

Chapter Five

IMPLICATIONS

Review of Study Purpose

The purpose of this study was to recognize and better understand the experiences of midlife and older gay men and lesbians who provide care for chronically ill partners as well as their experiences following the cessation of care. It was hoped that through this inquiry, implications for supportive policies and effective professional practice with this special population of caregivers could be identified.

Relation of the Findings to Previous Studies

Caregiving and Loss

An integrative diagram was developed to summarize the study findings and show relationships among its concepts (see Figure 5.1). In looking at the diagram, the concepts do not appear to reflect an experience that is dramatically different from what heterosexual couples might experience. Examination of the nuances within each concept, however, will uncover the unique aspects of this experience for midlife and older gay men and lesbians.

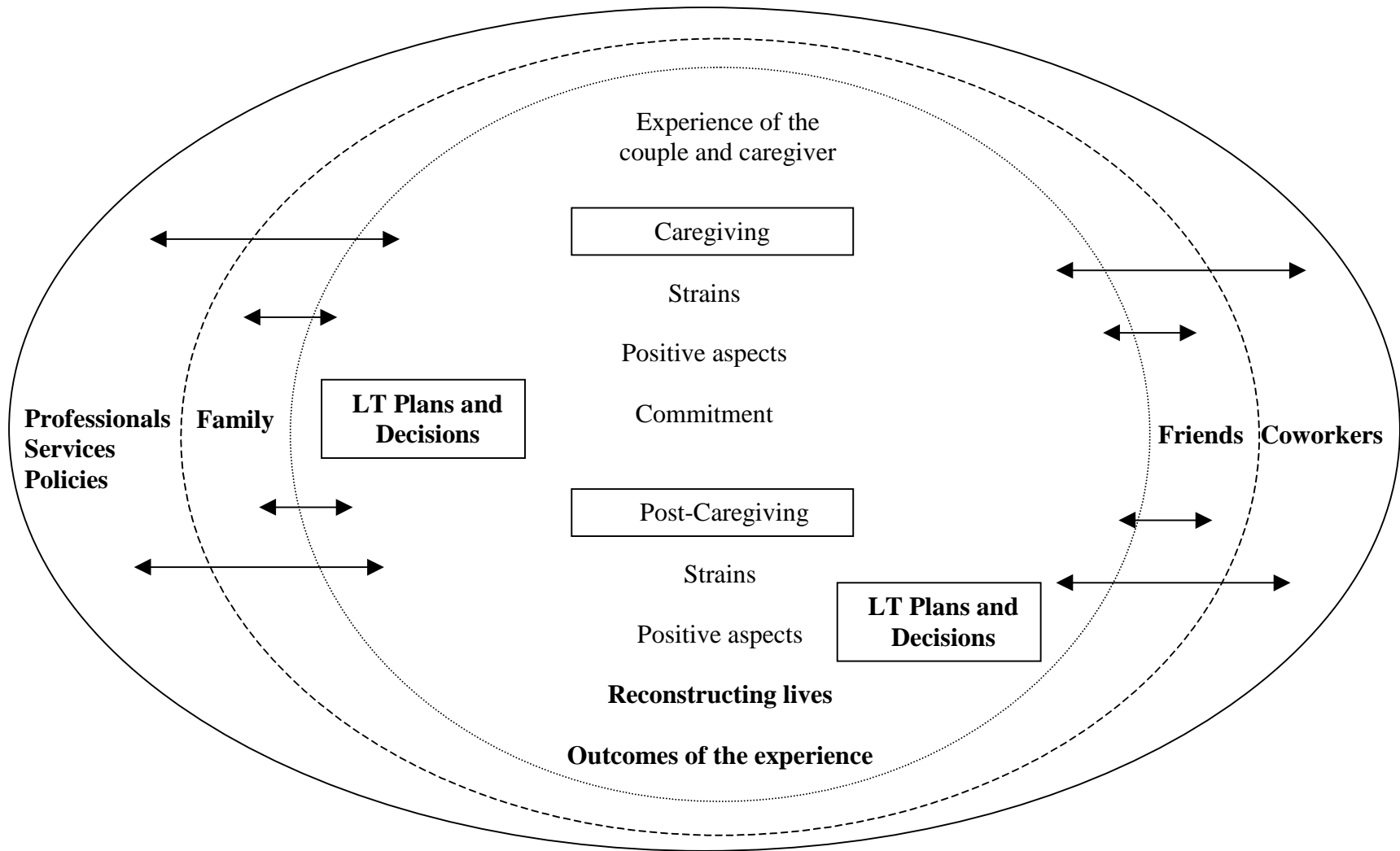


Figure 5.1. Integrative Diagram of Caregiving and Post-caregiving Experiences

Common Aspects of the Experience

It is clear that respondents in this study experienced many of the same strains and positive aspects of caregiving and post-caregiving as those in previous caregiving studies (see Table 5.1 for a summary of common and uncommon aspects). As in the general caregiving literature, one person managed the bulk of caregiving responsibilities (Baum & Page, 1991; Brody, 1985). This produced physical strains including exhaustion, lack of sleep, poor eating habits, and physical strain related to hands-on care. Decreased finances were also mentioned as were strains on the relationship and conflicts with employment responsibilities (e.g. Kinney & Stephens, 1989; Kosberg et al., 1990; Poulshock & Deimling, 1984; Zarit et al., 1980). Following the cessation of care, respondents experienced feelings of loneliness, loss, and depression and had difficulty adjusting to the loss of the caregiver role.

Table 5.1

Common and Unique Aspects of Caregiving and Post-caregiving for Midlife and Older Gay and Lesbian Primary Caregivers

	Common Aspects	Unique Aspects
Caregiving	<p>Shoulders most of the caregiving responsibilities</p> <p>Experiences emotional, physical, and financial strains as well as conflicts with employment responsibilities</p> <p>Values the opportunity to show love and commitment through providing care</p>	<p>Deals with family, coworkers, or professionals as well as policies and practices that are not sensitive to or supportive of their relationship</p> <p>Faces disclosure issues related to the nature of their relationship</p> <p>Makes unique plans and decisions and reasons for them may relate to being accepted or to protect the relationship</p>

	Common Aspects	Unique Aspects
Post-caregiving	Experiences emotional distress following the cessation of care	Has the challenge of re-entering the gay community
	Feels a sense of loss over the caregiver role	May have outcomes of the experience that are related to being gay or lesbian
	Experiences positive effects from no longer providing care	Deals with family, coworkers, or professionals as well as policies and practices that are not sensitive to or supportive of their relationship
	Faces the challenge of moving on after the cessation of care	Experiences grief that may not be recognized
		Makes unique plans and decisions and reasons for them may relate to being accepted or to protect the relationship

As in studies of the general population, positive aspects of caregiving and caregiving cessation were noted by respondents (e.g. Farran et al., 1991). Positive aspects of caregiving included an opportunity to show love and maintain a commitment to a significant other. As many coworkers, family members, and professionals were surprised, the commitment of these couples was just as strong as that of their heterosexual counterparts. As common positive aspects of post-caregiving, respondents enjoyed improved physical health, increased social interaction, and more time to attend to their own needs (e.g. Gold et al., 1995). As one would expect many caregivers to also experience, the respondents were challenged with reconstructing their lives following the cessation of care and moving on with their lives following the loss of the caregiver role. The caregiving experience and loss were also life-altering experiences that produced various outcomes in their lives.

Unique Aspects of the Experience

Important in this study are the unique aspects of caregiving and post-caregiving for this population. These aspects exist as the nuances within each of the study concepts. These concepts include reconstructing lives, outcomes of the experience, long-term plans and decisions, and informal and formal supports (noted in bold type in Figure 5.1). These are what make this experience unique to midlife and older gay men and lesbians

Reconstructing lives.

As evident in this study, post-caregiving is a time of tremendous change and growth for someone who has provided care to a significant other. During this time, the caregiver had the challenge of reconstructing his/her life following the cessation of care. For many this meant redefining themselves and getting a new focal point in their lives. They also faced the challenge of re-engaging in the outside world and moving on into new relationships. This process of re-engagement and moving on appears very different for gay men and lesbians.

In contrast to traditional caregivers, respondents ventured out in the gay community and sought out gay and lesbian peers and/or potential partners. For some this was a major challenge, as during caregiving they may have become disconnected from the supports available in the gay community. This re-engagement can be even more challenging for persons who had been partnered for decades and had been somewhat isolated or closeted in their relationship. Some also found dating to be quite difficult. In dating, gay men may also feel pressure related to physical attractiveness, as many described the gay dating scene as a “young market.”

Outcomes of the experience.

As one would expect for any individual, the caregiving experience and the loss of the caregiver role had a tremendous impact on the lives of the respondents. Some outcomes for these caregivers, however, were related to their sexual orientation. A few respondents became more “out” as a result of having provided care to a partner. Some also became more open about their sexual orientation in the workplace as well as with professionals

and family members. This experience propelled a few respondents into activism on behalf of issues related to gay men and lesbians. As mentioned, one female respondent even created an organization to meet the social needs of older lesbians.

Long-term plans and decisions.

In many ways the long-term plans and decisions made by the couple and the caregiver are very different from their heterosexual counterparts. Although many couples set up advanced directives, the reasons the respondents and their partners drafted these documents are seemingly very different. Many set up advanced directives to ensure that their wishes would be protected within health care and other settings. For some, this was based on a fear that their family members would try to interfere with their plans. These family members were not accepting of the partner relationship. Additionally, some used advanced directives to clarify the nature of their relationship and their wishes to health care professionals.

I would also guess that the financial and property arrangements of these couples are very different from midlife and older heterosexual partners. One would expect that the finances for heterosexual couples would be more combined in comparison. In thinking about retirement, these respondents had the added concern and desire to reside in a community where they would be accepted. Although most adults do not wish to reside in a facility, gay men and lesbians have an added fear of being ostracized or harassed because of their sexual orientation in these institutions.

Informal and formal supports.

As would be the case in any caregiving or post-caregiving situation, persons outside the relationship were involved and impacted the experiences. In the lives of the respondents, informal and formal support persons and services had the capacity to adversely or positively affect the couple and caregiver. Similarly, the couple and caregiver many times influenced and left a permanent impression on the lives of those they encountered. Through their interactions with the individual and couple, some were given the chance to better understand the relationship and its integrity.

Respondents dealt with special issues related to informal support persons. Most notably, they were often faced with persons who were not accepting of their relationship. As a result, some family and coworkers did not acknowledge the relationship or provide the level of support that was needed in caregiving or bereavement. Ex-spouses and adult children, in some cases, were particularly hostile toward the couple and the caregiver. Despite family and coworkers who were unsupportive, some respondents had the advantage of a strong network or “family” of friends. This type of network is considered unique to gay men and lesbians. Some friends, however, were too busy to help out or “dropped off” after the partner became ill or after he/she had died.

Respondents also dealt with special issues related to formal support persons and services. Although not always blatant in their expression, some professionals did not accept the rights or lifestyles of the respondents. In addition, the procedures and practices within organizations were not, at times, sensitive to their special needs and relationships. It is not surprising, then, that support from formal support persons was

generally not anticipated, as the respondents seemed to expect to be faced with insensitive and unsupportive individuals in health care settings. Additionally, they were apprehensive about using formal support services, including support groups and in-home services. Their need and ability to network with other professionals who are supportive of their lifestyle is also unique to this population of caregivers.

Another unique aspect of the caregiving and post-caregiving experience for the respondents is that they often faced disclosure issues. Although a couple may not have been “out” with persons outside their circle of friends, a health crisis may compel them to define the relationship to family members, employers, and professionals. Respondents had various styles of disclosure, from “don’t ask, don’t tell” to direct verbalization of the nature of the relationship.

Disclosure was an especially sensitive issue in the workplace. Asking for time off for caregiving and bereavement was complicated for many of these caregivers. Although many caregivers face conflicts with employment responsibilities, many gay and lesbian caregivers also feel that they must hide the true nature of their relationships. Some cannot risk being fired, as they are often the sole breadwinners during caregiving. As a result, they often had to “build” excuses for why they needed time off to care for an unrelated person. Even if a caregiver was “out” to employers, policies in the workplace (such as bereavement leave) were not always extended to same-sex partners.

In the workplace as well as among family and professionals, respondents had added challenges in bereavement. With regard to bereavement support in post-caregiving, this study further evolved the concept of disenfranchised grief. Not only must older gay and

lesbian widows(ers) deal with an immense loss, but they have the added strain of not having their grief recognized as legitimate. Because they were in a same-sex relationship, they were not granted the same level of support or sympathy from some family members, coworkers, or professionals. In some cases this was apparent through formal or informal policies in the workplace, in agencies, or in community businesses. Other times, it was evident in the expressions (or lack thereof) of sympathy from individuals. In addition, they may have also had to hide their grief from those they did not believe would be understanding.

Other Contributions of the Present Study

The present study provides for the unique caregiving and post-caregiving experiences of midlife and older gay and lesbians. This study also extends knowledge in the areas of caregiving and loss in other ways. First, the stories of caregivers after the cessation of care are rarely told. Instead, the literature has overwhelmingly focused on the experiences of persons currently providing care and has neglected the events that occur after caregiving ends. As this study reveals, the end of caregiving can be devastating for those who lose their partner or leave the caregiving situation.

Just as the experiences of post-caregivers are not often investigated, the stories of persons who leave a caregiving situation are not customarily considered. As was revealed in this study, not all caregivers cease caregiving because a care-receiver dies. Some chose to leave the situation and the caregiver role is transferred to a relative or friend. Others cease caregiving because the care-receiver is no longer ill. Despite the

reason for the cessation of care, post-caregiving involves a loss and major changes in the life of a caregiver.

The strains of caregiving have also been the focus of the bulk of caregiving studies. As learned from this study, though, caregiving is not just a burden. On the contrary, caregiving also offers great opportunities for growth. This experience can bring couples closer and can build strength in the caregiver. The experience can also provide a caregiver an opportunity to convey love to a partner through their commitment to provide care. Through this commitment and care provision, a caregiver can learn what he/she is truly capable of and can gain tremendous strength in the process.

Midlife and Older Adulthood for Gay Men and Lesbians

What was learned from the study respondents also adds to knowledge in the area of gay and lesbian midlife and older adulthood. This particular study reinforces the great diversity within gay and lesbian relationships in later life. For example, several of the respondents were in relationships where there was a ten to twenty-year difference in age. Additionally, four of the nineteen respondents were partnered with persons who were a different race.

This study also provides insight into the long-term planning and decision making of older gay and lesbian couples. Their division of finances and long-term plans also proved to be very diverse, with many different arrangements of personal finances and property. They also established advanced directives and other legal protections to ensure

that family members and professionals upheld their wishes as well as to define the nature of their relationships.

The respondents' own long-term plans also add to the understanding of retirement and care issues for gay men and lesbians in later life. Many thought specialized housing for gay and lesbian seniors was a good idea, although some did not find it to be an affordable option. For some, it was enough to live in an area with progressive laws and services. Like most adults, the respondents wish to be cared for in the community as opposed to a facility. Unlike most adults, though, they have the added fear of being treated poorly by staff because of their sexual orientation. Some also feared that they would not have support persons in the community in the event that they would need care in the future.

This study also tapped into certain attitudes held by the respondents, including their attitudes towards professionals and support services and their attitudes regarding disclosure to persons outside of the relationship. Interestingly, many respondents did not expect to encounter supportive professionals. This was true even for persons who had not had negative experiences with professionals to date. Many were also apprehensive about attending a "straight" support group, as they believed its members would not be supportive and would not understand what they were going through. Despite this fear, respondents that attended these groups all had very positive experiences and were supported by group members. Respondents also provided suggestions for how to increase the likelihood of having positive experiences with professionals and for how to deal with unsupportive professionals.

The current study also added insight into the support networks of midlife and older gay men and lesbians. Many respondents mentioned a close group of friends who provided support to the couple during the illness and to the caregiver following the cessation of care. A few also mentioned that their “family of friends” was their primary source of support. Others found ways of creating special support networks during caregiving. Some family members were also supportive and were included in these support networks.

The current study offers certain implications regarding “family of choice” and its role in this particular life crisis. A family of choice or “family of friends” may have good intentions and may provide support, but may not be equipped to assist with the increasing demands of a caregiving situation. Even in acknowledging a supportive network of friends, some noted that although friends provided emotional support, they were often too busy to assist with the hands-on care. In other cases, friends completely “dropped off” when the partner became ill and the couple was no longer able to attend social functions. In any case, the bulk of the caregiving tasks essentially fell upon the partners. It was only in rare instances when persons in the support network were fully entrenched in the daily caregiving experience. For many, a family of choice may be principally available for emotional support and comfort. Hands-on care may be solely the responsibility of the partner, another primary caregiver, or a formal support service.

Attitudes and Behaviors of Professionals

This study abounds with stories of the interactions respondents had with professionals and adds significantly to knowledge in the area of professional attitudes and behaviors. Interactions respondents had with professionals were both positive and negative and the majority of the negative experiences were very subtle. In fact, only a few respondents mentioned blatantly homophobic gestures made by professionals. Despite this fact, many respondents sensed that some professionals did not approve of their relationship and, as a result, were rude, hostile, or distant in their interactions.

Although blatant and subtle homophobia clearly exists in the field of health care, other issues compound the already difficult experiences of gay and lesbian caregivers. In fact, some respondents experienced layers of discrimination. This discrimination was based upon not only their sexual orientation, but also on age, race, HIV status, and mental health status. It is also important to note that poor treatment is not always due to underlying attitudes of professionals, as some are simply practicing in alignment with the culture of health care. The very nature of health care can be troublesome for many consumers as several respondents mentioned the fast-paced and impersonal treatment that all consumers receive in these settings. As a result, doctors, nurses and social workers are often too occupied to take the time to understand the unique needs of each client.

It is not just health and human services professionals who can adversely effect the caregiving and post-caregiving experiences of midlife and older gay men and lesbians. As the attitudes and actions of health and human service professionals have been expansively studied (e.g. Berkman & Zinberg, 1997; Douglas et al., 1985; Garfinkle &

Morin, 1978; Graham et al., 1984; Gramick, 1983; Harris et al., 1995; Kelly et al., 1987; Rudolph, 1988a; Rudolph, 1988b; Scherer et al., 1991; Wisniewski & Toomey, 1987; Young, 1988), attitudes and interactions with professionals in the business community have been neglected in the literature. These professionals, including those who work in funeral homes and cemeteries, can also make the post-caregiving experience even more difficult for these individuals. In some cases, they added significantly to the disenfranchised grief experienced by the respondents.

The consumer's response to poor treatment has also not been adequately explored in the existing professional attitude and behavior literature. These consumers are not simply passive victims, but can be very proactive in dealing with homophobia and heterosexism. Respondents in this study were able to combat the negative attitudes and behaviors they encountered. They were also able to educate professionals as to the nature and significance of their same-sex partnerships. Fortunately, this study also revealed professionals who were understanding and supportive of the respondents and their partners.

Implications for Change

As mentioned in Chapter Four, respondents provided several suggestions for changes that could be made to health and human services. These changes would allow professionals and organizations to better meet the special needs of midlife gay men and lesbians who care for chronically ill partners. The respondents suggested changes that

could be made to the practices of professionals as well as changes that should occur at the societal and governmental level. These suggestions will be incorporated into the suggestions and implications that follow.

Implications for Society and Larger Policies

Clearly, the institution of marital or domestic partner rights for same-sex partners would improve the lives of gay men and lesbians of many ages, in many areas of their lives. With that type of legal recognition in place, policies such as Social Security survivor benefits as well as equality within 401(k) and pension benefits would be the logical next steps. It would also set the stage for changes in “next of kin” policies in health care facilities. Supportive leave policies in private and public employment would also likely follow. Making discrimination on the basis of sexual orientation in housing and employment illegal would also go a long way in protecting the rights of same-sex couples. Cahill et al. (2000) offers several other policy recommendations that could further promote equality for gay and lesbian couples in later life.

Changes in policies have the potential to change the attitudes of individuals and create a society that is more accepting of same-sex relationships. Hopefully, this would also positively change the attitudes and behaviors of professionals (in health and human services as well as in the business community) who work with gay men and lesbians in caregiving and post-caregiving. Possibly, this would also ensure that family members and coworkers would become more supportive of same-sex relationships. When caregivers perform the same kinds of care and the commitment is just as solid as

opposite-sex couples, their relationships should be equally protected by law and respected and supported by organizations and individuals.

Implications for the Gay and Lesbian Community

In looking at the experiences of the study respondents, it is evident that members of the gay and lesbian community can have a tremendous impact on the lives of caregivers and post-caregivers. It is also clear that these caregivers and post-caregivers, themselves, can make a great impression on the lives of those they encounter. As such, there are considerable implications for the gay and lesbian community that can positively affect the lives of its caregiving and post-caregiving members.

As suggested by a few respondents, members of the gay and lesbian community can increase their awareness of and involvement in the lives of caregiving couples and bereaved individuals. In this way, members of the gay and lesbian community can organize to develop specialized services or supports. Anna's activism is a perfect example of how an individual can recognize a need in the gay community, join with others, and develop a supportive service or group that addresses that particular need. Or, as in Marjorie's case, individuals can form a type of co-op and provide supportive services to its individual members. Members of the community can also network with each other to ensure that individuals are referred to supportive professionals. This may be particularly important in regards to professionals in the business community, including those who work in funeral homes and at cemeteries. Regardless of the mode of

intervention, there is much that can be accomplished if individuals organize and attempt to meet the needs of this special population of caregivers.

In addition to organizing and providing services and supports, gay men and lesbians can ensure that established organizations provide a supportive environment and attend to the special needs of their caregiving and post-caregiving peers. Specifically, they can intervene in the policies of organizations and the attitudes and behaviors of professionals. Gay and lesbian staff members can assist in evaluating and changing formal and informal policies that exist in their organizations. In addition, they can become more visible to gay and lesbian consumers within their organizations. As one respondent mentioned, staff can wear pink triangle pins on their nametags, etc. Gay and lesbian consumers can also affect policies, practices, and organizational environments. Although it involves a risk, midlife and older gay men and lesbians can become more open with professionals about the nature of their relationships. This openness can give professionals and others the chance to be accepting and supportive. In many cases, they also have the capacity to educate professionals as to the integrity of the partner relationship as well as to their special needs and challenges. Along this same line, consumers can also identify and make known the organizational policies and individual practices that they find insensitive and unsupportive.

Implications for Organizations and Professionals

It is clear from Table 4.9 that the study respondents do utilize formal support services. Many of these services are also not gay or lesbian affiliated. It is also clear that many

respondents did not anticipate that professionals and services outside of the gay community would be accepting of their lifestyle or attentive to their special needs. With or without the support of larger policies, changes need to be made at the organizational as well as the individual practitioner levels to modify how these caregivers are treated as well as how they expect to be treated.

Organizations

To begin, health and human service organizations can evaluate their policies and procedures. According to Flynn (1992), policy can be formal and informal. Policies can be formal, as they are available in written form and are also verbalized. In light of formal policies, organizations can assure that “next of kin” is not limited to biological or legal family. Intake forms can also be evaluated to ensure that the language included is sensitive to diversity among human relationships. For example, forms that only contain categories such as “single, married, divorced, and separated” can be expanded to include choices such as “partnered” or even “other.”

Organizations can also evaluate the informal policies of the organization. Informal policies include those of individuals or groups of individuals that are not necessarily shared by other staff or condoned by the agency administration (Flynn, 1992). Jansson (1999) claims that informal policies are practices that develop in absence of a formal policy or as a way for practitioners to establish their own operating procedures. These informal policies can have the same effect as written policies in shaping everyday practice and can create an environment where these informal policies can flourish.

Informal policies, such as the behaviors of professionals towards gay and lesbian couples should be monitored by the organization. Individuals who make “slighting” or other derogatory remarks to gay and lesbian caregivers should be reprimanded by the organization. In assuring that formal and informal organizational policies are sensitive to and respectful of same-sex relationships, organizations can ensure that they provide an environment that is welcoming and supportive of this special population of caregivers.

To assure a welcoming and supportive environment, organizations can also provide sensitivity training to their staff related to gay and lesbian issues. Several resources are available to suggest content in this area (see Berger, 1983; Berger & Kelly, 1986; Connolly, 1996; Mallon, 1998a; Peterson & Bricker-Jenkins, 1996; Quam, 1997; Ramirez & Cohen, 2000; Sang, 1992; Schwartz, 1996; Tully, 2000; Van Wormer, Wells, & Boes, 2000). Many agencies and national organizations can also provide resources and advice for conducting sensitivity training in this area (see Appendix F).

Sensitivity training and education may be particularly important in skilled nursing and assisted living facilities, as gay and lesbian residents may be particularly vulnerable to poor treatment in these settings. Persons who must reside in these settings are less likely to be able to escape harassment and other actions of staff and residents. Because some gay and lesbian clients may be apprehensive about professionals coming into their homes, training should also be a priority for professionals in in-home services. It may make even more sense to train professionals to be sensitive before they become immersed in the fast-paced and often impersonal work world. In this case, higher education also

has a responsibility to train future professionals to be more sensitive to the special needs of gay men and lesbians.

Health and Human Service Professionals

Professionals in health and human service organizations (such as physicians, nurses, and social workers) need to acknowledge that midlife and older gay and lesbians have many of the same needs and challenges in caregiving and post-caregiving as those in the general population (see Table 5.1). They can also benefit from the same types of services to reduce the strain of caregiving and reconstruct their lives following the cessation of care. It can not be stressed enough that all caregivers, regardless of their sexual orientation, need to be treated as individuals. This becomes more difficult to achieve as health care organizations are under increasing pressure to cut costs and increase productivity. Although this involves more time, professionals need to make an effort to get to know consumers and their special needs and circumstances.

It is also important for professionals to recognize that this population of caregivers has unique challenges as well as unique resources in caregiving and post-caregiving (see Table 5.1). One of the most sensitive and delicate areas of practice with midlife and older gay men and lesbians is the area of sexual identity. As evident in this study, individuals have different styles of disclosure. Because older members of this population may not necessarily be comfortable with being out, professionals must tread lightly in this regard. Cook-Daniels (1997) suggests that practitioners “gently probe” about the nature of a suspected gay or lesbian relationship so as not to put an individual in an

uncomfortable position (by trying to identify them as gay or lesbian). With regard to disclosure, it is also important to listen to the client's definition of his/her identity and his/her relationships. For example, many women may not self-identify as "lesbian" or may refer to their partner as their "friend" (Humphreys & Quam, 1998; Kehoe, 1988).

Respondents have mentioned the need to be among persons who can understand, accept, and support them in caregiving and post-caregiving. This includes peers as well as professionals. To help meet this need, professionals need to be informed of resources in the community and ways clients can meet other gay men and lesbians who are going through the same experience. Similarly, they need to be informed of gay and lesbian support services in the community.

Some communities, such as New York City and San Francisco, have the luxury of specialized service organizations for gay men and lesbians in later life. Unfortunately, most professionals are not able to access such services for their clients and must rely instead upon referrals to respectful agencies and supportive groups within the gay community. Lists of gay and lesbian as well as "gay friendly" agencies and professionals should be made available and visible in all health and human service organizations. In addition, the Internet can be suggested (for those with computer access) as a way to connect with other midlife and older gay men and lesbians. Gay and lesbian clients can also be excellent resources for connections to "gay friendly" organizations and professionals.

Professionals must not only be aware of the formal supports that are available to midlife and older gay men and lesbians, but they should also seek to understand the

informal support persons involved in the client's life. In this sense, it is important for professionals to understand relationship patterns among midlife and older gay men and lesbians and to utilize their special support networks (Berger, 1982; Berger, 1984; Berger & Kelly, 1986). Additionally, professionals must deal with the "dual family" concept, which includes working with families of origin as well as families of choice (Gunter, 1992). In this manner, professionals can expect to work with not only the older gay man, but also with his partner, his former partner (now friend), mother, and possibly, his adult son from a previous marriage. On the other hand, professionals should not expect that a gay man or lesbian has a "family of choice" or that his/her friends are able to assist with care. Similarly, a professional must not assume that the families of origin are not available for support.

Regardless of the involvement of informal support persons, midlife and older gay and lesbian couples have special issues related to their long-term plans and decisions. Because they are not afforded many of the protections that come with legal marriage, gay and lesbian couples cannot be confident that their plans and wishes will be respected. In defense of partner relationships, professionals should be prepared to assist gay and lesbian consumers with advanced directives, including powers of attorney, living wills, and personal wills.

Implications for Social Workers

Social work has a historic tradition of and commitment to serving oppressed, marginalized, and disadvantaged populations (Fauri, 1988; Simon, 1994). This tradition

is continued and, in a sense, mandated by the NASW Code of Ethics (National Association of Social Workers, 1996). Through a commitment to social justice, social workers have a unique responsibility to attend to the special needs midlife and older gay men and lesbians have in caregiving and post-caregiving.

One of the most central values of the social work profession is that of social justice. According to Davis, Cox, and Adler (undated), social justice includes,

...equitable and fair access to societal institutions, laws, resources, opportunities, rights, goods, and services for all groups and individuals without arbitrary limitations or barriers based on observed or interpretations of the value of differences in age, color, culture, physical or mental disability, education, gender, income, language, national origin, race, religion or sexual orientation.

The Code of Ethics, in its commitment to social justice, entrusts social workers to “challenge injustice.” Injustice can include “issues of poverty, unemployment, and discrimination” (NASW, 1996, p. 5). In challenging injustice, social workers are to attempt to improve access to resources and opportunities as well as voice in decision-making for vulnerable and oppressed client populations. Additionally, social workers are asked to raise awareness of and sensitivity to oppressed and cultural minority populations. This can certainly be accomplished in work with midlife and older gay men and lesbians in caregiving and post-caregiving.

Because of social work’s focus on the challenge of injustice against members of oppressed groups, social workers are in a unique position to intervene on behalf of gay

and lesbian caregivers and post-caregivers. This intervention can and should occur through direct as well as policy practice.

Direct Practice

Direct practice “includes work with individuals, couples, families, and groups” (Hepworth, Rooney, & Larsen, 1997, p.24). Clearly, social workers in direct practice should engage in many of the same activities that were mentioned for all health and human service professionals. These activities include taking the time to understand the special needs and support systems of clients and connecting them to supportive organizations, groups, and professionals inside and outside of the gay community. Through their distinctive roles, though, social workers are in a unique position to assist gay and lesbian caregivers and post-caregivers.

As direct service providers, social workers may provide casework and counseling to individuals, therapy to couples and families, and guidance and skill development to groups (Hepworth et al., 1997). Awareness of and sensitivity to special problems, such as the lack of legal and social recognition of the partner relationship and isolation from the gay and lesbian community, are critical in planning direct service interventions with this special population of caregivers. An understanding of the unique support constellations and long-term plans and decisions of this population is also essential for effective and supportive work with this population. In addition, disclosure of sexual orientation is a significant and sensitive issue in direct service provision with this population. For example, social workers that facilitate support groups should be sensitive

to the apprehension on the part of some gay men and lesbians to disclosing their sexual orientation to heterosexual participants.

In addition to providing direct services, social workers often function as resource coordinators or case managers. In this capacity, social workers assess the needs of clients, make referrals to agencies to obtain needed resources, and follow-up with clients and agency staff to ensure the appropriate and timely remittance of services (Hepworth et al., 1997). As apparent in this study, midlife and older gay men and lesbians encountered unsupportive professionals who had the ability to make the caregiving and post-caregiving experiences especially difficult. In this role, then, it is crucial for social workers to have knowledge of gay or gay friendly professionals and services in the community. These professionals and services may provide health services, such as home health, or socialization to re-engage post-caregivers in the gay and lesbian community.

When clients have needs that cannot be met by existing services or when there are gaps in services, social workers may serve as program developers and planners (Hepworth et al., 1997). In this capacity, social workers are in the position to design programs and services that attend to the special needs of this population of caregivers and post-caregivers. Where feasible, social workers can also develop specialized programs and services for midlife and older gay men and lesbians. These services may include support groups or friendly visiting programs that specifically serve gay men and lesbians.

Policy Practice

Within their direct practice roles, social workers have the opportunity and responsibility to intervene in formal and informal policies. In fact, the NASW Code of Ethics calls for professional social workers' participation in policy implementation and change. Further, the importance of social workers' involvement in policy development, refinement, and reform has become so evident in the profession, that it has assumed the name of "policy practice." Jansson (1999) provides a definition of this concept and explains it as "efforts to change policies in legislative, agency, and community settings, whether by establishing new policies, improving existing ones, or defeating the policy initiatives of other people" (p. 10). Unfortunately, many feel that social workers have not fully engaged in this type of practice (Figueira-McDonough, 1993; Flynn, 1992).

Social workers can engage in policy practice by lobbying for legislative changes at the federal, state, and local levels. Lobbying on behalf of this special population of caregivers can include challenging the current legal statuses of same-sex marriages and advocating to include same-sex partners as social security beneficiaries. Lobbying can also be done in the areas of employment and housing discrimination. Many agree, however, that policy practice should occur not just in the federal and state policy arenas, but in the domain of agency policy as well (Flynn, 1992; Jansson, 1999). In fact, agencies may provide a very practical, readily available, and personal setting for policy practice and advocacy in the interest of consumers (Jansson).

As part of policy practice in agency policy, social workers should engage in "policy advocacy," which involves "interventions to help relatively powerless populations"

(Jansson, 1999, p.10). Social workers stand as the most likely policy advocates because of they work with powerless groups and are more “reformist” than other disciplines. Policy advocates often tackle “taboo” issues and issues that advance social justice (Jansson).

There are many ways in which social workers can engage in policy advocacy and advance social justice on behalf of midlife and older gay and lesbian caregivers. For example, social workers should review existing policies, such as intake forms, and assess their usefulness for this population. If an assessment form solely seeks information about a client’s legal spouse and children, this is clearly neglectful of alternative family constellations. Such information can be more appropriately elicited through asking about support persons involved in the client’s life. Additionally, social workers can examine protocols involving “primary contact” persons. Some agencies require “next of kin” as those notified in case of emergency and as those first sought to make decisions. In the case of an older lesbian, for example, her “next of kin” may not be the person she wants contacted first or someone she would want to make decisions for her. It may be that a partner or even a close friend is her preferred “primary contact.” Social workers can acknowledge this and similar discrepancies and push for changes to agency policies.

The above mentioned policies are most likely to be formal agency policies. In addition to intervening in formal policies, social workers should also advocate for changes in informal policies. As mentioned, informal policies are the practices and procedures that are carried out by individuals in absence of formal, written policies. In absence of a formal agency policy prohibiting discrimination on the basis of sexual

orientation, a social worker may need to intervene when the practice of staff members appears homophobic and/or heterosexist.

Social workers' participation in policy advocacy will necessarily occur within a variety of settings, including social service as well as health care organizations. Perhaps, the role of the social worker is even more crucial in settings other than social agencies, such as hospitals and nursing homes. These settings tend to employ staff from social service as well as medical disciplines. In this type of setting, the traditional social work values may not be as apparent in formal and informal policies as compared to a social agency setting. In this type of setting, policy advocacy for oppressed and vulnerable client populations may be even more important. As part of an interdisciplinary team, the social worker can provide education to other staff members as to the special issues of and the appropriate practice strategies with midlife and older gay men and lesbians. This education can perhaps add "psycho-social" knowledge to those who may be primarily focused on the "bio" aspects of adults. Additionally, this education could spawn interest in policy practice and social justice for this population among other disciplines. members.

Implications for Future Studies and for Researchers in this Area

Related Areas of Research

The current study has shed much light on the unique issues involved in gay and lesbian caregiving and post-caregiving. In addition, a few other areas can be further developed to better understand caregiving in the gay community. These areas include

younger caregivers providing care to partners who are in their thirties and forties, gay men and lesbians who provide care to their elderly parents, and gay men who care for partners with conditions other than HIV/AIDS. Caregiving should be examined in younger populations of gay men and lesbians, as breast cancer and HIV/AIDS are afflicting members of this community in their thirties and forties. In fact, I was contacted by caregivers in their thirties and forties (caring for partners around the same age) who were interested in the study and in being interviewed. Even though the ads for the study sought persons 50+, younger caregivers were also interested in sharing their experiences. Additionally, there were a few gay men and lesbians who were caring for their parents who also made contact and were interested in being interviewed. It is also important to continue to seek out the experiences of caregivers for male partners with health conditions other than HIV/AIDS.

There are other issues within the area of gay and lesbian aging that warrant further investigation. The social support networks of these caregivers could be more closely looked at as well as the types of support provided by persons in the network. Of particular interest are how “family of friends” networks assist couples and caregivers in crisis. Another area that deserves further study is the future plans of midlife and older gay men and lesbians, specifically, their plans and available supports in the event that they would need care. A better understanding of other plans, such as retirement and division of finances and property among these couples, would also further knowledge in this area. The legal challenges involved in these plans are also of interest.

Study Methods

Research Roles

When possible, respondents should be engaged as collaborators in the research process. As collaborators, respondents have a great deal to offer and can add greatly to the research. As this study showed, they are wonderful resources for sampling strategies and for avenues to disseminate study findings. They can also be of tremendous help with identifying study implications, as who better to ask what changes should be made to improve conditions than someone who has been through it and lives the challenges on a daily basis? Collaboration is especially important for members of oppressed populations, like gay men and lesbians, who have not been given the opportunity to share their unique experiences. A few of the respondents even mentioned that they had been waiting for this type of study and were very excited that others would finally be able to hear their stories. Member checking is important in this regard, to ensure that an accurate story is being told for persons who have not previously had a voice in the traditional literature.

In this type of research, respondents may also be personally invested in the study and its results. This was apparent as many of the respondents wanted to read the results and where interested in where the findings would be disseminated. Respondents would like to have their story heard and more importantly, they want the study to produce a change in the behavior and attitudes of others. Because of the investment and concern of the participants, dissemination for this type of study is particularly important. Dissemination, then, should include journals, newsletters, and organizations that would reach professionals whose practice could benefit from knowledge of this special population of

caregivers and post-caregivers. As mentioned by one respondent, it is also important to disseminate to places where other midlife and older gay men and lesbians can also benefit from the results. In this case, they can benefit from knowing that others have shared their experiences.

Self-disclosure may also be important in researching this particular area. As evident in this study, some respondents may be interested in knowing that the researcher is gay or lesbian before the interview proceeds. It is possible that some may be worried about being “outed” as a result of their participation or contact with the researcher. In these cases, self-disclosure may facilitate a more trusting and comfortable environment for some study participants. Respondents may also find that a gay or lesbian researcher may better understand challenges they face related to their sexual orientation. This self-disclosure, however, may complicate the research process if respondents assume that a gay or lesbian researcher understands all of the terms and situations they describe.

It is unclear whether the sexual orientation of a researcher significantly impacts the conduction of this type of study. Although it seemed to make a difference in rapport with some respondents, others reported that the sexual orientation of the researcher was not a factor in their willingness to share their experiences. For some respondents, it may be enough to know that the researcher is understanding and is interested in learning about their unique experiences and challenges.

Sampling Strategies

Sampling midlife and older gay men and lesbians has long been a challenge for researchers. The present study has slightly furthered the knowledge in this area. This study reached the majority of its participants through the gay media, including newspapers and newsletters. With this population, it is important to advertise nationwide to be able to attract an adequate number of participants. As a result, gay and lesbian newspapers with a large circulation seemed to be especially effective. Investing in large, eye-catching ads would likely improve the response through this medium. The electronic media, including gay and lesbian websites, also appeared promising since it allows one to reach persons from all over the country. Unfortunately, many of those who learned about the study over the Internet lost interest after discovering that the study did not involve an anonymous survey.

The mainstream media may be an untapped resource in sampling this population. This was not an avenue that was thoroughly explored in the conduction of the present study and was limited to advertising on general caregiving and aging websites. Regardless, running ads in the mainstream media may prove to be a productive avenue. Those who are not likely to read gay and lesbian newspapers, may instead read the local paper on a regular basis. Some larger newspapers (such as the Washington Post) also have special health care inserts that are run once a week and include numerous ads for studies. Although far more costly than placing an ad in a gay and lesbian publication, an ad in such an insert may receive numerous inquiries.

Whether mainstream or gay and lesbian media, writing up preliminary results in a newsletter or newspaper may attract additional study respondents. In this case, an ad requesting additional study participants can be placed within the article. As one respondent suggested, this is a way to convey the study's importance and the researcher's credibility. A reader's interest in participating may also be sparked by his/her ability to relate to the experiences of the initial study participants. It is likely that this type of advertisement would also decrease suspicion among potential respondents who fear being outed.

One of the most important lessons learned in the conduction of this study is that connections are essential in sampling this hard to reach population. Connections can be made with leaders in national organizations that serve this particular population (such as Senior Action in a Gay Environment-SAGE) as well as by attending national conferences related to this population (such as events sponsored by SAGE or the Gay and Lesbian Medical Association). These connections can help get the word out, often at a national level, that a study is being conducted in this area.

Making personal contacts with local health and human service agency staff may also be important. This can be done by personally visiting agencies and conveying the importance of and dedication to the research. Although this approach did not facilitate the recruitment of additional study respondents, it may be beneficial in other studies. It is not clear why contacting (in person or by mail) agencies and agency staff did not produce additional interest in study participation. Perhaps agency personnel did not feel comfortable in approaching gay and lesbian clients (or those they suspect to be gay and

lesbians) to participate in the study. Maybe they feared outing these clients within the agency or making them feel uncomfortable. They may, instead, choose not confront individual clients, but place study flyers on a bulletin board or on a table in the organization. An agency staff member may also have little time to attend to matters outside of their work responsibilities and their organization. This type of recruitment clearly involves the inclusion of an intermediary and the complications that ensue. In comparison, when a respondent learns of a study through a newspaper or website, he/she is not faced with another individual and can personally and anonymously decide whether he/she will make contact with the researcher.

Although this approach also did not elicit additional interest in the study, researchers should also ask respondents if they know others who would be interested in participating. Although this “snowball” sampling did not prove effective in the present study, it does hold promise for other studies. As evident in this study, it is very likely that respondents will know others who could participate. In theory and perhaps in future studies, snowball sampling could be effective in reaching this population.

The present study, through testing various sampling strategies as well as soliciting the advice of study participants, has made some progress in understanding sampling among midlife and older gay men and lesbians. Despite the progress made in the conduction of this study, the challenge of recruiting persons of color, persons of lower economic statuses and education levels, and persons residing in rural areas remains. Better representation of these populations can only strengthen the knowledge base in this area of research.

Technology

In the future, technology may be a strong ally in conducting research with this population. Technology presents exciting new avenues for recruiting study respondents and for collecting data. As this study shows, many midlife and older gay men and lesbians are “online.” As was mentioned, the majority of respondents emailed me as their first correspondence related to the study (even though they did not learn of the study on the Internet). Although somewhat evident in the present study, the Internet is fast becoming a way for gay men and lesbians of all ages to find community and support. As a result, it is a powerful tool to advertise studies related to gay and lesbian issues.

It was also apparent that persons who learn of a study online may prefer to remain anonymous. As mentioned, a few individuals did not follow up after learning that the interview was confidential as opposed to anonymous and that they would need to complete an informed consent form to participate. One interested person asked if the interview could be conducted in a chat-type of format, where the researcher and respondent would type questions and answers online and the respondent’s identity would not be revealed. In light of these experiences, the Internet may have great potential for survey research with gay men and lesbians of all ages. Posting advertisements on popular websites (including gay.com) and then linking to a survey, that could be taken online and submitted electronically and anonymously, may prove to be very successful. A chatroom format that could guarantee privacy, security, and anonymity could also be effective.

With the advent of webcams (cameras which attach to a computer and allow for video phone conversations), interviews may also become more feasible and successful with midlife and older gay men and lesbians. In this way, respondents can be economically interviewed across long distances. In addition, this type of interview would have many of the same advantages as face-to-face interviews including gestures and even environmental surroundings. As technology holds great promise for research in this area, webcams and other technologies may limit knowledge of a phenomenon to the experiences of those who are technologically savvy and who can afford the latest equipment. This potential bias cannot be overlooked.

Future Challenges in Caregiving and Post-caregiving

Case Scenario Two: Eileen and Amy

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Eileen (62) accompanies the ambulance that is taking her partner of forty years, Amy (68), to the hospital. Eileen called 911 when Amy became confused and dizzy and developed a severe headache earlier that morning.

Two years ago Amy was diagnosed with congestive heart failure and high blood pressure. Since that time, Amy has adhered to her medication regime and the couple has restricted their diet to foods low in fat and salt. Although she has occasional shortness of breath, she has been able to carry out her normal, daily routine.

At the hospital, they discover that Amy has had a stroke and she is admitted immediately to the critical care unit. She requires life support during three of the ten

days she spends in the hospital. The doctors discuss various treatment as well as life-sustaining options with Eileen. Eileen is at Amy's side for ten hours a day. Despite visitation hours, the nurses allow Eileen to sleep in the chair next to Amy's bed. When Amy's condition has stabilized, she is transferred to a nearby skilled nursing facility where she receives rehabilitation for the stroke. When Eileen is not by Amy's side, she keeps in close contact with the nursing facility staff who keep her abreast of her partner's improvements.

After three weeks at the skilled nursing facility, Amy returns home and continues her rehabilitation with therapists from a home health agency. Because the stroke has left Amy with memory loss and paralysis on her right side, the level of care she requires has increased dramatically. As a result, Eileen must now assist her with feeding, bathing, dressing and other personal needs. She must also assist her with transfers to and from chairs, the bed, and her walker. Eileen was able to take family leave from work for two weeks after Amy returned from the nursing facility. She eventually takes an early retirement to continue to care for Amy at home.

Six months later, Amy suffers a severe stroke and dies before help can arrive. Eileen received many kind cards of support from friends who saw Amy's obituary in the newspaper and many attended the memorial service as well. Eileen receives great support from her and Amy's family, friends, and former coworkers. She remains in the home she and Amy shared. Although she worries about money, she is able to collect Social Security survivor benefits as well as a portion of Amy's monthly pension.

Eileen joins a grief support group for spouses and partners through the nearby hospital and finds solace sharing her feelings with other widows and widowers. As she looks back on the caregiving experience, she feels fortunate that she was able to provide care to her loving partner.

Supporting Future Caregivers

The above scenario represents a hopeful vision for the future. In the future, it will be crucial to support those, like Eileen, Herb, and the nineteen study respondents, who accept the challenge of providing care to those that are chronically ill. If someone is willing and committed to providing care for another individual, that effort should be supported regardless of sexual orientation or relationship to the care-receiver. This primary caregiver is often the last line of defense in preventing nursing home placement and barriers that make their job even more difficult must be eliminated. Similarly, those who provide care to loved ones should be appropriately supported following the cessation of care.

In a society of ever-increasing diversity, future services must meet the needs of diverse caregivers and care-receivers. To meet these needs it is essential to be open to diversity among human relationships and seek to understand and support gay and lesbian as well as other populations of caregivers. For example, many of the difficulties experienced by the study respondents could also be encountered by other caregivers that are not legally related to the care-receivers. These persons may include friends or

unmarried partners. As Jane pointed out, “If I have a common law husband, what do I say when I take him in (to the hospital)?”

Along with increasing diversity, the future may also see a dramatic increase in the number of persons with chronic physical illnesses and the necessity to provide care to these individuals. Unfortunately, the resources (human and monetary) required to meet this need may be in short supply. Supporting and sustaining persons who agree to provide care, then, will become even more crucial. Understanding the needs of diverse caregivers and implementing changes on societal, organizational, and individual levels will be essential in providing needed supports to these caregivers. With adequate supports, individuals can remain in the community, surrounded by the persons who love them and who are enhanced through their ability to provide care.