

References

- AARP. (1999, 1999). AARP on the issues: Caregiving, [Webpage]. Available: <http://www.aarp.org/ontheissues/issuecaregiv.html>.
- Adelman, M. (1991). Stigma, gay lifestyles, and adjustment to aging: A study of later-life gay men and lesbians. Journal of Homosexuality, 20(3/4), 7-32.
- Attie, T. (1991). The importance of conceiving of grief as an active process. Death Studies, 15, 385-393.
- Barer, B. M., & Johnson, C. L. (1990). A critique of the caregiving literature. Gerontologist, 30(1), 26-29.
- Bass, D. M., & Bowman, K. (1990). The transition from caregiving to bereavement: The relationship of care-related strain and adjustment to death. Gerontologist, 30(1), 35-42.
- Bass, D. M., Bowman, K., & Noelker, L. S. (1991). The influence of caregiving and bereavement support on adjusting to an older relative's death. Gerontologist, 31(1), 32-42.
- Baum, M., & Page, M. (1991). Caregiving and multigenerational families. Gerontologist, 31(6), 762-769.
- Beeler, J. A., Rawls, T. W., Herdt, G., & Cohler, B. J. (1999). The needs of older lesbians and gay men in Chicago. Journal of Gay and Lesbian Social Services, 9(1), 31-49.

- Behney, R. (1994). The aging network's response to gay and lesbian issues. Outword, newsletter of the Gay and Lesbian Aging Issues Network of the American Society on Aging, Winter, 1994, 2.
- Benedict, A., & Zhang, X. (1999). Reactions to loss among aged men and women: A comparison. Activities, Adaptation and Aging, 24(1), 29-39.
- Berger, R. M. (1982). Unseen minority: Older gays and lesbians. Social Work, 27(3), 236-242.
- Berger, R. M. (1983). Health care for lesbians and gays: What social workers should know. Journal of Social Work and Human Sexuality, 1(3), 59-73.
- Berger, R. M. (1984). Realities of gay and lesbian aging. Social Work, 29(1), 57-62.
- Berger, R. M. (1996). Gay and gray: The older homosexual man (2nd ed.). New York, NY: Haworth Press.
- Berger, R. M., & Kelly, J. J. (1986). Working with homosexuals of the older population. Social Casework, 67(4), 203-210.
- Berkman, C. S., & Zinberg, G. (1997). Homophobia and heterosexism in social workers. Social Work, 42(4), 319-332.
- Bierhals, A. J., Prigerson, H. G., Fasiczka, A., Frank, E., & Miller, M. (1995). Gender differences in complicated grief among the elderly. Omega Journal of Death and Dying, 32(4), 303-317.
- Bogdan, R. C., & Bilken, S. K. (1998). Qualitative research for education: An introduction to theory and methods (3rd ed.). Needham Heights, MA: Allyn & Bacon.

Bonuck, K. A. (1993). AIDS and families: Cultural, psychosocial, and functional impairments. Social Work in Health Care, 18(2), 75-88.

Bradford, J., & Ryan, C. (1991). Who we are: Health concerns of middle-aged lesbians. In B. Sang, J. Warshow, & A. J. Smith (Eds.), Lesbians at midlife: The creative transition (pp. 147-163). San Francisco, CA: Spinsters Book Company.

Braithwaite, V. (1992). Caregiver burden: Making the concept scientifically useful and policy relevant. Research on Aging, 14(1), 3-27.

Brody, E. M. (1981). Women in the middle and family help to older people. Gerontologist, 21(5), 471-480.

Brody, E. M. (1985). Parent care as a normative family stress. Gerontologist, 25(1), 19-29.

Brookdale Center on Aging. (1999). Assistive housing for elderly gays and lesbians in New York City. New York: Brookdale Center on Aging and Senior Action in a Gay Environment (SAGE).

Cahill, S., South, K., & Spade, J. (2000). Outing age: Public policy issues affecting gay, lesbian, bisexual and transgendered elders. Washington, DC: The Policy Institute of the National Gay and Lesbian Task Force Foundation.

Cantor, M. H. (1983). Strain among caregivers: A study of the experience in the United States. Gerontologist, 23(6), 597-604.

Carter, R., & Golant, K. (1994). Helping yourself help others: A book for caregivers. New York: Random House.

Caserta, M. S., & Lund, S. (1992). Bereavement stress and coping among older adults. Omega Journal of Death and Dying, 25(1), 33-45.

Chenoweth, B., & Spencer, B. (1986). Dementia: The experience of family caregivers. Gerontologist, 26(3), 267-272.

Colerick, E. J., & George, L. K. (1986). Predictors of institutionalization among caregivers of patients with Alzheimer's Disease. Journal of the American Geriatrics Society, 34, 493-498.

Connolly, L. (1996). Long-term care and hospice: The special needs of older gay men and lesbians. Journal of Gay and Lesbian Social Services, 5(1), 77-91.

Cook-Daniels, L. (1997). Lesbian, gay male, bisexual, and transgendered elders: Elder abuse and neglect issues. Journal of Elder Abuse and Neglect, 9(2), 35-49.

Cornett, C. W., & Hudson, R. A. (1987). Middle adulthood and the theories of Erikson, Gould, and Vaillant: Where does the gay man fit? Journal of Gerontological Social Work, 10(3/4), 61-73.

Coss, C. (1991). Single lesbians speak out. In B. Sang, J. Warshow, & A. J. Smith (Eds.), Lesbians at midlife: The creative transition (pp. 132-140). San Francisco, CA: Spinsters Book Company.

Creswell, J. W. (1998). Qualitative inquiry and research design : Choosing among five traditions. Thousand Oaks, CA: SAGE.

Dane, B. O., & Miller, S. O. (1992). AIDS: Intervening with hidden grievers. Westport, CT: Auburn House.

Dardick, L. & Grady, K. E. (1980). Openness between gay persons and health professionals. Annals of Internal Medicine, *93*, 115-119.

Davis, K., Cox, L., & Adler, M. (undated). Defining social justice in social work education. Unpublished manuscript (Virginia Commonwealth University, Richmond, VA.).

Deevey, S. (1990). Older lesbian women: An invisible minority. Journal of Gerontological Nursing, *16*(5), 35-37.

Delgado, M., & Tennstedt, S. (1997). Puerto Rican sons as primary caregivers of elderly parents. Social Work, *27*(2), 178-183.

Delgado, J. R., & Rose, M. K. (1994). Caregiver constellations: Caring for persons with AIDS. Journal of Gay and Lesbian Social Services, *1*(1), 1-14.

Doka, K. J. (1987). Silent sorrow: Grief and the loss of significant others. Death Studies, *11*, 455-469.

Doka, K. J. (1989a). Disenfranchised grief. In K. J. Doka (Ed.), Disenfranchised grief: Recognizing hidden sorrow (pp. 3-11). Lexington, MA: Lexington Books.

Doka, K. J. (1989b). Disenfranchised grief: Recognizing hidden sorrow. Lexington, MA: Lexington Books.

Donaldson, C. (2000). Midlife lesbian parenting. Journal of Gay and Lesbian Social Services, *11*(2/3), 119-138.

Dorfman, R., Walters, K., Burke, P., Hardin, L., Karanik, T., Raphael, J., & Silverstein, E. (1995). Old, sad and alone: The myth of the aging homosexual. Journal of Gerontological Social Work, *24*(1/2), 29-44.

Douglas, C. J., Kalman, C. M., & Kalman, T. P. (1985). Homophobia among physicians and nurses: An empirical study. Hospital and Community Psychiatry, *36*(12), 1309-1311.

Dworkin, J., & Kaufer, D. (1995). Social services and bereavement in the lesbian and gay community. Journal of Gay and Lesbian Social Services, *2*(3/4), 41-60.

Elliott, P. (1996). Shattering the illusions: Same-sex domestic violence. In C. M. Renzetti & C. H. Miley (Eds.), Violence in gay and lesbian domestic partnerships (pp. 1-8). New York: Harrington Park Press.

Emlet, C. A. (1996). Case managing older persons with AIDS: Bridging systems, recognizing diversity. Journal of Gerontological Social Work, *27*(1/2), 55-71.

Erlandson, D. A., Harris, E. L., Skipper, B. L., & Allen, S. D. (1993). Doing naturalistic inquiry: A guide to methods. Newbury Park, CA: SAGE.

Ettlebrick, P. L. (1996). Legal issues in health care for lesbians and gay men. Journal of Gay and Lesbian Social Services, *5*(1), 93-109.

Farran, C. J., Keane-Hagerty, E., Sallowat, S., Kupferer, S., & Wilken, C. S. (1991). Finding meaning: An alternative paradigm for Alzheimer's Disease family caregivers. Gerontologist, *31*(4), 483-489.

Fauri, D. (1988). Applying historical themes to the profession in the foundation curriculum. Journal of Teaching in Social Work, *2*(1), 17-31.

Fengler, A. P., & Goodrich, N. (1979). Wives of elderly disabled men: The hidden patients. Gerontologist, *19*(2), 175-183.

Figueira-McDonough, J. (1993). Policy practice: The neglected side of social work intervention. Social Work, 38(2), 179-188.

Flynn, J. P. (1992). Social agency policy: Analysis and presentation for community practice. Chicago: Nelson-Hall Publishers.

Folkman, S., Chesney, M. A., & Christopher-Richards, A. (1994). Stress and coping in caregiving partners of men with AIDS. Psychiatric Clinics of North America, 17(1), 35-53.

Francher, J. S., & Henkin, J. (1973). The menopausal queen: Adjustment to aging and the male homosexual. American Journal of Orthopsychiatry, 43(4), 670-674.

Frederikson, K. I. (1999). Family caregiving responsibilities among lesbians and gay men. Social Work, 44(2), 142-155.

Fredman, L., Daly, M. P., & Lazur, A. M. (1995). Burden among white and black caregivers to elderly adults. Journal of Gerontology, 50(2), 110-118.

Friend, R. A. (1980). Gayging: Adjustment and the older gay male. Alternative Lifestyles, 3(2), 231-248.

Friend, R. A. (1991). Older lesbian and gay people: A theory of successful aging. Journal of Homosexuality, 20(3/4), 241-263.

Fullmer, E. M. (1995). Challenging biases against families of older gays and lesbians. In G. C. Smith, S. S. Tobin, E. A. Robertson-Tchabo, & P. W. Power (Eds.), Strengthening aging families: Diversity in practice (pp. 99-119). Thousand Oaks, CA: SAGE.

Garfinkle, E. M., & Morin, S. F. (1978). Psychologists attitudes toward homosexual psychotherapy clients. Journal of Social Issues, 34, 101-112.

George, L. K., & Gwyther, L. P. (1986). Caregiver well-being: A multidimensional examination of caregivers of demented adults. Gerontologist, 26(3), 253-259.

Glaser, B. G., & Strauss, A. L. (1967). The discovery of grounded theory: Strategies for qualitative research. Chicago: Aldine Publishing Company.

Gold, D. P., Reis, M. F., Markiewicz, D., & Andres, D. (1995). When home caregiving ends: A longitudinal study of outcomes for caregivers of relatives with dementia. Journal of the American Geriatrics Society, 43, 10-16.

Gonyea, J. G., & Silverman, N. M. (1991). The role of Alzheimer's Disease support groups in families' utilization of community services. Journal Gerontological Social Work, 16(1/2), 43-55.

Graham, D. L. R., Rawlings, E. I., Halpern, H. S., & Hermes, J. (1984). Therapists need for training in counseling lesbians and gay men. Professional Psychology: Research and Practice, 15(4), 482-496.

Gramick, J. (1983). Homophobia: A new challenge. Social Work, 27(2), 137-141.

Gray, H., & Dressel, P. (1985). Alternative interpretation of aging among gay males. Gerontologist, 25(1), 83-87.

Greene, J. G., Smith, R., Gardiner, M., & Timbury, G. C. (1982). Measuring behavioral disturbance of elderly demented patients in the community and its effects on relatives: A factor analytic study. Age and Aging, 11, 121-126.

Grossman, A. H., D'Augelli, A. R., & Hershberger, S. L. (2000). Social support networks of lesbian, gay, and bisexual adults 60 years of age and older. Journal of Gerontology, 55B(3), P171-P179.

Guba, E. G. (1990). The alternative paradigm dialog. In E. G. Guba (Ed.), The paradigm dialog (pp. 17-27). Newbury Park, CA: SAGE.

Guba, E. G., & Lincoln, Y. S. (1989). Fourth generation inquiry. Newbury Park, CA: SAGE.

Gunter, P. L. (1992). Social work with non-traditional families. In N. J. Woodman (Ed.), Lesbian and gay lifestyles: A guide for counseling and education (pp. 87-109). New York: Irvington Publishers Press.

Gurevitch, J. (2000). Filial bereavement: Midlife lesbian daughters and intersubjective thoughts. Journal of Gay and Lesbian Social Services, 11(2/3), 49-76.

Gwyther, L. (1990). Letting go: Separation-individuation in a wife of an Alzheimer's patient. Gerontologist, 30(4), 698-702.

Haley, W. E., Levine, E. G., Brown, L., Berry, J. W., & Hughes, G. H. (1987). Psychological, social, and health consequences of caring for a relative with senile dementia. Journal of the American Geriatrics Society, 35, 405-411.

Harris, M. B., Nightengale, J., & Owen, N. (1995). Health care professionals' experience, knowledge, and attitudes concerning homosexuality. Journal of Gay and Lesbian Social Services, 2(2), 91-107.

Harry, J. (1986). Sampling gay men. Journal of Sex Research, 22(1), 21-34.

Hayes, R. B., Chauncey, S., & Tobey, L. A. (1990). The social support networks of gay men with AIDS. Journal of Community Psychology, 18, 374-385.

Hayslip, B., & Panek, P. E. (1989). Adult development and aging. New York: Harper Row Publishers.

Hegge, M., & Fischer, C. (2000). Grief responses of senior and elderly widows: Practice implications. Journal of Gerontological Nursing, 26(2), 35-43.

Hepworth, D. H., Rooney, R. H., & Larsen, J. A. (1997). Direct social work practice: Theory and skills (5th ed.). Pacific Grove, CA: Brooks/Cole.

Herd, G., Beeler, J., & Rawls, T. W. (1997). Life course diversity among older lesbians and gay men: A study in Chicago. Journal of Gay, Lesbian, and Bisexual Identity, 2(3/4), 231-246.

Hinrichsen, G. A., & Ramirez, M. (1992). Black and white dementia caregivers: A comparison of adaptation, adjustment, and service utilization. Gerontologist, 32(3), 375-381.

Horowitz, A. (1985). Family caregiving to the frail elderly. In C. Eisdorfer, M. P. Lawton, & G. Maddox (Eds.), Annual review of gerontology and geriatrics (Vol. 5, pp. 194-246). New York: Springer.

Humphreys, N. A., & Quam, J. K. (1998). Middle-aged and old gay, lesbian, and bisexual adults. In G. A. Appleby & J. W. Anastas (Eds.), Not just a passing phase: Social work with gay, lesbian, and bisexual people (pp. 245-268). New York: Columbia University Press.

Jacobs, R. J., Rasmussen, L. A., & Hohman, M. M. (1999). The social support needs of older lesbians, gay men, and bisexuals. Journal of Gay and Lesbian Social Services, 9(1), 1-30.

Jacobson, S. A. (1995). Methodological issues in research with older lesbians. Journal of Gay and Lesbian Social Services, 3(1), 43-56.

Jansson, B. S. (1999). Becoming an effective policy advocate: From policy practice to social justice (3rd ed.). Pacific Grove, CA: Brooks/Cole.

Johnson, C. L. (1983). Dyadic family relations and social support. Gerontologist, 23(4), 377-383.

The Robert Wood Johnson Foundation. (1996). Chronic care in America: A 21st century challenge. Princeton, NJ: The Robert Wood Johnson Foundation.

Jones, P. S., & Martinson, I. M. (1992). The experience of bereavement in caregivers of family members with Alzheimer's disease. IMAGE: Journal of Nursing Scholarship, 24, 172-176.

Karpiak, S., Cantor, M., Chernesky, R., Ensig-Brodsky, E., & South, K. (2000). Will the LGBT communities meet the challenge of caregiving for their seniors? Paper presented at the Out of the closet--into the future: Midlife and aging in gay America conference, New York, NY.

Kart, C. S., Metress, E. K., & Metress, S. P. (1990). Human aging and chronic disease. Boston: Jones and Bartlett.

Kastenbaum, R. (1995). Death, society, and human experience (5th ed.). Boston: Allyn and Bacon.

Katchadourian, H. (1987). Fifty: Midlife in perspective. New York: W. H. Freeman and Company.

Kehoe, M. (1986a). Lesbians over 65: A triply invisible minority. Journal of Homosexuality, *12*(3/4), 139-152.

Kehoe, M. (1986b). A portrait of the older lesbian. Journal of Homosexuality, *12*(3/4), 157-161.

Kehoe, M. (1988). Lesbians over 60 speak for themselves. Journal of Homosexuality, *16*(3/4), 1-111.

Kelly, J. (1977). The aging male homosexual: Myth and reality. Gerontologist, *17*(4), 328-332.

Kelly, J. A., St. Lawrence, J. S., Smith, S., Jr., & Cook, D. J. (1987). Stigmatization of AIDS patients by physicians. American Journal of Public Health, *77*(7), 789-791.

Kiecolt-Glaser, J., et al. (1987). Chronic stress and immunity in family caregivers of Alzheimer's Disease victims. Psychosomatic Medicine, *49*, 523-535.

Kimmel, D. C. (1978). Adult development and aging: A gay perspective. Journal of Social Issues, *34*(3), 113-30.

Kimmel, D. C., & Sang, B. E. (1995). Lesbians and gay men in midlife. In A. R. D'Augelli & C. J. Patterson (Eds.), Lesbian, gay, and bisexual identities over the lifespan: Psychological perspectives (pp. 190-214). New York: Oxford University Press.

Kinney, J. M., & Stephens, M. A. P. (1989). Caregiving hassles scale: Assessing the daily hassles of caring for a family member with dementia. Gerontologist, *29*(2), 328-332.

Kirkpatrick, M. (1989). Middle age and the lesbian experience. Women's Studies Quarterly, *17*(1/2), 87-96.

Kooden, H. (1997). Successful aging in the middle-aged gay man: A contribution to developmental theory. Journal of Gay and Lesbian Social Services, *6*(3), 21-43.

Kosberg, J. I., Cairl, R. E., & Kellor, D. M. (1990). Components of burden: Interventive implications. Gerontologist, *30*(2), 236-242.

Kramer, B. J., & Kipnis, S. (1995). Eldercare and the work-role conflict: Toward an understanding of the gender differences in caregiver burden. Gerontologist, *35*(3), 340-348.

Laner, M. R. (1997). Growing older female: Heterosexual and homosexual. Journal of Lesbian Studies, *1*(1), 87-95.

Lawton, M. P., Kleban, M. H., Moss, M., Rovine, M., & Glicksman, A. (1989). Measuring caregiving appraisal. Journal of Gerontology, *13*(4), 43-71.

LeCompte, M. D. (1993). A framework for hearing silence: What does telling stories mean when we are supposed to be doing science? In D. McLaughlin & W. G.

Tierney (Eds.), Naming silenced lives: Personal narratives and processes of educational change (pp. 9-27). New York: Routledge.

Lincoln, Y. S. (1995). Emerging criteria for quality in qualitative and interpretive research. Paper presented at the Annual Meeting of the American Educational Research Association, San Francisco, CA.

Lincoln, Y. S., & Guba, E. G. (1985). Naturalistic inquiry. Newbury Park, CA: SAGE.

Lund, D. A. (Ed.). (1989). Older bereaved spouses: Research with practical implications. New York: Hemisphere Publishing Corporation.

Lund, D. A., Caserta, M. S., & Dimond, M. F. (1993). The course of spousal bereavement in later life. In M. S. Stroebe, W. Stroebe, & R. O. Hansson (Eds.), Handbook of bereavement: Theory, research, and intervention (pp. 240-254). Cambridge: University of Cambridge.

Mace, N. L., & Rabins, P. V. (1981). The 36-hour day: A guide to caring for persons with Alzheimer's Disease, related dementing illnesses, and memory loss in later life. Baltimore, MD: Johns Hopkins University Press.

Mallon, G. P. (Ed.). (1998a). Foundations for social work practice with lesbian and gay persons. New York: Harrington Park Press.

Mallon, G. P. (1998b). Knowledge for practice with gay and lesbian persons. In G. P. Mallon (Ed.), Foundations of social work practice with gay and lesbian persons (pp. 1-30). New York: Harrington Park Press.

Marshall, C., & Rossman, G. B. (1995). Designing qualitative research (2nd ed.). Newbury Park, CA: SAGE.

Martin, J. L. (1988). Psychological consequences of HIV-related bereavement among gay men. Journal of Consulting and Clinical Psychology, 56(6), 856-862.

Martin, J. L., & Dean, L. (1993). Bereavement following death from AIDS: Unique problems, reactions, and special needs. In M. S. Stroebe, W. Stroebe, & R. O. Hansson (Eds.), Handbook of bereavement: Theory, research, and intervention (pp. 317-330). Cambridge, England: University of Cambridge.

Martin, J. L., & Doka, K. J. (2000). Men don't cry...women do: Transcending gender stereotypes of grief. Philadelphia, PA: Brunner/Mazel.

Maykut, P., & Morehouse, R. (1994). Beginning qualitative research: Philosophic and practical guide. Philadelphia, PA: The Falmer Press.

McMillan, J., & Schumacher, S. (1997). Research in education: A conceptual introduction (4th ed.). New York: Longman.

Mellor, M. J. (1996). Special populations among older persons. Journal of Gerontological Social Work, 25(1/2), 1-10.

Miles, M. B., & Huberman, A. M. (1994). Qualitative data analysis: An expanded sourcebook (2nd ed.). Thousand Oaks, CA: SAGE.

Miller, B., & Cafasso, L. (1992). Gender differences in caregiving: Fact or artifact. Gerontologist, 32(4), 498-507.

Miller, N. (1995). Out of the past: Gay and lesbian history from 1869 to the present. New York: Vintage Books.

Mitchell, V. (2000). The bloom is on the rose: The impact of midlife on the lesbian couple. Journal of Gay and Lesbian Social Services, 11(2/3), 33-48.

Montgomery, R. J., Gonyea, J. G., & Hooyman, N. R. (1985). Caregiving and the experience of objective and subjective burden. Family Relations, 34, 19-26.

Mui, A. C. (1992). Caregiver strain among black and white caregivers: A role theory perspective. Gerontologist, 32(2), 203-212.

Mui, A. C., & Morrow-Howell, N. (1993). Sources of emotional strain among the oldest caregivers: Differential experiences of siblings and spouses. Research on Aging, 15(1), 50-69.

Mullan, J. T. (1992). The bereaved caregiver: A prospective study of changes in wellbeing. Gerontologist, 32(5), 673-683.

National Academy on an Aging Society. (2000). Caregiving: Helping the elderly with activity limitations (Number 7): National Academy on an Aging Society.

National Alliance for Caregiving and American Association of Retired Persons. (1997). Family caregiving in the U. S.: Findings from a national study.

National Association of Social Workers. (1996). Code of ethics. Washington, DC: Author.

National Center for Health Statistics. (2000). Health, United States, 2000. Hyattsville, MD: National Center for Health Statistics.

Novak, M., & Guest, C. (1989). Application of a multidimensional caregiver burden inventory. Gerontologist, 29(6), 798-803.

O'Conner, D. L. (1995). Supporting spousal caregivers: Exploring meaning and service use. Families in Society, 76(5), 296-305.

Patton, M. Q. (1990). Qualitative evaluation and research methods. Newbury Park, CA: SAGE.

Pearlin, L. I., Mullan, J. T., Semple, S. J., & Skaff, M. M. (1990). Caregiving and the stress process: An overview of concepts and their measures. Gerontologist, 30(5), 583-594.

Peterson, K. J., & Bricker-Jenkins, M. (1996). Lesbians and the health care system. Journal of Gay and Lesbian Social Services, 5(1), 33-47.

Peterson, P. G. (1999). Gray dawn: The global aging crisis. Foreign Affairs, January/February, 42-55.

Pittman, M. A., & Maxwell, J. A. (1992). Qualitative approaches to evaluation: Models and methods. In M. D. LeCompte, W. L. Millroy, & J. Preissle (Eds.), Handbook of qualitative research in education (pp. 729-769). San Diego, CA: Academic Press.

Poulshock, S. W., & Deimling, G. T. (1984). Families caring for elders in residence: Issues in the measurement of burden. Journal of Gerontology, 39(2), 230-239.

Pruchno, R. A., & Resch, N. L. (1989). Husbands and wives as caregivers: Antecedents of depression and burden. Gerontologist, 29(2), 159-165.

Quam, J. K. (Ed.). (1997). Social services for senior gay men and lesbians. Binghamton, NY: Haworth Press.

Quam, J. K., & Whitford, G. S. (1992). Adaptation and age-related expectations of older gay and lesbian adults. Gerontologist, 32(3), 367-374.

- Rabins, D., Mace, N., & Lucas, M. (1982). The impact of dementia on the family. JAMA, 248, 333-335.
- Ramirez, C. C., & Cohen, H. L. (2000). Lesbian and gay elders: An invisible minority. In R. L. Schneider, N. P. Kropf, & A. J. Kisor (Eds.), Gerontological social work: Knowledge, service settings, and special populations (pp. 343-367). Belmont, CA: Brooks Cole.
- Raphael, S. (1997). Lesbian and gay elders. Paper presented at the National Conference on Elder Abuse, Long Beach, CA.
- Raphael, S. M., & Meyer, M. K. (2000). Family support patterns for midlife lesbians: Recollections of a lesbian couple. Journal of Gay and Lesbian Social Services, 11(2/3), 139-150.
- Robinson, B. C. (1983). Validation of a caregiver strain index. Journal of Gerontology, 38(3), 344-348.
- Rose, S., & Zand, D. (2000). Lesbian dating and courtship from young adulthood to midlife. Journal of Gay and Lesbian Social Services, 11(2/3), 77-104.
- Rosenfeld, D. (1999). Identity work among lesbian and gay elderly. Journal of Aging Studies, 13(2), 121 ff.
- Ross, M. M. (1991). Spousal caregiving in later life: An objective and subjective career. Health Care for Women International, 12, 123-135.
- Rubin, A., & Babbie, E. (1997). Research methods for social work (3rd ed.). Pacific Grove, CA: Brooks/Cole Publishing.

Rubin, H. J., & Rubin, I. S. (1995). Qualitative interviewing: The art of hearing data. Thousand Oaks, CA: SAGE.

Rudolph, J. R. (1988a). The effects of a multimodal seminar on mental health practitioners' attitudes toward homosexuality, authoritarianism, and counseling effects. , Lehigh University, Bethlehem, PA.

Rudolph, J. R. (1988b). Counselors' attitudes towards homosexuality: A selective review of the literature. Journal of Counseling and Development, *67*, 165-168.

Sandelowski, M. (1995). Qualitative analysis: What it is and how to begin. Research in Nursing and Health, *18*, 371-375.

Sanders, C. M. (1993). Risk factors in bereavement outcome. In M. S. Stroebe, W. Stroebe, & R. O. Hansson (Eds.), Handbook of bereavement: Theory, research, and intervention (pp. 255-267). Cambridge, England: University of Cambridge.

Sanders, C. M. (1999). Grief: The mourning after: Dealing with adult bereavement (2nd ed.). New York: John Wiley & Sons, Inc.

Sang, B., Warshow, J., & Smith, A. J. (Eds.). (1991). Lesbians at midlife: The creative transition. San Francisco, CA: Spinsters Book Company.

Sang, B. E. (1991). Moving toward balance and integration. In B. Sang, J. Warshow, & A. J. Smith (Eds.), Lesbians at midlife: The creative transition (pp. 206-214). San Francisco, CA: Spinsters Book Company.

Sang, B. E. (1992). Counseling and psychotherapy with midlife and older lesbians. In S. H. Dworkin & F. J. Gutierrez (Eds.), Counseling gay men and lesbians:

Journey to the end of the rainbow (pp. 35-48). Alexandria, VA: American Association for Counseling and Development.

Sankar, A. (1991). Ritual and dying: A cultural analysis of social support for caregivers. Gerontologist, 31(1), 43-50.

Schaie, K. W., & Willis, S. L. (1996). Adult development and aging (4th ed.). New York: Harper Collins.

Scherer, Y., Wu, Y. W., & Haughey, B. P. (1991). AIDS and homophobia among nurses. Journal of Homosexuality, 21(4), 17-27.

Schuchter, S. R., & Zisook, S. (1993). The course of normal grief. In M. S. Stroebe, W. Stroebe, & R. O. Hansson (Eds.), Handbook of bereavement: Theory, research, and intervention (pp. 23-43). Cambridge, England: University of Cambridge.

Schulz, R., Newsom, J. T., Fleissner, K., Decamp, A. R., & Nieboer, A. P. (1997). The effects of bereavement after family caregiving. Aging and Mental Health, 1(3), 269-282.

Schwandt, T. A. (1997). Qualitative inquiry: A dictionary of terms. Thousand Oaks, CA: SAGE.

Schwartz, M. (1996). Gay men and the health care system. Journal of Gay and Lesbian Social Services, 5(1), 19-32.

Sell, R. L., & Petruccio, C. (1996). Sampling homosexuals, bisexuals, gays, and lesbians for public health research: A review of the literature from 1990 to 1992. Journal of Homosexuality, 30(4), 31-47.

Seltzer, M. M., & Li, L. W. (2000). The dynamics of caregiving: Transitions during a three-year prospective study. Gerontologist, *40*(2), 165-178.

Shernoff, M. (Ed.). (1997). Gay widowers: Life after the death of a partner. Binghamton, NY: Harrington Park Press.

Shultz, R. (1990). Theoretical perspectives on caregiving: Concepts, variables, methods. In D. E. Biegel & A. Blum (Eds.), Aging and caregiving: Theory, research, and policy. Newbury Park, CA: SAGE.

Shultz, R., Visintainer, P., & Williamson, G. M. (1990). Psychiatric and physical morbidity effects of caregiving. Journal of Gerontology, *45*(2), 181-191.

Siegel, J. (1996). Aging into the 21st century (HHS-100-95-0017): Administration on Aging.

Simon, B. L. (1994). The empowerment tradition in American social work: A history. New York: Columbia University Press.

Skaff, M. M., Pearlin, L. I., & Mullan, J. T. (1996). Transitions in the caregiving career: Effects on sense of mastery. Psychology and Aging, *11*(2), 247-257.

Smith, E. M., Johnson, S. R., & Guenther, S. M. (1985). Health care attitudes and experiences during gynecologic care among lesbians and bisexuals. American Journal of Public Health, *75* (9), 1085-1087.

Spaid, W. M., & Barusch, A. S. (1994). Emotional closeness and caregiver burden in the marital relationship. Journal of Gerontological Social Work, *21*(3/4), 197-211.

Stephenson, J. S. (1985). Death, grief, and mourning: Individual and social realities. New York: The Free Press.

Stevens, P. E., & Hall, J. M. (1988). Stigma, health beliefs, and experience with health care in lesbian women. Image, 20(2), 257-263.

Stone, R., Cafferata, G. L., & Sangl, J. (1987). Caregivers of the frail elderly: A national profile. Gerontologist, 27(5), 616-626.

Strauss, A. L. (1987). Qualitative analysis for social scientists. Cambridge, England: Cambridge University Press.

Taylor, S. J., & Bogdan, R. C. (1998). Introduction to qualitative research: A guidebook and resource (3rd ed.). New York: John Wiley & Sons, Inc.

Thompson, E. H., Futterman, A. M., Gallagher-Thompson, D., Rose, J. M., & Lovett, S. B. (1993). Social support and caregiving burden in family caregivers of frail elders. Journal of Gerontology, 48(5), 245-254.

Thompson, L. W., Gallagher-Thompson, D., Futterman, A., Gilewski, M. J., & Peterson, J. (1991). Effects of late-life spousal bereavement over a 30-month interval. Psychology and Aging, 6(3), 434-441.

Tully, C. T. (1989). Caregiving: What do midlife lesbians view as important? Journal of Gay and Lesbian Psychotherapy, 1(1), 87-103.

Tully, C. T. (2000). Lesbians, gays and the empowerment perspective. New York: Columbia University Press.

Turner, H. A., & Catania, J. A. (1997). Informal caregiving to persons with AIDS in the United States: Caregiver burden among central cities residents eighteen to forty-nine years old. American Journal of Community Psychology, 25(1), 35-59.

Turner, H. A., Catania, J. A., & Gagnon, J. (1994). The prevalence of informal caregiving to persons with AIDS in the United States. *Social Science Medicine*, 38(11), 1543-1552.

U. S. Census Bureau. (1995). *Statistical brief: Sixty-five plus in the United States* : Economics and Statistics Administration, U.S. Department of Commerce.

van der Meide, W. (2000). *Legislating equality: A review of laws affecting gay, lesbian, bisexual, and transgendered people in the United States*. Washington, DC: The Policy Institute of the National Gay and Lesbian Task Force.

Van Wormer, K., Wells, J., & Boes, M. (2000). *Social work with lesbians, gays, and bisexuals: A strengths perspective*. Needham Heights, MA: Allyn & Bacon.

Vitaliano, P. P., Russo, J., Young, H. M., Becker, J., & Maiuro, R. D. (1991a). The screen for caregiver burden. *Gerontologist*, 31(1), 76-83.

Vitaliano, P. P., Young, H. M., & Russo, J. (1991b). Burden: A review of measures used among caregivers of individuals with dementia. *Gerontologist*, 31(1), 67-75.

Wardlaw, L. A. (1994). Sustaining informal caregivers for persons with AIDS. *Families in Society*, 373-384.

Warshow, J. (1991). Eldercare as a feminist issue. In B. Sang, J. Warshow, & A. J. Smith (Eds.), *Lesbians at midlife: The creative transition* (pp. 65-72). San Francisco, CA: Spinsters Book Company.

Weinstock, J. S. (2000). Lesbian friendships at midlife: Patterns and possibilities for the 21st century. *Journal of Gay and Lesbian Social Services*, 11(2/3), 1-32.

Weston, K. (1991). Families we choose: Lesbians, gays, kinship. New York: Columbia University Press.

Wisniewski, J. J., & Toomey, B. G. (1987). Are social workers homophobic? Social Work, 32(5), 454-455.

Wood, J. B., & Parham, I. A. (1990). Coping with perceived burden: Ethnic and cultural issues in Alzheimer's family caregiving. Journal of Applied Gerontology, 9(3), 325-339.

Worden, W. (1982). Grief counseling and grief therapy. New York: Springer.

Young, E. W. (1988). Nurses' attitudes toward homosexuality: Analysis of change in AIDS workshops. Journal of Continuing Education in Nursing, 19(1), 9-12.

Zarit, S. H. (1989). Do we need another stress and caregiving study? Gerontologist, 29(2), 147-148.

Zarit, S. H., Reever, K. E., & Bach-Peterson, J. (1980). Relatives of the impaired elderly: Correlates of feelings of burden. Gerontologist, 20(6), 649-655.

Zarit, S. H., Todd, P. A., & Zarit, J. M. (1986). Subjective burden of husbands and wives as caregivers: A longitudinal study. Gerontologist, 26(3), 260-266.

Zisook, S., & Schuchter, S. R. (1991). Early psychological reaction to the stress of widowhood. Psychiatry, 54(4), 320-333.

APPENDIX A: STUDY FLYER

**STUDY OF CAREGIVING AND POST-CAREGIVING
EXPERIENCES OF OLDER GAY MEN AND LESBIANS**

You are invited to participate in a study of caregiving and post-caregiving experiences of gay men and lesbians who are **50 years of age or older** and are currently providing or have previously provided care to chronically ill partners. Chronic illnesses are long-term illnesses and include conditions such as heart disease, cancer, HIV/AIDS, diabetes, etc. The study is being conducted as part of a dissertation by Kristina Hash, a Ph.D. student in social work at Virginia Commonwealth University in Richmond, Virginia. Kristina is involved in the gay community and has experience working with older adults.

The study will involve a telephone or face-to-face interview that will last 1 to 1 ½ hours in length. The interview will be audio tape recorded and will be done in the setting most comfortable for you. Questions will focus on the strains, rewards, and role changes involved in providing care. For post-caregivers, interviews will also include questions related to your experiences following the death or relocation of your partner.

There will be no reimbursement for participation, although the information you provide will benefit others by enabling social scientists to learn more about the caregiving and post-caregiving experiences of older gay men and lesbians. Additionally, it may help you to talk about your experiences.

ALL INFORMATION WILL BE KEPT CONFIDENTIAL.

If you would like to participate in the study or for more information about the study, please contact **Kristina Hash** by phone at **(804) 266-5136** or by email at **s2kmhash@atlas.vcu.edu**

Please leave a message if there is no answer by phone.

Collect calls accepted.

APPENDIX B: INTERVIEW GUIDE

**Interview Guide for Study of Caregiving and Post-caregiving Experiences
of Midlife and Older Gay Men and Lesbians**

Demographics

- Demographic information: gender; race; age; highest level of education; occupation; care duration; relationship duration; former partner's health conditions; marital status.

Description of experience

- Describe your caregiving experience (for caregivers and post-caregivers)
Strains? Positive aspects?
- Describe how your life has been since the loss of your partner (for post-caregivers)
Strains? Positive aspects?

Formal and informal supports

- What types of services have you utilized in caregiving (hospice, home health, support groups, etc)? (for caregivers)
Describe these experiences
- What types of services did you utilize in caregiving (hospice, home health, support groups, etc)? (for post-caregivers)
Describe these experiences

- In caregiving, did you receive help from informal support persons, including family, friends, neighbors, coworkers, pets, church members? (for caregivers and post-caregivers) Describe these experiences
- Following the loss of your partner, did you receive help from informal support persons, including family, friends, neighbors, coworkers, pets, church members? (for caregivers and post-caregivers) Describe these experiences
- How did you deal with unsupportive informal support persons? (if applicable)
- Did you disclose the nature of your relationship to these persons?
- What types of formal support services have you utilized since the loss of your partner? (post-caregivers) Describe these experiences
- What have your experiences been with physicians, nurses, social workers, counselors, and other health and human service professionals? Describe these experiences
- How did you deal with unsupportive professionals? (if applicable)
- Did you disclose the nature of your relationship to these persons?
- What are some changes that could be made in the health and human services that would better attend to the special needs of older, same sex partners?

Future plans/Decision-making

- Have/did you and your partner make plans for the future together? What were these plans?
- Do/Did you and your partner have joint or separate finances/property ownership? Explain reasons for these decisions

- Had/did you and your partner set up advanced directives? Explain reasons for these decisions
- What are your future plans? for retirement? for own long-term care?
- How do you feel about specialized housing for older gay men and lesbians?

Sampling suggestions

- What are some good ways to recruit persons for this study?
- Do you know of other persons who may be interested in participating in this study?

Future contact

- Would it be OK if I contacted you in the future if I have any additional questions?

APPENDIX C: SAMPLE FIELDNOTES

ID: #001-F-PG

Interview with Female Post-caregiver (Interview 1)

Demographics of Respondent

Gender: Female

Race: White

Age: 62

Education: Associate degree in Business

Occupation: Retired for past 3 yrs

Care duration: 25 yrs, last 10-12 yrs they were over 50; Caregiving started 3-4 yrs after beginning the relationship.

Former Partner's health conditions: Diabetes, heart problems, high blood pressure, vascular clotting, arthritis (building conditions)

Interview Specifics

Date: 11/11/98

Duration: 1hr 20 minutes, 2:00-3:20 PM EST

Setting of the interview: Respondent's home in Southern U.S. A home in a middle-class neighborhood. There are baseball cards set out on the table, she collects them and has had more time to pursue this hobby in retirement. The interview was contained to the living room.

Impressions of respondent: Respondent appears self-confident and is comfortable with being identified as a lesbian as well as comfortable with this interview. Respondent is also very hospitable and attempts to make the interviewer feel comfortable as well.

Others present during the interview: Her current friend arrives at the conclusion of the interview. We are introduced and she waits in the kitchen until we emerge from the living room.

How recruited for the study: Saw ad in lesbian newsletter.

Events prior to beginning of the interview: The initial phone call made to the interviewer by the respondent...respondent said she thought I would be very interested in hearing about her experience as she had basically been a caregiver for 25 years. At the respondent's home, one of the first questions she asked was about my own sexual orientation (and I answered her). This seemed to be important information to her and it felt as though it would set the stage (as far as trust and disclosure goes) for the interview.

Descriptive and Reflective (OC) Notes

We begin with general details about the caregiving situation and demographic information (also see section above). The respondent is a sixty-two year old white female who is retired and holds an Associates Degree in Business. She provided care on and off for 25 years to her female "friend". She uses the term "friend" as she has used it for most of her life. She explains that "The expression 'partner' is more an 80s & 90s term." Her friend suffered from diabetes, heart problems, vascular clotting, high blood pressure, and arthritis.

OC: The use of terminology to describe significant other may vary with respondents. This may have implications for future advertisement of the study (currently seeking "partners"). I also need to change my language to include "friend" in the rest of the interview. This is also an example of extended caregiving for multiple, chronic illnesses.

Cessation of caregiving. The relocation of her friend to her sister's home had been inevitable. Unfortunately, her friend had always refused to discuss future plans and arrangements and felt that the relocation was simply a way to "get rid of" her. They did not talk seriously about the topic until her friend was at her sister's home, recovering after a hospital discharge. They then talked about her friend's need for 24-hour care. Her friend's mind was a "closed trap" when talking about living wills or any future plans for care.

OC: This case is unique because it involves relocation as the reason for caregiving cessation. Typically, cessation is the result of death or institutionalization. She really stresses the one-sidedness of this decision-making process, one that was very stressful and burdensome. She speaks about her friend as if she and the situation are from the distant past, even though the cessation of caregiving occurred less than 2 years ago.

Respondent's own future plans. For herself, she never wanted joint property ownership, "I'm just too independent and didn't want any legal hassles." This was in light of experiences she has heard of from others. She also had a will for herself and funeral and burial arrangements.

OC: At this point I wonder if this attitude about joint property is the result of her friend being ill for such a long period of time (did she know this was coming and was preparing for it?). She is very adamant about this, which is evident in her voice.

Cessation of caregiving. The relocation decision was made primarily between the participant and her friend's sister, coming to the decision that she needed around-the-clock care. The move was tough on both she and her friend. She got through this time with the help of two friends. The friends were female, same-sex partners.

Caregiving strains. The caregiving experience had more of an effect on her than she had realized. She was "constantly running to ER in the middle of the night" and had lost considerable weight and could not sleep. She was also very isolated while caregiving. She states, "I had an office job during the day and a nursing job at night". She did not have much relief and her friend's sisters did not help much. The sisters did not even relieve her at the hospital. She did seek help from her friend's family but she ended up being the sole support person and caregiver.

OC: The original plan of study was to look at post-caregiving experiences, although it is now apparent that the details and strains of the caregiving experience have important implications for caregiving cessation. The study of post-caregivers (including former caregiving experiences and post-caregiving experiences) may be more beneficial as it captures the experience in its entirety.

Support from and relations with family. She has one sister who is aware of her being a lesbian. This is an untouchable subject in her family. Her brother ran around with a lot of different women and few guys in college and both sisters have been married twice. "You tell me, which one of the four of us has lead the most normal life? If you can't answer that one, then what is normal?" Her younger sister offered support after the relocation of her friend and was very sympathetic. She called to see if she was OK and recognized that she was with her friend for 25 years and was now experiencing a great loss.

OC: Her commentary about her siblings' love relationships is priceless! Really puts things in perspective.

Effects of her friend's relocation. Following the relocation of her friend, it took her a year to get back on her feet and not minding coming home to empty house. To her, "The house became 10x as large as it once was. It was like walking into a canyon". She did,

however, learn how to adjust to it but it was a “tremendous transition”. She feels it is similar to being widowed.

OC: This marks a change in demeanor. Prior to this point, the respondent spoke very matter-of-factly about the experience. This shows how much the relocation affected her.

Similarity to widowhood and prior experience with loss. This is not her first experience with caregiving or with loss and it was reminiscent of prior experience. Her first partner and first love died of Hodgkin’s Disease in 1964. This is when she learned how to be widowed. 5 yrs later met most recent partner. That prior experience helped her deal with the recent loss and she feels that “experience is the best teacher”.

OC: Prior experiences with loss may be a good question to ask in the future.

Moving on after the relocation in relationships and other areas of her life. She is currently involved with someone 10 years younger. After her friend relocated, she got involved in another relationship in a little after 1 year. After the relocation she got involved in life and realized she wanted a partner and wanted to share things with someone. She got tired a being a 3rd wheel. Being alone, she said, “Hit me in the face like a brick wall” and outings became extremely awkward. But she did enjoy not having to chase rescue squad in the middle of the night. There is a trade-off there. With the help of her two friends she renovated the house after her friend relocated and got rid of a lot of furniture. She changed the whole atmosphere of the home and completely remolded her friend’s old room. At first couldn’t even go in the room after the relocation.

Difficulties and adjustments of post-caregiving. After her friend relocated she had to “get a life”, get a new focal point. She hadn’t been able to express interests while caregiving, but now have time to do so. She gained a sense of freedom. She also used to hate to hear the phone ring, but now can enjoy it because it is not bringing bad news. She has also had improved health since caregiving cessation...improved eating habits and sleep and is a “happier person”.

OC: She has really been through a major transition in the last few years. It is nice to hear the positive aspects of this transition. Even though it is awkward to ask about the positive aspects of caregiving cessation, it seems very important in understanding this experience.

A reunion with former friend. She hasn’t seen her friend in about a year. She was disappointed when she saw her last as she was not taking care of herself. It was a friendly visit though.

OC: She does not say much about this encounter. Again pointing to her moving on.

Encounters with health professionals. She has had mixed experiences with health professionals, but has had “more of the negative” kind of experiences. She explains, if a heterosexual couple go to an MD, the MD would confide with wife/husband. In gay world, this is the exception as in her experience the MD would not want to discuss care issues with a same-sex partner and will “instead be looking around for the husband, mother, sister, etc.” In attempt to be recognized by the MD, she would “go through the generalizations” such as “I’m her best friend” or “She lives with me.” Sometimes, the MD will catch onto these hints. She doesn’t know if the MDs just don’t understand or that they are opposed to it. It also didn’t matter whether she was dealing with a male or female MD. On the other hand, social workers encountered tended to be very accepting and compassionate. With Nurses, it was “50-50”, as some were compassionate and other gave you the “ice cube treatment”.

OC: This topic area (experiences with professionals) was not originally planned but has brought out a very pertinent topic and one in which the respondent appears emotionally charged. Interviewer is also very interested in this area and continues questioning. These are definitely experiences worth soliciting in future interviews.

Formal supports. In regard to formal in-home support, she had VNA periodically but not often from 1993-95, and 1984. It bothered her greatly to have others coming into the house and she worried about what they would think about the relationship.

Help from therapy and clergy. She did not seek help from church but did see a therapist. She describes the therapist as the “strongpoint”. Initially she had “a lot of squeamishness” about going to a therapist and thought “there is nothing wrong with my mind”. She states that “mental health today is different than what they thought of years ago.” The therapist showed her she was in the closet, told her to get out and meet people, and told her about the gay community. Through therapy and getting out, she realized others had gone through the same thing.

OC: This shows a positive experience with a helping professional. Interesting to see the initial reluctance and attitude towards therapy (which is very common among older adults).

Future plans, attitudes toward facilities and specialized communities. In regard to her own decision making and plans for care in the future, she has the same apprehension of entering a SNF as walking into MD office as a lesbian as it the same medical staff/society. She feels that if she “is lucky”, she will run across someone accepting. She has thought some about alternative living arrangements for herself and is familiar with local assisted living facilities. She admits that she does not “dwell on it” or plan for future arrangements in detail. If SNF needed, so be it. She also thinks specialized communities for older gay men and lesbians are a good idea. “We’ve been mixing all of our lives in the heterosexual world, so why not have special freedoms in the later

years?...Why go back to a closeted-style of living? In the last few years of life, you should live it.”

OC: This was also an added question. Seems pertinent in light of the current talk of specialized services and communities for this special population of older adults. Again, she points to her negative experiences with health care professionals.

Suggestions for future sampling. She offers suggestions for reaching this population, including newsletters and general media and says, “They have come a long way and have proven that they can now spell homosexual.” She suggests putting an article in the general media, although it may run the risk of attracting “hate people”.

OC: This was an afterthought. Asking the experts (older gay men and lesbians themselves) may be the best way to devise a sampling plan!

ID: #017/M/PG

Interview with Male Post-Caregiver

Demographics of Respondent:

Gender: Male

Race: Caucasian, his partner was African American

Age: 59, his partner was 13 years younger

Education: Masters Degree

Occupation: Teacher

Care duration: 1 ½ years (partner died in 1992)

Relationship duration: 7 years

Former Partner's health conditions: HIV/AIDS

Marital status: both he and his partner were never married

Interview Specifics:

Date: 8/6/00

Duration: 1 hour 30 minutes, 10:30AM-12:00PM EST

Setting of the interview: Over the telephone (respondent at home in Northeast U.S.)

Impressions of respondent: Respondent appears to be comfortable with the interview and the interviewer.

Others present during the interview: None.

How recruited for the study: Website (gay.com)

Events prior to beginning of the interview: Respondent emailed me to express interest and inquire about the study. Email correspondence continued until the conduction of the phone interview.

Descriptive and Reflective (OC) Notes

Beginning of relationship. He begins by describing how he and his partner met and began their relationship.

Finances. They had separate finances throughout the relationship. They did, however, buy a house together. The respondent says that they had very careful and open communication about these issues.

Daily losses and role reversal. He says of his partner's condition, "I did not do anything for him that he could do for himself...I didn't do it until I was told I could. It was a matter of not taking away from him things that he was already losing faster than..." He says of this experience, "That was very difficult and a learning lesson." It was difficult to "see each of these pieces go away...seeing his losses...the role reversal was difficult on him and me."

Decision-making. He says he was always a part of his partner's decision-making. He had POA and they were very clear about it to everyone that was involved. His partner also left him money when he died.

Dying at home. His partner died at home and he describes that "as a gift."

Caregiving. "I had friends that said 'I don't understand how you do this' and I said 'Well, you just do it. You don't think about it while you're doing it. I didn't see him changing on a day to day basis.'" "The person was still there and that person overwhelmed the physical challenge." "It's still the person even though there is a change."

OC: Others have mentioned something similar, "you just do it" and don't really think about it.

Positive aspect of caregiving, growth experience. He says of his partner, "He gave me the opportunity to become an adult. I had never been around long-term illness. I had never had the long-term experience or had the responsibility that went along with it. It was very good for me. It was an awful way to get it (the experience) but at the same time I found out what I was capable of." His family members had all died quickly. When asked if it was a growth experience he said "very much so."

OC: Others have mentioned that caregiving gave them the chance to realize what they were capable of. This was an outcome of the caregiving experience. Being a first-time caregiver may be even more challenging.

Positive aspect, communication and intimacy. The experience deepened their communication and intimacy. But, good communication and intimacy always existed in their relationship.

OC: Caregiving provides an opportunity to deepen the relationship. This is a re-occurring theme.

Outcome of caregiving, clarity. As a result of caregiving he became “very clear about the kind of person I wanted in my life.” He agrees that he learned what was important in a relationship and shared, “I needed the communication, I needed the honesty, directness...and these were his characteristics...someone who was completely comfortable being a gay man.”

Other’s views and relationship history. He talks about others’ perceptions of his partner and how his partner really was and his relationship history.

OC: Slightly off the topic here.

Stressful aspects of caregiving, roles. He says about the stressful aspects of caregiving, “I became sick with him...although I continued with my life and the roles I had agreed upon in the relationship, I had to pick up others...it was simple stuff, we no longer shared the walking of the dogs...it was things like that.”

OC: There was a change in the relationship, including the shifting roles and responsibilities.

Other changes. He adds that he gained weight from the change in the relationship. He was eating to “fill a hole.”

Family involvement. The respondent’s family would call and ask about his partner but did not help with care. He says that they did provide emotional support. His partner’s family was also supportive. His partner’s mother had a hard time dealing with it (the fact that her son had HIV/AIDS) and he had a hard time dealing with her “because it meant she didn’t do a whole lot as far as the day to day stuff but I also got to understand that...this was part of my growth...people do the best that they can and they do what they are able to do and sometimes it is not what I would like but it’ what they are able to do. The flip side of that is that she never interfered with any of his decisions, she never second guessed him or criticized me for anything that I ever did and she really tried to be there as best she could.”

OC: Here is the added stigma of HIV/AIDS. This case also shows how having family members who are not very involved can be a positive. This is an amazing realization: “people do the best they can do and what they are able to do...”

Family. When asked whether his partner's family had a difficult time with his being gay (as African American families are thought to be less accepting of homosexuality) he states, "They didn't have any choice with him in terms of his being gay, he was slam, bam, out there." He says his partner's mother was accepting of the respondent and they are still in touch. He was nervous about her at first but it worked out fine. They didn't interfere with any of their decisions and his partner was very clear about his decisions.

Respite from family and formal services. His partner's family (mother, brother, and sister) would provide some respite. His partner also had a respite volunteer from an agency.

Friends. Of the support they received from friends he states, "The friends were amazing." Some, however, "dropped off." Through this time, he says, "We became very aware of the people who can walk with you and the people who cannot." "Some of the best friends were (name's partner) former partners." "Everybody had keys to everybody else's house." Friends provided respite and socialized with them. Some friends were also HIV positive. He says they really needed the socialization and says, "The laughter was there and he needed people around like that."

OC: As with other respondents, former partners were in their circle of friends. Others have also noted that some friends "dropped off." The emotion in his voice is apparent as he talks about the wonderful support they received from friends.

Caregiving and prognosis. He said "I was in my denial mode. I could talk about the mechanics of it (of the care)." It was difficult to think about the prognosis and what was ahead.

OC: Denial about the situation is a common theme among the respondents.

Advocates, etc. "In a long-term chronic illness and especially if it's terminal illness, you need to have an advocates...it becomes a full-time job. When he went to the doctor, I went so I could drop in information that he might forget. I knew what all the medications were and he didn't always." You need advocates because "there was so much stuff you had to keep track of. When he was in the hospital I went with him and I was the one opening the book...you know, the one's that the nurses at that time were saying you couldn't open...saying excuse me but I need to know what you are doing with the medications because some of the medications he was getting they couldn't give him in the hospital because they were coming out of test and not coming out of the hospital pharmacy."

OC: Need for an advocate is another common theme. There is so much to manage in these situations.

Disclosure to professionals. When asked about how they disclosed the nature of their relationship to professionals he says, “From the first time he ever went to the hospital it was a definite from him ‘This man comes with me everytime I come in. This man is my partner and he stays with me whenever he wants to and whenever I need him to.’” “We were always in the same hospital and it had to only be done once.” The hospital and the doctor were both known for HIV/AIDS care. He said, “It only had to be said the first time.” They were living in a large metropolitan area on the East Coast during caregiving.

OC: Hospitals with large numbers of HIV/AIDS clients are often more supportive. Here again, connections are important. This couple was very direct in their disclosure and it worked well for them in their interactions with medical professionals.

Future plans together and moving on. If his partner could have moved his health plan they would have moved West. Respondent has since moved out there. He has also started working on a degree in counseling. He says of his partner, “He is still sort of like my guardian angel.” He said the caregiving experience “sharpened” his desire and motivation to get a counseling degree. He wants to work in grief and loss issues but does not see himself as being restricted to the gay community. He says he wants to work in the areas of grief and loss because “these are my issues.”

OC: He gets very emotional talking about his partner being his guardian angel. This experience has influenced his desire to help others who are grieving.

Support group. He joined a caregivers support group for HIV/AIDS during his partner’s illness. This was a positive experience. There was one straight man in the group whose wife contracted HIV from a transfusion. There were no problems with being accepted in this group. He adds that the “straight” man had “too many other things on his plate” to be homophobic.

OC: It seems that all of those who attended support groups (gay or mixed) have had good experiences. Perhaps the common experience of illness and loss keeps others from focusing on differences (sexual orientation)??

In-home services. They had home health at the very end. This was a good experience except for that they kept “switching schedules” on him. This was stressful because he didn’t want any surprises because of his work schedule, etc. One of the MDs changed a drug on him and he looked it up and found a side effect. He had to keep up on the doctors and nurses and what they were doing. He said, “I learned to be assertive.”

OC: Most have also mentioned good experiences with in-home services. Becoming more assertive is another outcome of the experience.

Professionals. He didn’t have any problems with professionals because it was “big city.” He does describe a situation when his partner became ill while doing business in the

Midwest. His partner had an accident and a head injury while there (in a small town). The respondent flew out there and the staff didn't know what to do with his partner because he had HIV/AIDS. One of the doctors said to the respondent, "'Well, of course you are positive too.' And I said, 'well, no.' And he said, 'How can that be?' And I said, 'Doctor, haven't you ever heard of safe sex?'"

HMO. He said the HMO was very good.

Disclosure to professionals. They were up front with the home health staff about their relationship. "And, again, this was always from the standpoint of as long as you are secretive and as long as you tip-toe around, it remains your problem. Put it out on the table, be direct and up front and do the things you need to do for yourself and it then becomes other people's problem. They can either deal with it or they can't. They can make a choice."

OC: Wonderful insight...put it out there and it becomes their problem, otherwise it remains your problem.

Disclosure. He said his previous partner was very much in the closet and he got tired of it. With the partner he cared for, things were always up front and he says things were much easier that way. "You have all of things to deal with and that (being in the closet) shouldn't be one of them."

OC: From experience, he has become an advocate for directness.

Coworkers. People at his workplace (the family business) were supportive during this time. He went back to teaching and said when his partner died he had just started in a new school. He couldn't confide a lot initially but they were supportive in time. The city where they lived also had sexual orientation statutes related to employment.

OC: This is the first respondent to mention sexual orientation statutes in their area. I'm sure this makes a difference who persons who might otherwise fear losing their jobs.

HIV services. They were also connected to an HIV/AIDS organization but didn't use them much. They didn't really need a case manager at the time because they could do it all (finances, etc.) themselves.

Activism. "One of the things that made it easier was that (name's partner) was so politically active." His partner helped pass sexual orientation legislation in their city. "Of course if they had fired every gay teacher, they would have had to shut the school system down."

Discrimination. His partner grew up middle class. Even though this was the case, he says, "Everybody assumed that he was inner city." This included the hospital staff (in the

Midwest town where he had the accident). “You do get into a black and white thing.” At one point he was taken to the “poor” hospital. When they found out he had insurance, they moved him to a different hospital (during his accident in the Midwest).

OC: Added discrimination because of race.

Layers of discrimination. “These layers were always there...with the racial difference and the age difference and same sex... we were always very much aware of it.” They always dealt with it head-on.

Therapy for loss. He went to therapy after partner’s death. He says, “The level of loss was so overwhelming...it still is.”

OC: He gets very emotional talking about this.

Moving on. He has had 2 partners since this loss and is currently in a one-year relationship. In his current relationship he says, “All the pieces that I always wanted are there...but I still cry over (name’s former partner).”

OC: This loss is not something that is replaced by a new relationship.

Goals, etc. Says he has met every goal since he lost his partner. He says he has anger that “he isn’t here experiencing the things that I am...in some way he has missed these things.” “He was on his way with his stuff and he couldn’t do it (he had started his own business).” They got tested together and they found out that his partner was HIV positive. At that time, people were not living long with this illness so he didn’t know what long-term care was. “This long-term care thing hadn’t hit yet and if it was it was underground.”

OC: This isn’t easy for him to talk about.

Outcome of the experience. He says that his partner was his “motivator.” “This is somebody that I still love.” The experience gave him clarity about what he wants in relationships, in life, etc. and “brought things into focus.”

Moving on. He became a facilitator of a support group. He also gave a workshop on caregiving at a national gay health care conference.

Retirement. “I don’t see myself retiring. The people my age bore me to death because they want to retire.” Says he has extraordinary good health. Says he has money but will always have to work, “There is no retirement fund.”

OC: Others have mentioned not having much money for retirement.

Changes to health and human services. He suggests, “Accepting people as human beings...knowing that, regardless of who this person is...whether it’s a older man or a older woman...that there are feelings there, there are needs there. It’s a sort of a hard one. I’m sort of spoiled. I’m in an area where there are really good services. That’s one of the reasons I chose to move here. I didn’t wanna start all over again. I wanna go somewhere where they have a sexual orientation bill. I’m not fighting this battle again. So, when I go (move), I’m gonna be a place where I’m comfortable. So, I’m in a place where there is a lot of awareness. It’s just for people to be aware. Be accepting of people for who they are, what their limitations are, and as a professional do your job...do what it is you are trained to do...if you are trained to be a good doctor, be a good doctor and don’t be a judge of human nature...just take care of the patient and understand what the limitations for the patient are and the people around them. It goes back to my thing ...in the long run, people do the best that they can...they do what they know how to do as well as they are able to do it at the time and to expect them to do what you want them to do isn’t always fair when they don’t know how you’ve learned to do it.”

OC: This is great...professionals should do their jobs and not be judges of human nature. A concern in retirement is living in a progressive area.

Internet. He heard about the study on the Internet. He didn’t discover the Internet until after his partner died.

Sampling suggestions. He suggests recruiting from HIV/AIDS organizations. He might also personally know of other people for the study. He mentions a friend who is a “serial caregiver” and has taken care of a few partners.

Progressive area. He talks about how progressive the area he lives in is.

Services. When his partner was ill, they had Meals on Wheels that were for persons with HIV/AIDS.

Caregiving experience and commitment. He says of the experience, “For myself I would say that if I had to do it all over again, I would. No exception to that. I remember that minute when they told us that (names partner) was positive and he turned around to me and said, ‘Well?’ and I looked at him and I said, ‘What do you mean well? Do you think that I’m going to give up one minute...ya know, I don’t know, but we’ll deal with it. It’s OK.’ I was not gonna give up one second with this man. I was just totally, madly in love with him. This commitment brought us a lot closer and he was surprised I didn’t jump ship.”

OC: This is interesting, receiving this news early in a relationship and making a commitment to a partner during this time.

Study. Says he “really appreciate the opportunity” to participate in the study.

Post-caregiving support. “One of the things that was so important for me in that first 6 months after (names partner) died was the experience on the Internet, talking to other people who had gone through or were going through comparable experiences. That whole support group sort of mentality. I was constantly meeting people to my total amazement that it would turn out that we were going through these parallel experiences. People were able to pull me along because it had happened to them much earlier. I, in turn, was able to talk to other people who were at a place I had been.” He agrees that it is important to connect with people who have been through or are going through the same experience and people “who need the support also, it has to work both ways.” He is really for group support.

OC: The Internet appears to be a good place for these folks to meet others who have been through the same experience. Again, the importance of finding others who have been through what you have been through.

Changing to counseling field. He says he feels like “I have found where I belong.” (in getting into the counseling field).

APPENDIX D: CODING SAMPLE

(Represents one page of coding)

Post-caregiving

Period following the cessation of care

Outcomes of the experience

Changes made in life or outlook on life that were influenced by the caregiving experience and, for some, by losing their partner

#002-M-PG, P5/L44-47

The experience has made him much more emotionally sensitive to other's loss and to what they need. In the past he always worried about what to say, etc.

He is also having a colonoscopy next week at his annual check up because he doesn't "want any surprises".

#004-M-PG, P4/L11-14

What he got out of this is the importance of balance in his life, time for family, church, etc. He is no longer interested in "building up a huge retirement account" or cares if he is poor the rest of his life. "To be able to have that kind of a relationship with someone and going through that death experience is an eye-opener".

2#004-M-PG, P1/L18-20

As the result of the caregiving experience, he says material things aren't really important to him. He recently had a fire in his house since the last time we talked and lost a lot of items.

2#004-M-PG, P1/L43-44

He says he "never wants to go back a position like that, that stress, when a job was more important than a relationship."

#006-M-PG, P2/L42-43

He feels the intimacy he experienced in this situation empowered him to move on into another relationship. Respondent was in another relationship within 6 months.

APPENDIX E: INFORMED CONSENT FORM

CONSENT TO PARTICIPATE IN A STUDY OF CAREGIVING AND POST-CAREGIVING EXPERIENCES OF OLDER GAY MEN AND LESBIANS

You are invited to participate in a study of caregiving experiences of gay men and lesbians who are currently or have previously provided care for older partners with a chronic illness. This study is being conducted as part of a doctoral dissertation. The research interview includes questions about your experiences in providing care, including the strains and role changes which may have resulted, the positive aspects of providing care, and the informal and formal social support networks and services that you may be currently using or may have previously used. If your partner has died or has relocated, questions will also focus on the changes that have occurred since the loss or relocation of your partner. The interviewer will use an audio tape recorder during the interview.

Benefits: You will derive no personal benefit from the study. Your participation will benefit others by enabling social scientists to learn about the experiences of gay men and lesbians providing care to a partner. This information may help in the development of appropriate services to be provided to people like you. You may request a copy of the study report.

Alternative Therapy: This is not a therapeutic study. You have the alternative not to participate.

Risks, Inconveniences, and Discomforts: The study asks about experiences that may be unpleasant to recall. This recall could stir up feelings that may cause some discomfort. Additional risks associated with your participation in this study are: having confidential information collected, being asked personal questions, being taped using an audio device, and being inconvenienced by the time spent in the interview (a total of about one to one and one-half hours).

Cost of Participation: The only cost to you for participating in the research is the time that you will spend during the interview.

Research Related Injury: In the event of physical and/or mental injury resulting from your participation in this research project, Virginia Commonwealth University/MCV Hospitals will not provide compensation. If injury occurs, medical treatment will be available at the MCV Hospitals. Fees for such treatment will be billed to you or to appropriate third party insurance.

Confidentiality of Records: The researchers will treat your identity with professional

standards of confidentiality. The information obtained in this study may be published, but your identity will not be revealed. No identifying information will be used to connect personal information about you to the audio tape recording. No identifying information will be used to identify you in the data analysis or the final report of study findings. Access to research data is limited to the principal investigator and her dissertation committee.

Withdrawal: Participation in this study is voluntary. You are free to withdraw your consent and discontinue participation at any time. You may ask that the interview be stopped and that the audio recording be destroyed. You may also request after the interview that the information gathered in your interview be destroyed.

If you decide to withdraw from this study, you should contact Dr. F. Ellen Netting, Professor at (804) 828-0404. Discontinuation will in no way affect or jeopardize the quality of care you receive now or in the future at this institution.

Authorization for Participation: I understand that as a participant in this research study:

- My participation is voluntary. I am not required to participate; I can choose to quit at any time.
- The confidential research interview will be recorded using an audio recording device.
- My identity will not be revealed in any publication or document resulting from this study, or to anyone other than the research interviewer and her faculty mentor.

I have read or had read to me the above, and I have decided that I will participate in the research interview. Its general purposes, the particulars of involvement and possible risks and benefits have been explained to my satisfaction. My signature also indicates that I have received a copy of this consent form.

Research Participant's Name (Print): _____

Research Participant's Signature: _____

Date: _____

Witness Name (Print): _____

Witness Signature: _____

If you have further questions about the research interview you may contact the Principal Investigator, Kris Hash, MSW at (804) 266-5136 or Dr. F. Ellen Netting (804) 828-0404. If you have questions about your rights as a research subject you may contact the VCU Committee on the Conduct of Human Research at (804) 828-0868.

APPENDIX F: RESOURCE LIST

RESOURCES FOR CAREGIVERS AND WIDOWS/WIDOWERS

Pride Senior Network

(212) 757-3203

www.pridesenior.org

Senior Action in a Gay Environment (SAGE)

(212) 741-2247

www.sageusa.org

Gay Mens Health Crisis

(212) 367-1000

www.gmhc.org

Gay and Lesbian Medical Association

(415) 255-4547

www.glma.org

Family Caregiver Alliance

(415) 434-3388

www.caregiver.org

National Alliance for Caregiving

Email: gailhunt.nac@erols.com

www.caregiving.org

The Eldercare Locator

(800) 677-1116

www.aoa.gov.elderpage/locator.html

**Your local area agency on aging, department of social services, and office of mental health are often excellent resources for support services in your area or for help if you are in crisis.

APPENDIX G: MEMBER CHECK LETTER

12/15/00

Dear Participant:

Thank you so much for agreeing to be a “member checker” for my dissertation study. A member checker is someone who initially participated in the study and later provides feedback on the findings. Your time and effort is greatly appreciated and your input will truly enhance the quality of the study.

As you may recall, the purpose of this study was understand the unique experiences of gay men and lesbians 50+ who are currently or had previous provided care for a partner. Information was collected by phone or face-to-face interviews with those who participated in the study.

I have enclosed a draft the “Findings” section for the study. I call this a “draft” because it may be adjusted depending on the input received from the member checkers. Please carefully examine this document and judge the accuracy of its main points, conclusions, and interpretations. You may want to note areas that need clarification, or information that you feel should be added or deleted. Please also note any problems you see that may jeopardize the confidentiality of those whose experiences are cited in the findings.

In approximately four weeks I will call you to discuss your feedback. I will contact you in advance to arrange a date and time that is most convenient for you. The feedback you provide will be considered, along with the suggestions of other member checkers as well as those made by my dissertation committee, for inclusion in the final draft.

If you have questions or need to reach me, feel free to contact me at (804) 266-5136 or by email at s2kmhash@atlas.vcu.edu. Please also contact me if you find that you are unable to assist with this process.

Thank you so much again for your time and commitment to this process and this study. I look forward to talking with you again soon.

Sincerely,

Kristina Hash
Ph.D. Candidate

APPENDIX H: SAMPLE FIELD JOURNAL

Date: 7/18/00

Re: #008-F-PG

I began the interview with these questions in mind:

1. What are the strains and positive aspects involved in providing care and following the cessation of care?
2. Given these experiences, what are the long-term plans and decisions that are made and how are they made?
3. What are the implications of the caregivers' experiences for health and social service professionals and for supportive policies and programming?

As the result of this interview, I learned the following:

The respondent appears to have a lower income level than previous respondents. There was also 10-year age difference between the respondent and her partner. The respondent was very upfront with professionals about the nature of the partner relationship and suggests that being upfront and having legal documents (POA's etc.) on hand can assure more respectful treatment. This case also highlights the importance of connections with gay/lesbian or gay friendly professionals to assure better treatment. The respondent also reports much better treatment (as a couple) at the hospitals as opposed to the nursing homes. Here we are also seeing additional discrimination based upon mental health status in health care settings. This is also a clear example of disenfranchised grief, as she did not receive consideration in bereavement from her mother or many of her coworkers.

Continuing themes:

connections, upfront disclosure and documentation, additional discrimination, disenfranchised grief

Other topics worth investigating in future interviews include:

Differences between treatment of the relationship at hospitals v. nursing homes
Does having POAs etc. really make a difference for these couples?

Keep looking for signs of disenfranchised grief
Keep track of reasons for not wanting to go to “straight” support groups
Be aware of large age differences between the couples
Stay in tune with styles of disclosure

Respondent’s recommendations for sampling this population:

Two groups, Mountain Mammals and OWLS (both lesbian groups).

Issues for sampling:

Try to get more rural respondents
Connect with gatekeepers in rural areas
Need to attract persons of different economic statuses
Continue to place ads in G/L newspaper with large circulation

Vita**KRISTINA MICHELLE HASH**

Kristina Hash was born on December 6, 1968, in Newark, Ohio and is the daughter of V. Wade and Anne Smith Hash. She grew up in Columbus, Ohio and received a Bachelor of Arts Degree from the College of St. Catherine in St. Paul, Minnesota in 1990. At The College of St. Catherine she majored in Psychology and Sociology, minored in Women's Studies, and was a member of the Varsity Tennis Team. The Master Degree in Social Work was earned from West Virginia University in Morgantown, West Virginia, in 1993. A Graduate Gerontology Certificate was also earned from West Virginia University in 1996. She was the recipient of the Phi Kappa Phi award at Virginia Commonwealth University in 1998. Her volunteer and paid work experience includes positions in residential independent living, hospice, home health and social work continuing education.