABILITY	100
5.5.3	OBSERVER/RESEARCHER BIAS	101

5.6	RECOMMENDATIONS	101
5.6.1	RECOMMENDATIONS FOR PRACTICE	101
5.6.2	RECOMMENDATIONS FOR TRAINING	102
5.6.3	RECOMMENDATIONS FOR FUTURE RESEARCH	102
5.7	QUALITY CRITERIA	103
5.7.1	CREDIBILITY	103
5.7.2	TRANSFERABILITY	103
5.7.3	DEPENDABILITY	104
5.7.4	CONFIRMABILITY	104
5.8	CONCLUSION	104
	LIST OF REFERENCES	105
	APPENDIX A	114
	APPENDIX B	115
	APPENDIX C	116
	APPENDIX D	117
	APPENDIX E	118
	APPENDIX F	119
	APPENDIX G	120
	APPENDIX H	121
	APPENDIX I	122
	APPENDIX J	123

LIST OF TABLES

		Page
Table 1.1	Secondary research questions and methods used for data collection	3
Table 1.2	Research design and data collection methods	5
Table 1.3	Literature to be discussed in Chapter 2	8
Table 3.1	Particulars of participants involved in the study	41
Table 3.2	Methods of data collection and data capturing used during the research process	44

LIST OF FIGURES

	Page
Figure 1.1 Using an audio-visual method of data collection	4
Figure 2.1 The Integrated Community-based Home Care Model (ICHC)	30
Figure 4.1 Main- and sub-themes uncovered during data analysis process	64
Figure 4.2 An example of a memory box as made by a volunteer	67
Figure 4.3 A lifeline drawn by a volunteer	70

LIST OF REFERENCES

Akukwe, C. (2003). HIV/AIDS in Africa: Politics, Policies, Programs and Logistics. *The Perspective*. Retrieved from the World Wide Web on 26 June 2004 from: http://www.theperspective.org/december2003/hiv_aidinafrica.htm

Amundson, N.E. (1998) *Active Engagement: enhancing the career counselling process*. Richmond: Ergon Communications. In Chen, C. P. (2001). Career Counselling as Life Career Integration. *Journal of Vocational Education and Training*, **53**(4), 523-542.

Avert.org. (2005). *HIV and AIDS statistics for South Africa*. Retrieved from the World Wide Web on 16 June 2004 from: <http://www.avert.org/safricastats.htm>

Babbie, E. & Mouton, J. (2001). *The practice of social research (2nd ed)*. Oxford: Oxford University Press.

Becvar, D. S. & Becvar, R. J. (1996). *Family Therapy: A Systemic Integration (3rd Ed)*. Boston: Allyn & Bacon.

Berg, B. L. (2001). *Qualitative Research Methods For The Social Sciences*. Needham Heights: Allyn & Bacon.

Bergen, A. & While, A. (2000). A Case for Case Studies: Exploring the use of Case Study Design in community nursing research. *Journal of Advanced Nursing*, **31**(4), ¶1-14. Retrieved from the World Wide Web on 25 February 2005 from: <http://0-web17.epnet.com.innopac.up.ac.za/citation.asp?>

Beverly, J.A., Wells, L.M., Goldie, R.S., DeMatteo, D. & King, S.M. (2001). Challenges of Parenting for Families Living with HIV/AIDS. *Social Work*, **46**(2): 159-169.

Bless, C. & Higson-Smith, C. (1995). *Fundamentals of Social Research Methods: An African Perspective (2nd ed)*. Kenwyn: Juta & Co, Ltd.

Bottorff, J. L. (1994). Using videotaped recordings in qualitative research. In Morese, J. M. (Ed.), *Critical issues in qualitative research methods*. Thousand Oaks: Sage. In De Vos, (1998). *Research at Grass Roots: A primer for the caring professions*. Pretoria: Van Schaik Publishers.

Christensen, L.A., Reininger, B.M., Richter, D.L., McKeown, R.E. & Jones, A Wright, M.T. (1996). Defining the elements of a successful volunteer program in the provision of AIDS services. *Journal of Volunteer Administration*, **14**(4): 9-19.

Cohen, L., Manion, L. & Morrison, K. (2000). *Research Methods in Education (5th ed)*. London: Routledge Falmer.

Coovadia, H. M. (2000). Access to voluntary counselling and testing for HIV in developing countries. *Annals of New York Academy of Science*, **918**: 57-63.

Creswell, J. W. (2003). *Research Design: Qualitative, Quantitative and Mixed Methods Approaches (2nd Ed.)*. California: Sage Publications.

Denis, P. (2000). Memory boxes: helping AIDS orphans to remember. *Bulletin for Contextual Theology in Africa*, **7**(1):34-36.

Denis, P., Mafu, S. & Makiwane, M. (2003). *Memory Boxes & the Psycho-social needs of children: Trainer's Manual*. Sinomlando Project. Retrieved from the World Wide Web on 16 June 2005 from:

<http://www.hs.unp.ac.za/theology/sinomlando/memory%20boxes.htm>

Denzin, N. K. & Lincoln, Y. (1998). *The Landscape of Qualitative Research: Theories and Issues*. London: Sage Publications.

Denzin, N. K. & Lincoln, Y. (Eds). (1994). *Handbook of qualitative research*. Thousand Oaks: Sage. In De Vos, (1998). *Research at Grass Roots: A primer for the caring professions*. Pretoria: Van Schaik Publishers.

Department of Health. (2000). *The Primary Health Care Package for South Africa: a set of norms and standards (Part 2a – Community Level Home-Based Care)*. Retrieved from the World Wide Web on 31 May 2005 from: <http://www.doh.gov.za/index.html>

Department of Health. (2005). *National Guideline on Home-Based Care (HC) / Community Based Care (CC)*. Retrieved from the World Wide Web on 31 May 2005 from: <http://www.doh.gov.za/index.html>

De Vos, (1998). *Research at Grass Roots: A primer for the caring professions*. Pretoria: Van Schaik Publishers.

Donald, D., Lazarus, S. & Lolwana, P. (2002). *Educational Psychology in Social Context*. Oxford: Oxford University Press.

Exline, J. J., Dorrity, K. & Wortman, C. B. (1996). Coping with Bereavement: A Research Review for Clinicians. *Psychotherapy in Practice*, 2(4): 3-21.

Ferguson, D. L. (1993). Something A Little Out Of The Ordinary: Reflections On Becoming An Interpretivist Researcher In Special Education. *Remedial and Special Education*, 14(4): ¶1-13.

Garrick, J. (1999). Doubting the Philosophical Assumptions of Interpretive Research. *International Journal of Qualitative Studies in Education*, 12(2): ¶1-11.

Huberman, A. M. & Miles, M. B. (2002). *The Qualitative Researcher's Companion*. California: Sage Publications, Inc.

Inger, J. (2002). *Memories of the past provide hope for the future*. International Federation of Red Cross and Red Crescent Societies. Retrieved from the World Wide Web on 16 June 2005 from: <http://www.ifrc.org/docs/news/02/02112001/>

Jansen, J. (2004). An Introduction to Education Theory. In Eloff, I. & Ebersöhn, L. (2004). *Keys to Educational Psychology*. Cape Town: UCT Press.

Kelly, M. J. (2000). *Planning for education in the context of HIV/AIDS*. United Nations: Educational, Scientific and Cultural Organization.

Kmita, G., Baranska, M. & Niemiec, T. (2002). Psychosocial intervention in the process of empowering families with children living with HIV/AIDS – a descriptive study. *AIDS CARE*, **14**(2): 279-284.

Kübler-Ross, E. (1989). *On Death and Dying*. London: Tavistock-Routledge.

Kübler-Ross, E. (1987). *AIDS: The ultimate challenge*. New York: Macmillan Publishing Company.

Laurie, A. G. (2004). *The Framework for the Protection, Care and Support of Orphans and Vulnerable Children Living in a World with HIV and AIDS*. UNAIDS & UNICEF.

Lindsey, E., Hirschfield, M., Tlou, S. & Ncube, E. (2003). Home-Based Care in Botswana: Experiences of Older Women and Young Girls. *Health Care for Women International*, **24**: 486-501.

Lofland, J. (1971). *Analysing Social Settings*. Belmont, CA: Wadsworth. In Patton, M. Q. (2002). *Qualitative Research & Evaluation Methods (3rd ed)*. London: Sage Publications.

Louw, D. A., van Ede, D. M. & Louw, A. E. (1998). *Menslike ontwikkeling (3e uitgawe)*. Pretoria: Kagiso Uitgewers.

Mail & Guardian. (2004). *Cultivating a lifestyle to cope with AIDS*. Kwazulu-Natal, May 28 – June 3, 2004.

McCausland, J. & Pakenham, K. I. (2003). Investigation of the Benefits of HIV/AIDS Caregiving and Relations Among Caregiving Adjustment, Benefit Finding, and Stress and Coping Variables. *AIDS CARE*, **15**(6): 853-869.

Morgan, J. (2004). *The Memory-Box Manual*. Retrieved from the World Wide Web on 17 June 2005 from:

<http://web.uct.ac.za/depts/cgc/Johathan/Life%20Story%20Manual.html>

Morgan, J. (2002). *Memory Boxes and Memory Books: Centering the Child. Memory work involving orphans and vulnerable children – some guidelines*. Cape Town: AIDS and Society Research Unit.

Morgan, J. (2004). Memory work: Preparation for death? Legacies for orphans? Fighting for life? One size fits all, or time for product differentiation. *AIDS bulletin, June 2004*. Retrieved from the World Wide Web on 7 July 2005 from:

<http://web.uct.ac.za/depts/cgc/Jonathan/Aids%20Bulletin.htm>

Mouton, J. (2001). *How To Succeed In Your Masters And Doctoral Studies. A South African Guide And Resource Book*. Pretoria: Van Schaik Publishers.

Morgan, J. (2001). Boxes and remembering in the time of Aids. *AIDS Bulletin*, **10**(2):17-20.

Oaklander, V. (1988). *Windows to Our Children: A Gestalt Therapy Approach to Children and Adolescents*. New York: The Gestalt Journal Press.

Olshansky, S (1962). Chronic Sorrow: A response to having a mentally defective child. *Social Casework*, **43**, 190-193. In Beverly, J.A., Wells, L.M., Goldie, R.S., DeMatteo, D. & King, S.M. (2001). Challenges of Parenting for Families Living with HIV/AIDS. *Social Work*, **46**(2): 159-169.

Owens, S. (2003). African American Women Living with HIV/AIDS: Families as Sources of Support and of Stress. *Social Work*, **48**(2): ¶1-10.

Pakenham, K.I. (2001). Adjustment to Multiple Sclerosis Caregiving: Application of a Stress and Coping Model to Caregiving in Multiple Sclerosis. *Psychology, Health and Medicine*, **6**, 13-27.

Parker, W., Dalrymple, L., Durden, E. (2000). *Communication beyond AIDS awareness: A manual for South Africa*. Auckland Park: Department of Health, South Africa.

Patton, M. Q. (2002). *Qualitative Research & Evaluation Methods (3rd ed)*. London: Sage Publications.

Pitney, W. A. (2004). Strategies for Establishing Trustworthiness in Qualitative Research. *Research Digest*, **9**(1): 26-28.

Richter, L., Manegold, J. & Pather, R. (2004). *Family and Community Interventions for Children affected by AIDS*. Cape Town: HSRC Publishers.

PlusNews Weekly. (2004). *AFRICA: Memory boxes to help say goodbye*. CAPE TOWN, 27 October.

Rosa, S. & Lehnert, W. (2003). Children without adult caregivers and access to social assistance (Workshop Report). *University of Cape Town, Childrens Institute*.

Rubin, H. J. & Rubin, R. S. (1995). *Qualitative Interviewing: The art of hearing data*. Thousand Oaks: Sage. In Babbie, E. & Mouton, J. (2001). *The practice of social research (2nd ed)*. Oxford: Oxford University Press.

Semple, S., Paris, M. & Howieson, C. (2002). *A Longitudinal Study of Young People in Ayrshire*. Universities of Strathclyde & Edinburgh: Ayrshire Careers Partners Ltd.

Sikkema K. J., Kochman, A., DiFranceisco, W., Kelly, J. A., & Hoffmann, R. G. (2003). AIDS-Related Grief and Coping With Loss Among HIV-Positive Men and Women. *Journal of Behavioral Medicine*, **26**(2): 165-181.

Sikkema, K. L., Kalichman, S. C., Hoffman, R., Koob, J. J., Kelly, J. A.. & Heckman T. G. (2000). Coping Strategies and Emotional Wellbeing Among HIV-infected Men and Women Experiencing AIDS-related Bereavement. *AIDS CARE*, **12**(5); ¶1 –12.

Sinomlando Project. (2003). *Memory Box Programme*. School of Theology, University

of Natal, Pietermaritzburg. Retrieved from the World Wide Web on 16 June 2005 from: <http://www.hs.unp.ac.za/theology/sinomlando/memory%20boxes.htm>

Sinosizo Home-based care and Oral History project. (2001). *Child bereavement counselling and memory boxes*. Durban: University of Natal. Retrieved from the World Wide Web on 16 June 2005 from: <http://www.securethefuture.com/grant/data/commun.html>

Siyam'kela Project. (2003). *Measuring HIV/AIDS related stigma. Literature Review*.

Smart, R. (2003). *Policies for Orphans and Vulnerable Children: A Framework for Moving Ahead*. USAID.

Smetherham, J. (2002). *People Living with HIV/AIDS Tell their Stories: Boxes transformed into treasures*. Cape Times, 26 February.

Stake, R. E. (1995). *The art of case study research*. London: Sage.

Stake, R. E. (1998). *Case Studies (Chapter 16)*. In Denzin, N. K. & Lincoln, Y. (1998). *The Landscape of Qualitative Research: Theories and Issues*. London: Sage Publications.

Tesch, R. (1990). In Cresswell, J. W. (1994). *Research design: Qualitative and quantitative approaches*. Thousand Oaks: Sage. In De Vos, (1998). *Research at Grass Roots: A primer for the caring professions*. Pretoria: Van Schaik Publishers.

The Ten Million Memory Project and Memory Work (2005). Retrieved from the World Wide Web on 7 July 2005 from: <http://web.uct.ac.za/depts/cgc/Jonathan/index.htm>

Terre Blanche, M. & Kelly, K (2002). *Interpretive Methods (Chapter 7)*. In Ter Blanche, M. & Durrheim, K. (2002). *Research In Practice: Applied Methods For The Social Sciences*. Cape Town: University Cape Town Press.

Terre Blanche, M. & Durrheim, K. (2002). *Research In Practice: Applied Methods For The Social Sciences*. Cape Town: University Cape Town Press.

Thompson, C. L. & Rudolph, L. B. (2000). *Counselling Children (5th Ed)*. Belmont: Wadsworth.

UNAIDS. (2004). *Report on the global AIDS epidemic*. Bangkok. Retrieved from the World Wide Web on 16 June 2005 from: <http://www.unaids.org/bangkok2004/report.html>

UNAIDS. (2002). *A Conceptual Framework and Basis for Action: HIV/AIDS Stigma and Discrimination*. Geneva.

UNICEF. (2005). *Memory Boxes*. HIV & AIDS - Care and support for orphans and families affected by HIV & AIDS. Retrieved from the World Wide Web on 16 June 2005 from: http://www.unicef.org/aids/index_orphans.html

Uys, L. R. (2003). Aspects of the Care of People with HIV/AIDS in South Africa. *Public Health Nursing*, **20**(4): 271-280.

Viljoen, J.R. (2005). *Identifying Assets in the Memory Box Making Process by Vulnerable Children*. Pretoria: University of Pretoria.

Visser, M. & Moleko, A. (2001). *Introduction to Community Psychology*. Pretoria: University of Pretoria.

Velentgas, P. Bynum, C. & Zierler, S. (1990). The buddy volunteer commitment in AIDS care. *American Journal of Public Health*, **80**(11): 1378-1380.

Verschuren, P. J. M. (2003). Case study as a research strategy: some ambiguities and opportunities. *International Journal of Social Research Methodology*, **6**(2): 121-139.

Webb, N. D. (ed). (1993). *Helping bereaved children. A Handbook for Practitioners*. New York: Guildford Press.

Winkler, G. (2003). *Courage to Care: A workbook on HIV/AIDS for schools*. Southdale: Catholic Institute of Education.

Woznick, L. A. & Goodheart, C. D. (2002). *Living with Childhood Cancer: A Practical Guide to Help Families Cope*. Washington: American Psychological Association.

Yin, R. K. (2003). *Case Study Research: Design and method*. California: Sage Publications.