eISBN: 978-1-68108-349-0
ISBN: 978-1-68108-350-6

OLDER WOMEN

CURRENT AND FUTURE CHALLENGES OF PROFESSIONALS WITH AN AGING POPULATION

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Bentham Books

Older Women: Current and Future Challenges of Professionals with an Aging Population

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ISBN (eBook): 978-1-68108-349-0

ISBN (Print): 978-1-68108-350-6

First published in 2016.

Acknowledgements:

Many thanks go to those who contributed and to those who inspired this work in progress. As we age and simultaneously reflect upon the wisdom and courage displayed by our mothers and grandmothers in their own lives, we are in awe. We hope to make use of their lessons as we move through our own aging processes and create a legacy of caring and strength for our daughters, as well as our sons. We also wish to acknowledge the assistance of our graduate assistants, Tracy Swenson, Christine Flynn and Alysha Primmer, for their willingness to participate in the preparation of this manuscript.

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FOREWORD

The statistics are astounding. Between the years 2000 and 2040, the population of older adults in the United States will more than double, to the point that one in five people you see on the street will be older than 65. Over half of those older people will be women. Many of those women will be widows. Many will live alone. Many will be fighting poverty while still more will be providing care for another person while also caring for themselves. In the face of these growing numbers, we cannot afford not to think about aging for the sake of our communities and the sake of our friends, neighbors, family members, and colleagues who will be the 79.7 million older Americans in 2040.

The numbers tell both a tale of caution and one of opportunity for women, as you will read in this book. The experience of aging for women can be a time of struggle and challenge – both anticipated and unexpected – especially for those who are not prepared to be older. Today we live in a world where no one teaches us how to age, and women are particularly vulnerable as they face a reality of living longer, potentially alone, with limited resources and a shrinking network of support.

But aging does not have to be a time of trauma if we continue to talk and think and plan. It does not have to be a time of stigma if we acknowledge that people are aging all around us, and we are aging with them. Knowing what we know, we are at a pivotal moment right now where we can change the experience of aging for women for the better if we are willing to speak up, and loudly, about what it means to be an aging woman. This book from some of the aging field's most respected thinkers starts the conversation.

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PREFACE

It has become common knowledge that the demographic of older adults has shifted. The expectation to live longer is a world-wide phenomenon. Globally, older people represent increasing proportions of the population. The importance of this book rests on the fact that older women, age 65 and up, represent the majority of the older adults in the United States. While men still slightly outnumber women world-wide, women represent a greater percentage of older adults. This will remain true as long as women continue to live longer than men. Currently women are expected to outlive their male counterparts by six years.

Longevity clearly brings challenges as well as opportunities. This book is about some of the obstacles that women are likely to face and provides examples of professional interventions that might help them to overcome barriers to achieve a desirable quality of life. There is also an emphasis on the strength and resilience that women display in the face of difficult situations. These strengths are exemplified by the willingness of older women to take on complicated roles as they age. For instance, many older women care for their grandchildren as replacement parents. This role may take a toll on the well-being of grandmothers who suffer health problems and financial difficulties as a result of the added stress. However, these grandparents often take on the primary care of grandchildren, usually in times of crisis, offering the children stability and care. The limitation of their legal rights to make parental decisions often complicates the experience. In the first chapter, Coupet and Cryer-Coupet provide an overview of the benefits and burdens of fulfilling this caretaking role.

Monahan reminds us in the second chapter that as women age, they are likely to take on caretaking roles. In fact, women make up the greatest number of caregivers worldwide. It is likely that women will provide care for their spouses or other relatives and the trend is likely to increase as men and women live longer despite chronic illnesses. Monahan describes the trends for women providing care as well as policy and practice implications for clinical social workers and other service providers. While caregiving provides a great benefit to care recipients and often to the caregivers, the role is also associated with higher rates of physical and mental health issues, already inherent in economic and health disparities.

The challenges of economic disparities between the genders have existed for decades. However, for older women, concerns about poverty and inequitable access to social security benefits based on fewer years in the work force and lack of employment opportunities are but a few of the issues discussed. George, Hilvers and Grossman examine in the third chapter the various pathways that lead to economic distress for older women, including the potential for homelessness. These factors include single-family head status, reduced labor force participation due to care giving, and low wages and benefits from work due to job segregation

and discrimination.

Sokolec continues with the fourth chapter on health disparities among older women. While this is an increasing concern for many within the U.S., it presents a specific challenge to women. Older women are likely to suffer more chronic illness and disability as they age. Many older women live alone without social supports. The discussion of differences between the genders, as well as between older and younger women, highlights some of the difficulties older women face in accessing equitable health care. Access to affordable health insurance is frequently tied to employment and marital status. Since many women are underemployed, preoccupied with caregiving responsibilities or widowed, this puts many older women at a distinct disadvantage.

Assumptions are often made about the lives of older women that pose as a disadvantage to their own self-perception. Spira, Sheehan and Primmer, for instance, recognize that the exclusion serves to censor women's desire to talk about sexuality and increase potential feelings of guilt or shame for having sexual feelings. The expectation that asexuality is normative is challenged in this fifth chapter and replaced with the recognition that continued need for intimacy extends throughout life.

Many of these factors combine to increase vulnerabilities and reduce access to needed and effective health services. Orwat, Bessinger and Morgan continue with chapter six on substance use and abuse by women. They depict older women as more vulnerable due to the many disparities articulated in previous chapters. Unique life changes experienced by older women contribute to the difficulty in identification of substance misuse and abuse within this population. Such experiences include loss of loved ones, loneliness, physiological changes, financial stress, pain management, and other co-occurring mental and physical health conditions.

Older women are also vulnerable to abuse by others. In chapter seven, Kilbane validates the experience that intimate partners too often continue a pattern of "domestic abuse grown old." Unfortunately, many cases of abuse are ignored or overlooked. Cases are difficult to substantiate, but perceptions of professionals seem important in the service provided for particular clients. This chapter looks at the how elder abuse investigators and domestic violence workers perceive abuse that has been inflicted upon older abused women clients by an intimate partner.

These non-normative events may create an image of older women as being more burdened than benefited by the struggles of their older years. However, as Nelson-Becker and Gilbert state in the eighth chapter which discusses spirituality, mental health professionals need to support the spiritual lives of women as they age. While the search for meaning and spiritual

struggle is viewed as normative, "Aging invites women to come alive in new ways as they honor the journey home to their authentic self, a self that is always larger than what they can dream., " (Nelson-Becker & Gilbert, p. 1)

While many problems and challenges of older women are discussed, anecdotal evidence does not necessarily lead to program development or policy change. Research and interpretation of data collected on the various issues is imperative to create change. However, methodological challenges have been encountered in some of the most common forms of data when researching older women. Rucinski discusses the problems encountered in survey research in chapter nine. While the survey is one of the most widely used tools used to plan, set program agendas and evaluate usefulness or satisfaction; recognition is given to some of the potential errors created by cognitive limitations, proxy reports or other concerns. Caution is offered to make accommodations as necessary to maximize quality and balance accuracy.

The final three chapters highlight the positive effects of validating the strengths of older women as they age and navigate issues of loss, and decline. Simon and Spira focus on the powerful positive impact that membership in groups has on older women's sense of well-being in chapter ten. The healing qualities of groups have the potential to mitigate issues of social isolation and loneliness. Women find support, camaraderie and hope through group membership.

Dentato, Craig & McInroy remind readers in chapter eleven that the unique experiences of the lesbian community deserve recognition in an exploration of the lives of older women. The women in this community underscore the resilience of aging women, particularly focused on combating discrimination and engaging in activism and advocacy.

The final, twelfth chapter of the book reminds readers that older women retain the potential to teach and mentor younger people, even in the face of a progressive illness. Morhardt shares the evaluation of the journals submitted by a young medical student on her experiences of participating in The Buddy Program with a 74 year old woman diagnosed with Alzheimer's disease. The journals reveal the profound impact of the relationship on helping the medical student recognize the whole person of her mentor, not just symptoms of illness.

While present cohorts of women may well continue to suffer from higher rates of disability than their male counterparts, be more likely to live alone, and lack sufficient income and health care supports, more positive self-images and social supports should enable many women to take charge of their lives and improve the quality of their older adult years.

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ACKNOWLEDGEMENTS

Many thanks go to those who contributed and to those who inspired this work in progress. As we age and simultaneously reflect upon the wisdom and courage displayed by our mothers and grandmothers in their own lives, we are in awe. We hope to make use of their lessons as we move through our own aging processes and create a legacy of caring and strength for our daughters, as well as our sons.

We also wish to acknowledge the assistance of our graduate assistants, Tracy Swenson, Christine Flynn and Alysha Primmer, for their willingness to participate in the preparation of this manuscript.

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CHAPTER 1

Grandmothers Raising Grandchildren: Balancing Burdens and Blessings

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Abstract: This chapter explores the increasing phenomenon of grandparent caregiving and the impact on caregiver health and well-being. This chapter presents demographic data on grandparent caregivers as well as a profile of the unique challenges that they face with the hope of informing readers about how to best serve this particular group of older women. The population of grandparent caregivers is predominately female and, although the majority of grandmothers are not necessarily within the traditional 'aging' population, a significant portion of this population is over age 60. This chapter focuses on the ways in which these grandmothers differ from their non-caregiving grandparent peers as well as the unique challenges that they face, including risks to their physical, psychological and social well-being, balanced against the benefits that they describe associated with their caregiving roles. The authors include practice and policy implications for interventions with grandmother caregivers to assist social workers in their work with this population and present case examples with follow up questions to place the issue in context.

Keywords: Grandmothers, Grandparent caregivers, Health and well-being of caregivers.

GRANDPARENT CAREGIVING

Introduction

Grandparent roles, historically as diverse as the population itself, are increasingly

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expanding. Although grandmothers and grandfathers have long played a significant role in caring for grandchildren, many are now providing such care for prolonged periods of time, often without the assistance or involvement of biological parents. Grandparents raising grandchildren have become an increasingly visible population over the past decade. Recent data from the American Community Survey (ACS), which is the Census Bureau's Population Estimates Program, reveals that in 2010 of the 183 million grandparents residing in the United States, there were 7 million grandparents residing with grandchildren [1]. Of this population of co-resident grandparents, 2.7 million were "grandparent caregivers" defined as grandparents with primary responsibility for co-resident grandchildren under the age of 18. Put in the context of gender, there are currently 4.5 million *grandmothers* in the United States, and fully 38% of them (1.7 million) have primary responsibility for grandchildren under the age of 18 [2]. The remaining 1 million are grandfather caregivers. As shown in Fig. (**1**), far from a short-term or temporary caregiving arrangement, as might have been the case more often in years past, many grandparents today are assuming caregiving roles for prolonged periods of time. Indeed, according to the same ACS 2010 survey, of the 2.7 million grandparent caregivers, almost 1 million had been providing primary care for the past 5 years or more.

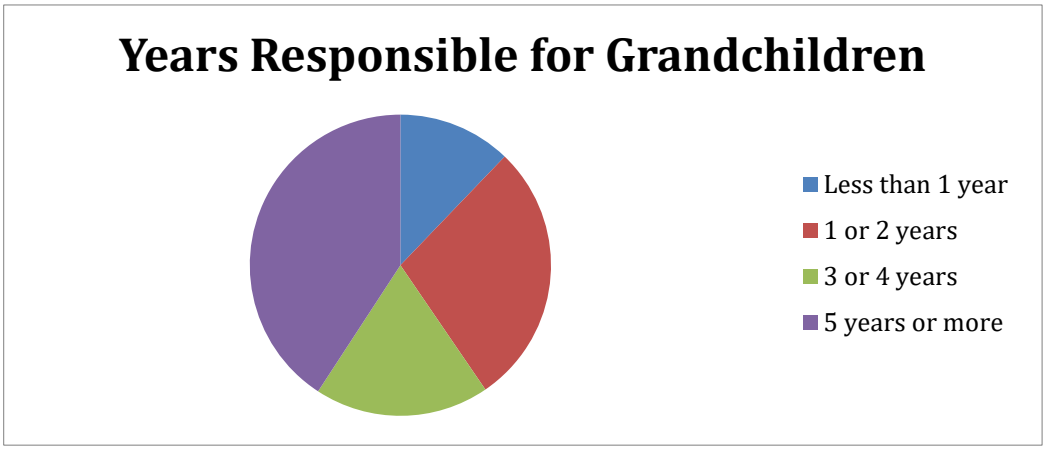

Fig. (1). American community survey 2010 one year estimates.

According to a 2010 Pew Research Center Report, rates of grandparent caregiving have risen sharply during the past decade, a period that corresponds with the recent economic recession [3]. Indeed, the number of grandparents serving as primary caregivers to their grandchildren rose 8% from 2.4 million in 2000 to 2.6 million in 2008, when the most severe effects of the economic recession began to

surface. Three percent of that increase occurred from 2000 to 2007, and 5% occurred from 2007 to 2008 [3]. Consistent with this trend, the number of grandparent caregivers continues to rise [4]. It is important to keep in mind when assessing data regarding rates of grandparent caregiving that, outside of census figures, no precise means of assessing the exact total number of grandparent caregivers exists. The inability to accurately measure the phenomenon of grandparent caregiving likely has policy repercussions with rippling effects for individual caregivers. For example, service delivery and resources for grandparent caregivers may be underdeveloped and insufficient in the absence of more accurate figures.

Moreover, although current rates of caregiving appear high at 2.7 million, it is fairly likely that the 2010 census figure, like earlier figures, is actually an underestimate of the actual prevalence of grandparent caregiving in the U.S [5, 6] [6]. For several reasons, including loss of senior housing, distrust of social service agencies, fear of reprisals from drug-involved biological parents, or shame and guilt about an adult child's absence, many grandparent caregivers are reluctant to report themselves as such, which may have the effect of suppressing the perceived prevalence of grandparent caregiving. The grandparent caregiving population about whom the most precise data exist are those grandparents providing *formal* care to grandchildren who are in the legal custody of the state, specifically those within the child welfare system. Because these children are formally within the child welfare system, we refer to these placements as formal grandparent caregiving households. We know more about the prevalence of such households because states are required to track data pertaining to the care of children in the child welfare system, including whether they are residing and being cared for by a grandparent. The population of formal grandparent caregivers, however, pales in size when compared with those doing so *informally*, or outside of the supervision or custody of the state. Since informal grandparent caregivers are not connected to or tracked by any formal system, we know far less about their unique challenges and needs. However, it is reasonable to conclude, based on smaller scale studies, that this population bears a strong resemblance to those providing care through formal means. The purpose of this book chapter is to provide information drawn from the larger grandparent caregiving population and apply it to the specific

CHAPTER 2

Caregiving Responsibilities of Older Women for Chronically Ill and Disabled Family Members

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Abstract: As women age, the likelihood that they will become caregivers increases. Older women perform caregiving roles in their homes and informally in long term care facilities for chronically ill and disabled family members. Married older women often provide eldercare to their spouses and caregiving roles are increasing as women age and men live longer. Providing eldercare has become a normative life transition for older women and a significant concern when their own health status is waning. Although older men also provide eldercare to parents and wives, their numbers are not as large. While less research has focused on the health implications of older women who are caregivers—the majority has focused on middle-aged adult daughters. Many older women provide care for family members and spouses in their home; however, when family members are too vulnerable and require higher levels of care (*e.g.* nursing homes or assisted living facilities), they spend considerable time visiting and helping care for them once they are in the long term care system. The purpose of this chapter is to examine the influence of demographic factors on the propensity of older caregivers to provide care to chronically ill and disabled family members and to examine the trends, policy and practice implications for social workers.

Keywords: Older women and adult daughters, Older women caregivers.

LITERATURE REVIEW AND DEMOGRAPHICS

For older women caregivers, the process of providing care to a chronically ill or disabled relative often requires a variety of adaptations. These adaptations include

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less time for self and self care, more physical, psychological and emotional stress as care responsibilities increase. Older women caregivers are usually retired, their income may be limited, and the costs of care may outstrip their resources. Although a high proportion of family members provide eldercare (80%), parent care is generally considered a normative stress of adulthood [1 - 3]. Burnout may occur for older women who spend several years as caregivers to their parents and then become caregivers to their spouses (sometimes simultaneously). Whether or how the current economic recession will impact eldercare decisions by older women caregivers is not known. The purpose of this chapter is to examine the influence of demographic factors on the propensity of older caregivers to provide care to chronically ill and disabled family members and to examine the trends, policy and practice implications for social workers.

In the report, *Caregiving in the United States* [4] based upon telephone interviews with 1,480 family caregivers age 18 or older, two-thirds were female, 86% cared for a relative, and 36% cared for a parent. The major reasons given for providing care were old age and dementia (Alzheimer's disease). The study found that "the older the caregiver is, the more likely she or he is to be in a high burden situation" (page 29). One of the main concerns of older women caregivers is their health and whether they have the strength to provide physical caregiving. Long term caregiving is stressful and can place some individuals at higher risk for negative health outcomes. Poor psychological health of caregivers has been associated with the increased burdens of care [5]. Caregiving has also been associated as a risk factor for mortality and morbidity [6, 7]. Monahan and Hooker found that caregivers with higher levels of perceived social support had better health [8]. While considerable focus has been paid to the stress-illness paradigm, researchers have found that health promoting and self care behaviors act as mediators to reduce the effect of caregiver stress on general well-being [9].

In an updated national profile of caregivers of frail elders from the National Long-Term Care Survey and Informal Caregiver Survey [10], primary caregivers were more likely to be children (41.3%) or spouses (38.4%); however, they were also more likely to be working alone, without secondary caregivers than in previous national surveys. In the ten-year time change for the study (1989 *vs.* 1999) the authors found that caregivers had a decrease in the number of hours per week from 31 to 30 (p.353) [10] and shifted their work so that more hours were spent with administration of medicine and less with household tasks, shopping or

transportation. The authors speculate that this may be attributed to declines in instrumental activities of daily living (IADLs) and disability in the community-dwelling elderly, increased uses of assisted living facilities and technology (p.354) [10].

Whether disability and underlying physical, cognitive and sensory limitations are inevitable consequences of aging have been challenged recently in a review of trends in disability and functioning among older adults in the United States [11]. These authors suggest that problems with old age, disability and limitations have shown improvements in the last decade and note that these changes might be due to an increase in the educational attainment of the older population and that improvements in functioning have occurred despite chronic conditions. They also caution that the exact causes for these improvements are not fully known at this time and will require further investigation.

The effects of caregiving on physical health were studied by Wallsten [12] who found that the chronic, ongoing nature of caregiving produces negative effects on the caregiver's health symptoms and ability to carry out activities of daily living. In another study predictors of decline in physical health of caregivers were found to be poorer physical health at the start of the study, the amount of help they provided and a decline in their own mental health [13]. Researchers report that the majority of caregivers rated their own health as the same or worse than their impaired spouse and that physical health indicators were substantially poorer than older adults in the general population [14].

The intricate juggling act of caregiving and work was examined using in-depth interviews with women who reported that their health *prior to* caregiving was an important indicator of their capacity to provide care along with a complex process of coordination, negotiation, and mediation [15]. Women who face the multiple roles of caregiving, work and family roles also report the highest levels of stress [16]. Physical illness may also occur because caregivers fail to seek appropriate care for themselves [17]. Caregivers have also been found to be at a higher risk of developing clinical depression and cardiovascular problems [18].

The experience of caregiving varies by ethnicity and culture. When studying

CHAPTER 3

Older Women at the Edge: Economic Disparities of Older Women

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Abstract: This chapter examines the economic wellbeing of older women. As the baby boom generation of women is moving into early "old age" they join earlier cohorts of older women, many of whom are in economically precarious situations, their wellbeing compromised by their economic instability. This chapter focuses on the various "pathways" and contexts that lead to economic distress among segments of older women, including a focus on factors that increase the likelihood of homelessness. Finally, it discusses various policies and programs that could both ameliorate this situation for older women in economic distress and also prevent future cohorts of women falling into economic difficulties.

Keywords: Aging of women, Economic disparities, Homelessness, Income levels, Older women.

AGING IS A WOMEN'S ISSUE: THE ECONOMICS OF OLDER WOMEN

In many ways when you talk about the issues of the aging, you are likely to be talking about issues related to women or more likely to impact women. That is because the majority of the older adults in the United States are women. And, these women are much more likely to be at economic risk than their male counterparts. This economic precariousness of older women is related to a

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Teresa Kilbane & Marcia Spira (Eds.)

confluence of factors associated with the fragile economic circumstances - often dire poverty - that women experience in this society. These factors include single-family head status, reduced labor force participation due to care giving, and low wages and benefits from work due to job segregation and discrimination. These factors, experienced during the life course, combined with other factors pertaining to aging create challenges, many of which are unique to women. First, we explore some of the demographic and economic realities of older women. Then, we look at how these factors work together over the life course to contribute to poverty, exploring the pathways to economic precariousness. Last, we discuss the policy implications and propose policies that would begin to address the economic circumstances of older women. These recommendations fall into two broad categories. One set of policies relates to structural changes that should occur earlier in the life course that would put women in a better economic position. A second set of policies speaks to the ways in which we support older adults in general and older women in particular. It is our hope that these recommendations will help guide our thinking about how to address the challenges to their well-being faced by older women.

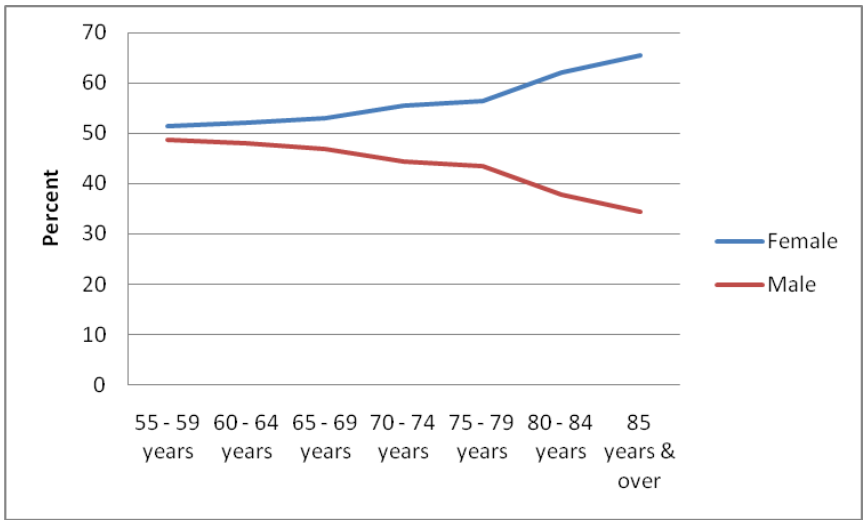
A Profile of Older Women

The number of older Americans is increasing in this country, with some projections that within the next generation it will double. In 2012, roughly 79.4 million individuals or 25.7% of the population were 55 or older, with the majority, 54%, being women [1]. And looking at those 85 and older, 64% are women (see Fig. **1**) [1]. The extent of this gender disparity is highlighted in a recent report by the Administration on Aging [2] that notes in 2012, the female to male sex ratio for individuals ages 65 and over was 129, or 129 women for every 100 men. In contrast, for those 85 and above, the ratio was 200 [3].

Race and Ethnicity

While currently the vast majority of older women are white, this is changing and by mid-century will reflect the increasing diversity of the general U.S. population. Currently, the majority (80%) of 55 + women are non-Hispanic white, followed by non-Hispanic Black (9%); Hispanic of all races 7%, and non-Hispanic Asian,

3% [4]. However, population projections made by the U.S. Census Bureau suggest that in the next 40 years, the proportion of white, non-Hispanic individuals who are 65 and older will decline as a proportion of all older adults while racial and ethnic minorities will be increasingly represented [4]. Especially notable in these census projections is the forecast that the number of Hispanic individuals (both male and female) over 65 will almost triple, from 6.9% in 2010 to 19.8% in 2050 [5].



[a] Source: [1]

Fig. (1). Percent of men to women by age group.

Living Status

The older women get, the more likely they are to be living alone. While just under one-third of women between the ages of 65 and 74 live alone (27.7% in 2010); just under 50% of women between the ages 75 and older live alone (47.4% in 2010 [5]. While the older a man gets the more likely he is to live alone, in no age group are the majority of men living alone [5]. Most of this increase in living alone is due to the death of a spouse, which is more likely to be the male spouse. And, living alone is strongly associated with increased poverty in older individuals [6].

CHAPTER 4

Healthcare Disparities and Older Women

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Abstract: Healthcare disparities in the United States have increasing become a concern in relation to healthcare outcomes, as well as to social justice issues. These disparities are reflected in statistical differences in healthcare outcomes for different population groups. In addition more recognition is being given to the role of factors influencing health in general. Older women are a subset of those experiencing disparities in access and differential care and many of the disparities are outcomes of the socio-cultural aspects of health. Two areas of inquiry regarding older women and their healthcare (1) are the differences between men and women, generally and more specifically older men and older women and (2) differences in healthcare between younger and older women. This discussion has implications for the practice of medicine, especially in the field of gerontology, as well as for social workers who advocate for individual clients as well as for programmatic and policy changes. This chapter will discuss some of these issues.

Keywords: Healthcare, Health disparities, Older women.

INTRODUCTION

Healthcare disparities among older women are a subset of disparities that exist between gender, racial/ethnic and socioeconomic groups. Disparities in healthcare are generally defined as statistical differences between populations on selected measures that are deemed measureable benchmarks for assessing issues of access (gaps in care) and quality of care. For groups experiencing issues of access and differential care, it is not their healthcare issue per se that contributes to the disparity but rather other variables such as race/ethnicity, socio-economic status

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and gender. The presence of more than one of these variables has been referred to as "multiple jeopardy" [1]. Gaps in access to care and differential care can lead to healthcare outcomes that are potentially harmful for individuals and when reaching significant proportions, for a specific group of individuals.

In the United States, the National Healthcare Disparities Report (NHDR) [2] is the primary document for the study of healthcare disparities. It is published yearly by U.S. Department of Health and Human Services, Agency for Healthcare Research and Quality (AHRQ). When data are available, the Report typically shows contrasts by:

Race— Caucasians with non-whites
Ethnicity—Hispanics compared with non-Hispanic Whites
Income—Poor, near-poor, and middle-income people compared with high-income people.
Education—People with less than a high school education and high school graduates compared with people with any college education.
Geographic location—People who reside in micropolitan areas are compared with metropolitan areas. Within metropolitan areas, people who reside in large central, large fringe, medium, or small metropolitan areas are compared with metropolitan (total).

The Report also identifies "priority" populations and examines disparities "in quality of and access to health care" among recent immigrant and limited-English-proficient populations; women; children; older adults; residents of rural areas; individuals with disabilities and special health care needs. Gender disparities are also documented and can be seen as a covariate of race/ethnicity and socio-economic status. Older women can be seen as a subgroup of the gender covariate.

Social epidemiology is a newer field within epidemiology that is specifically concerned with the "social characteristics or psychosocial risk factors associated with patterns of disease within and across populations" [3]. Healthcare disparities can be found in attitudes about health in different populations, in actual access to healthcare services, in access to "quality" healthcare and in actual treatment for health conditions. Within each of the steps to healthcare, the causes for disparities

occur on several levels: the patient, the provider and the healthcare system. For example, having or not having health insurance is a systemic condition which in the United States is generally provided by or obtained through one's employment. It is those in minority groups who often do not have the type of employment or out-of –pocket funds to purchase insurance. Women have traditionally been dependent on their spouses for health insurance. At the provider level, attitudes about population groups and cultural awareness effect how illness is perceived and treated by healthcare providers. At the patient level, health behaviors have an impact on general health and chronic health conditions. Socio-economic status, because healthier food is generally more expensive, has an important impact on health behaviors such as eating healthier food for conditions such as diabetes or avoiding obesity.

This chapter is concerned with a specific group within these broader statistics: older women and more specifically older women v. older men and comparisons within the older women subgroup by race/ethnicity and income.

THEORIES OF "HEALTH"

Healthcare needs to be seen in the larger context of health defined by the World Health Organization as "a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity" [4]. The National Wellness Institute now recognizes eight "dimensions," or essential life areas which collectively comprise the wellness (well-being) of all human beings: spiritual, emotional, intellectual, physical, cultural, occupational, social, and environmental [5]. By expanding the concept of health beyond the physical and/or disease reinforce the importance of health and by implication suggest the potential consequences of disparities. Again using a broad lens, health care is the maintenance of the various dimensions of health including mental and social well-being.

While there may be agreement, at least among organizations such as the World Health Organization and other health-related institutes, about the definition of health, there are larger questions that relate specifically to the details of health care provision.

CHAPTER 5

Why Doesn't Anyone Ask? Myths and Taboos about Older Women and Sexuality

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Abstract: The older adult population in the US age 65 and older expected to grow from 12.9% of the population in 2009 to 20% by 2030 (Administration on Aging, 2011) [1]. The increasing proportion of Baby Boomer older adults are expected to live longer and attain a higher quality of life, dependent on improved management of health issues. However, there is a paucity of research in the area of sexual health in older adulthood, especially concerning older women. The reluctance to consider the conversations around sexuality may have direct consequence on health and well-being, Negative societal stereotypes, including a prevalent view of diminishing physical attractiveness, perpetuate false assumptions about aging and sexuality. Women in particular seem vulnerable to expectations of society people that a disengagement from sexual interest and acceptance of asexuality is normative. This myth that older adults are not sexually active individuals may impact the level of medical attention that they receive for issues related to sexual health. Many healthcare professionals are reticent to broach the subject of sexuality with their older adult patients. In this paper we discuss how societal and personal attitudes toward sexual behavior and aging perpetuate myths and taboos about sexual health and overlook the significance of sexuality identity and need for physical and emotional intimacy among older women.

Keywords: Older women, Sexuality, Sexual health, Taboos.

SEXUAL BEHAVIOR IN OLDER WOMEN

A recent study in the New England Journal of Medicine that surveyed over 3,005 adults between the ages of 57 to 85 years old found that while sexual activity may

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decline with age, almost half of individuals age 65 to 74 remain sexually active, as well as 26% of those aged 75-85. In the latter group, 54% reported having sex at least two to three times a month and 23% reported having sex once a week or more (Lindau *et al.*, 2007) [2]. In another study, Gott and Hinchliff (2003) [3] measured the level of importance of sex for older adults (aged 50-92 years old). Using both qualitative and quantitative data they found that participants who had a sexual partner deemed sex to be of at least some importance with many rating sex as "very" or "extremely" important. The importance of sexual activity is not only physical, for many older adults it is also psychological in nature and is intertwined with feelings of intimacy. The need for connection and intimate contact is a human need that is sustained throughout the life cycle.

In fact studies have shown that while the frequency of intercourse tends to decline with age, satisfaction with sexuality may not be affected (AARP, 2005) [4]. Laumann and colleagues [5] reported on the quality of sexual behavior among older adults. Subjective fulfillment was found to be associated with an increased sense of happiness and well-being; maintaining a sexual relationship is associated with love, intimacy and closeness that can further improve older people's general well-being by DeLamater & Moorman [6]. Sexual expression is not only defined as vaginal penetration; it includes words of affection, activities and gestures involving touching, holding hands, kissing, and hugging. Engaging in these types of behaviors with a partner provides opportunities for older adults to express warmth, caring and affection and to experience intimacy by Langer [7]. The findings in a study by Ginsberg, Pomerantz and Feeley [8] support this notion of sexual preferences and behaviors of older adults. They surveyed 166 participants, aged 60 years and older and found that a majority preferred experiences such as touching/holding hands (66.9%), embracing/hugging (72.5%) and kissing (67.9%) on a regular basis. Sexual experiences such as mutual stroking (62.4%), masturbation (80.1%) and intercourse (66.4%) were less desirable. Regardless of how older adult women may wish to engage in sexual activity it should be recognized that sexuality continues to be an essential part of their lives and continued wellbeing [2]. For older women, sexual activity is still an important means for expressing love and caring [9].

BIOLOGICAL REALITIES

Normal physiological changes such as decreased vaginal secretions and flattening of the vaginal epithelium in women, and delayed or diminished sexual response are common [8]. However, the impact of these variables on sexual activity in women is not entirely clear [10]. Further health related issues in the form of normative biological changes like the effects of menopause for women, and prostate changes and erectile dysfunction for men, can also affect the level of sexual functioning for older adults. Apparently women treated with a transdermal testosterone patch and given lubricants to combat vaginal drying do report higher sexual satisfaction [11]. Prior functioning and relationship factors are more important than hormonal determinants in female sexual activity in midlife.

The idea of older adults engaging in sexual activity is still a rather taboo topic in our society. This stigma limits the willingness to engage in conversations for fear of exposure to judgment. Consequently many sexually transmitted diseases go undetected. Considering the rise in sexually transmitted infections (STI's) including human immunodeficiency virus/ acquired immune deficiency virus (HIV/AIDS) [12] for older adults in recent years, older adult sexual health is no longer a topic that can be ignored. Approximately 10% of AIDS cases are among people older than 50. Many health care providers lack an awareness of the risk of HIV/AIDS in the elderly population [13]. Additional research is needed to determine the extent of the problem and how health care providers can best serve their older patients' needs.

BIOPSYCHOSOCIAL CONSIDERATIONS

Generally, sexual activity is associated with overall health [14]. While illness may be an interference with sexual health and lack of sexual health may be a symptom of illness, the focus on sexual dysfunction as a symptom of women's lack of well-being is often obscured or ignored, However, sexual activity can lead to depression or withdrawal [2].

The biological changes that occur in older women's sexual function intersect with a social and psychological context. Weeks [15] claims that negative stereotypes and cognitive distortions foster misconceptions of sexuality in older adulthood. It

CHAPTER 6

Substance Abuse Among Older Women

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Abstract: As the baby boomer generation ages, the problem of substance abuse continues to grow among older adults in America. Older women remain one of the most vulnerable among those affected by substance misuse, abuse, and addiction, yet this population remains misunderstood, stigmatized, and overlooked. Unique life changes experienced by older women contribute to the difficulty in identification of substance misuse and abuse within this population. Such experiences include loss of loved ones, loneliness, physiological changes, financial stress, pain management, and other co-occurring mental and physical health conditions. Alcohol remains one of the most prevalent and relevant substances older women use to cope with these changes. This chapter explores the major issues surrounding alcohol abuse among older women by defining the problem, identifying key risk factors, signs, and symptoms, outlining useful screening and treatment tools, and providing implications for future research on this critical yet overlooked issue.

Keywords: Alcohol abuse, Coping, Older women, Substance abuse.

INTRODUCTION

Substance abuse is one of the fastest growing health problems among the elderly, fueled by the aging of the baby boomer generation. Not only has this generation of older adults had more exposure to substances, but they are also more likely to use substances to treat conditions. This misuse and abuse is likely to create complications with co-occurring health issues and a healthcare system that is unprepared to deal with subsequently unique issues and demands. Furthermore,

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rates of substance use among older adults are increasing: the prevalence of substance dependence among adults older than 50 is expected to increase from 1.7 million in 2001 to 4.4 million by 2020 [1]. Older adults face complex issues related to decreased income, loss of social supports, loss of spouse, adverse life experiences, withdrawal from social routines, anxieties over incapacities, and insomnia, which together can lead to loneliness and depression [2]. The elderly may use substances, including alcohol, to cope with these changes and disruptions. Substance abuse among older adult women requires specific attention due to its unique biological, social, and psychological impact. However, older adult women are not often considered, in part due to myths about those who use substances, but also due to differences in older women's lived experience that make the identification of substance abuse more challenging. Additionally, women make up a majority of the elderly population since women tend to live longer than men. At any age, women face unique concerns related to substance use due to biological, psychological and social differences when compared with men. In older age, chronic health conditions and changes in metabolism exacerbate these differences, putting older women at a higher risk for poor outcomes in their physical and mental health and interpersonal relationships as a result of their substance abuse. Furthermore, these heightened risks make women more susceptible than men to severe and often fatal consequences related to their substance abuse [3, 4]. Further, despite evidence of the effectiveness of substance abuse treatment for the elderly, gender differences for treatment entry rates still require further research. Some studies suggest minimal differences between treatment entry rates for women and men overall [5]. Other studies suggest lower treatment entry rates for women than men due to a tendency among women to address their substance abuse more obliquely through mental health services [3, 6]. These issues illustrate the need to better understand the unique challenges and experiences facing older women who abuse substances.

This chapter will explore substance use in older women, specifically women over 50. The chapter is organized into six topic areas: defining substance abuse for older women, prevalence, risk factors, signs and symptoms, screening and treatment, and implications for research. Two particularly relevant issues this chapter will highlight include prescription drug abuse among older women along

with the increasing occurrence of alcohol use. It is the hope for this chapter that the reader will take away a greater sensitivity and understanding of older women and substance abuse as well as an awareness of the appropriate means for intervening and delivering competent services.

PREVALENCE OF ALCOHOL AND DRUG ABUSE AMONG OLDER WOMEN

Prevalence: The Big Picture

The National Survey on Drug Use and Health (NSDUH) estimates that 1.4 million older adults or 1.8% have used an illicit drug in the past month [7]. The 2005 DASIS Report estimated that the number of substance dependent older adults (aged 50 and over) will increase to 4.4 million by 2020 [8]. The National Survey on Drug Use and Health (2005) found that older adults use substances at much lower rates than those age 18 to 49. In the past month, 17.1% of older adults had smoked cigarettes, 45.1% had drank alcohol, 12.2% reported binge drinking, 3.2% reported heavy alcohol use and 1.8% reported illicit drug use (Fig. **1**) [7]. Overall, older adults are more likely to abuse alcohol than any other substance. Older men are more likely to use all substances than older women (Fig. **2**); almost 20% of women used alcohol in the previous month [7].

Non-Hispanic whites constitute the largest proportion of older adults who reported alcohol use within the last month (Fig. **3**). However, Non-Hispanic Black or African Americans reported high cigarette use and illicit drug use in the past month, but were the least likely to report alcohol use and heavy alcohol use. Hispanics or Latinos were the least likely to engage in cigarette use, alcohol use, and illicit drug use within the past month, but surprisingly the most likely to engage in binge alcohol use.

Overall, older adults are most likely to drink alcohol when compared with other substances, while older men are more likely to abuse drugs/alcohol when compared with older women. White older adults report the highest incidence of alcohol use, but Hispanics/Latinos report the highest incidence of binge alcohol use.

CHAPTER 7

Defining Abuse in Older Women: Voices of the Professionals in Elder Abuse and Domestic Violence

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Abstract: Women in their later years' experience abuse from their intimate partner. This abuse can be 'domestic violence grown old' or 'abuse in later life'. Two service systems in the public sector respond to these women-adult protective services and domestic violence programs. This chapter compares how elder abuse investigators and domestic violence workers identify intimate partner violence among older abused women by an intimate partner served at their respective agencies in a major urban city. The research study collected qualitative data from interviews of seven elder abuse investigators and nine domestic violence workers describes how they define and contrast elder abuse *versus* domestic violence. Both systems serving the older woman experiencing intimate partner violence (IPV) define domestic violence similarly. Entry into the systems can be based on mandate of the system rather than the needs of the client. Older women experiencing IPV require the expertise of each system. With strong leadership from both professions, the establishment of collaborative mechanisms, and cross training opportunities, the older woman facing harm from her partner will be served more effectively.

Keywords: Abuse in later life, Adult protective services, Domestic violence, Older women.

INTRODUCTION

Older women experience intimate partner violence (IPV) but receive less attention

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than their younger counter parts [1]. IPV is a more narrow definition of elder abuse: the physical, sexual, or psychological abuse or neglect is perpetrated by a current or former partner, spouse or paramour, as opposed to a family member or caretaker. These two systems have a difference in their philosophy on how to treat abuse in later life, thus, these women face the possibility that neither adult protective services (APS) nor domestic violence services (DVS) will meet their service needs [2 - 4]. APS does not include safety planning and the cycle of violence in their training so the older abused women may not be safe. DVS does not include the aging process in their training, thus, they tend to advocate for younger women and their children possibly ignoring age-specific needs of the older abused women. Therefore, the older abused woman in later life needs our attention to ensure she is living a safe and satisfying life.

The purpose of this research study was to investigate the perceptions of professionals who serve older abused women. Toward that end, the study compares and contrasts elder abuse investigators and domestic violence workers related to how they view women ages 50 and over who have been abused by an intimate partner. While thee qualitative interview covered a wide range of topics, the focus here is on definitions of elder abuse *versus* domestic violence, prevalence of intimate partner violence (IPV) prevalence among women who are age 50 and over, and the interface with each other's profession. The guiding question for this study is to whether the older abused woman is considered an abused elder, a battered woman, has characteristics of both, or should it really matter when seeking help? The answer to this question is important to these women who need these two systems to respond to their needs in a timely manner no matter how they are classified by the first responder. In order to create an approach to appropriately respond to the needs of older abused women, the profession needs to understand how all the key participants, including the adult protective service workers and domestic violence shelters and agencies, define the problem of abuse in later life so better interventions and services can be developed for these women [5].

LITERATURE REVIEW

This section addresses a number of important areas to address in comparing and

contrasting these two types of professionals who serve older abused women. Since I assume their perception will be based on: their theoretical model of how they view the abused woman, their definition of elder abuse *versus* domestic violence, and the depth of their experience of working with intimate partner violence at a later age I explore the literature in these areas in this next section.

THEORETICAL MODELS

Although the older abused woman should have at least two systems to turn to for assistance, domestic violence or adult protective services, "neither system has been particularly successful at understanding and meeting the needs of older women who are abused by intimate partners and family members" (p.1) [2]. Domestic violence agencies and shelters tend to serve younger abused women while adult protective services tend to serve abused women at the older range that can range from able-bodied to those who are frail or incompetent. Regardless of their capability or competency to take care of them, the type of intervention the older abused woman receives relies heavily on who first responds. Each system has their own philosophy and model for service delivery, and how the older abused woman's safety is regulated. APS is sometimes aligned with Child Protective Services which also focuses primarily on protection of the client, in this case, minor children. Domestic violence services take an opposite stance with its feminist empowerment model, with a specific focus primarily on younger abused women and their offspring [1]. APS characterize the older abused woman as less capable, thus, the system needs to make sure they are safe in their homes. DVS views the older abused woman as capable of advocating for herself when provided services in such areas as safety planning, securing protective orders, and groups for peer support.

Hightower [3] believes that older abused women become part of the 'elder abuse' system rather than the 'domestic violence' system, thus, they are viewed with the medical model used within elder abuse focusing on their frailty and daily living needs. She further reports that "This model supports a view of the elderly as 'sexless'" and "to homogenize older people by not taking into account individual differences, including gender" (p.1) [3]. The ramifications is that "This perspective on older adults has resulted in the failure of advocates and service

CHAPTER 8

Spirituality and Older Women: The Journey Home to Self

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Abstract: The self unfolds through a life long journey of becoming and making meaning. This chapter elucidates the role of spirituality in older women's lives. First it sets the context for the role of religion, addressing demographics and research on gender and faith. The distinction between spirituality and religion is discussed. Spiritual struggle and suffering are identified as normative experiences. In a section on theory and models, feminism, gerotranscendence, and narrative are described as they relate to spirituality. Three modern writers and one research participant provide examples of the variation that may occur on a spiritual path. Discussion provides further elaboration and guidance to mental health professionals who want to address and support the spiritual lives of women. Aging invites women to come alive in new ways as they honor the journey home to their authentic self, a self that is always larger than what they can dream.

Keywords: Older women, Religion, Spirituality.

SPIRITUALITY AND OLDER WOMEN: THE JOURNEY HOME TO SELF

[In older ages] *one has ample time to face everything one has had, been, done: gather them all in: the things that come from outside, and those from inside. . . . When you truly possess all you have been and done, you are fierce with reality* --Florida Scott-Maxwell (p.41-42) [1].

Spirituality of women at older ages is concerned with understanding past events

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and future possibilities in light of the eternal now. This search for understanding welcomes the difficult experiences of life as much as time spent in gentle merriment with friends and family. Finding home, or the place where one is at a place of deep peace, is an archetype for returning to soul. Home is an essential space of safety, nurture, and creativity. However, in the turbulence of family life, vulnerabilities are also exploited and grave injury sometimes ensues. Ultimately the challenges become essential points of learning, kindling for growth. Spirituality is a lens that sees connection, value in relationships, and a persistent search for meaning and identity through the changing social, emotional, and physical landscape of older years.

As women age, they limit their social networks to contacts that are more satisfying and emotionally fulfilling [2]. They select social partners for their environment who are not peripheral but instead are highly engaged in their lives at multiple levels. They develop emotional resilience. Older women increase their ability to manage ambiguity and uncertainty through change in their emotional stance toward difficult situations [3], especially if they are unable to alter the situation itself. Aging women may experience chronic illnesses, but universally express their desire to age in place with supports instead of moving into assisted living or nursing care facilities [4, 5].

Florida Scott-Maxwell, a female pioneer in psychoanalysis, herself embodied a resilient path through life, living in an enriched way. As a young woman, born in 1883, she was educated mostly at home with only brief periods spent in public classrooms. At age 15 she left home to build a life on the New York City stage, but she exited that life at age 20 to write short stories. In 1910 she married and moved with her partner to his native Scotland, tending to women's suffrage, plays, and children. In 1933, she became a psychoanalyst, studying under Jung and practicing in clinics in the UK. In some ways her life, viewed from a distance, seems to be made of distinctive threads, yet in the end she fashioned them together in a whole cloth that revealed her as an intense observer of aging. "Life does not accommodate you, it shatters you. It is meant to, and it couldn't do it better" (p.65) [1]. While women may hope for an easy, tranquil life that is not what most collect. As Scott-Maxwell suggests, they are better for the struggle.

This chapter elucidates the role of spirituality in women's lives. First it sets the context for the role of religion in the lives of older adults. Then it addresses demographics and research on gender and faith. The distinction between spirituality and religion is discussed. Spiritual struggle and suffering are identified as normative experiences. In a section on theory and models, feminism, gerotranscendence, and narrative theory are described as they relate to spirituality. Three modern writers and one research participant provide examples of the variation that may occur on a spiritual path. The Discussion section provides further elaboration and finally guidance to mental health professionals who want to address and support the spiritual lives of women.

OLDER PEOPLE AND RELIGION

In the US, 82% of women consider religion important to any extent compared to 73% of men [6]. In terms of the practice of prayer, 79% of women indicate they pray while only 62% of men report such behavior [7]. Christian religions currently predominate in America: 84% of adults ages 60-69 and 88% over age 70 express an affiliation with a faith under this category [8]. Still, with increasing immigration, the numbers of older adults proclaiming affiliation with world religions will grow. On a global context, religious expressions and levels of faith adherence vary considerably. The term *world religions* refer to faith traditions that predominate in other countries, such as Hinduism in India and Buddhism in Japan. The UK has long hosted a more diverse population than the US. In the UK, only 72% of the populace reports holding Christian affiliation and 15% endorses atheism or agnosticism [2]. This diversity and complexity has probably made it even more difficult to address religion and spirituality in the public sphere in the UK than in the US.

As cohorts age, spirituality will likely become a more universally endorsed term than religion for new generations of older adults across the globe [9]. Even though religious affiliation remains high, frequency of attendance tends to diminish with age due to increasing frailty and transportation hurdles. While there is a general view in society that older adults may become more religious as they age, this has not been supported by empirical evidence [10]. In fact, for those who acknowledge a spiritual journey, it is often marked by steps forward and

CHAPTER 9

Methodological Challenges in Conducting Surveys with Mature Women

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Abstract: This chapter outlines the major challenges presented when conducting a survey with older women from a "total survey error" perspective. The total survey error perspective considers sampling error, coverage error, measurement error and non-response error in designing and executing a survey. Noting that multiple surveys are routinely conducted with mature populations for estimation, policy analyses, and program evaluation, the chapter discusses special circumstances that should be taken into account when mature women are in the sample or are the focal population. The chapter provides guidance in avoiding or mitigating error through design and adjustment.

Keywords: Mature women, Research methodology, Survey research.

INTRODUCTION

Surveys are one of the most widely employed tools for social research, policy planning, program implementation and evaluation. Surveys are frequently used to establish population estimates of health, social, and economic conditions of the elderly. Prior to, during and after community wide interventions social surveys are often used to determine program impact as well as program implementation. Population estimates are used to allocate resources.

To be most useful, sample survey statistics must be valid and reliable. Estimates derived from sample surveys should fully reflect characteristics of the target

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population. The methods employed to generate those sample statistics should yield consistent results when applied under consistent conditions. That is, the tools of measurement should yield the sample results when repeated on the sample population.

The core population surveys of the Federal Statistical System, the American Community Survey, the Current Population Survey, the Survey of Income and Program Participation, the Panel Survey of Income Dynamics, the National Health Interview Survey, the Behavioral Risk Factor Surveillance System, and the Medical Expenditures Panel Survey are designed to represent the general population, including mature adults. Complementing these key sources of population estimates are surveys specially designed to represent mature populations. These include the Health and Retirement Survey, the Longitudinal Studies of Aging (LSOAs), National Longitudinal Surveys of Young and Mature Women, and the National Health and Aging Trends Study. Apart from generating population statistics, the execution of these surveys have richly informed our understanding of the general and special considerations that must be taken into account when conducting surveys with mature populations.

TOTAL SURVEY ERROR

In survey research, survey methodologists frequently refer to "Total Survey Error" when making survey design decisions. Total survey error includes sampling error, coverage error, measurement error, nonresponse error, and processing error. Most surveys are designed to minimize all of the types of the aforementioned errors at an acceptable cost [1]. This chapter focuses on whether and how the first four of the listed errors are particularly problematic for sample surveys of elderly respondents and suggest strategies for reducing these errors. The final source of error, processing error, does not present unique challenges in surveys of mature women.

Sampling Error

The goal of sample surveys as a research tool is to reliably and validly represent the population to which the results of the research can be generalized. This requires that sample selection methods are employed to reduce the influence of

selection bias. Probability samples permit the use of inferential statistics. Conducting a survey that accurately reflects the target population means that each estimate based on survey data contains as little error or bias as possible. Achieving the smallest measurement bias is in part a function of survey design decisions that in turn are often dictated by the costs, time, and effort associated with using various survey techniques.

Sampling error is the result of measuring a random sample instead of the whole population, varies with the size of the random sample, and is not differentially affected by the age of the population group. In the case of random samples, mathematical theory is used to assess the sampling error. Estimates from random samples can be accompanied by measures of the uncertainty associated with the estimate, such as standard error and confidence intervals.

However, the use of convenience samples is common in certain areas of elder research. Convenience samples are used because of the cost of identifying and recruiting hard-to-reach or rare populations, the absence of good sampling frames, and the perceived high costs of screening and recruiting individuals to participate in a random sample survey. Hultsch, MacDonald, Hunter, Maitland and Dixon [2] found that only 10% of surveys of caregivers conducted between 1990 and 1998 were based on random selection methods. Caution should be exercised when interpreting or attempting to generalize research findings generated though non-probability samples. In comparison to a randomly selected sample, convenience samples of caregivers are more likely to include caregivers who are married to and live with the care recipient, and are more likely to have higher levels of education and income [3]. These differences in sample representativeness often have important implications for key study variables. For example, Pruchno *et al.* [3] report that convenience sample respondents expressed higher levels of caregiver burden and increased signs of depression compared with respondents from a randomly selected sample. They speculate that respondents who were drawn to the convenience sample recruitment methods and volunteered for the study may have been more needy and overburdened than the probability sample.

Respondent driven sampling (RDS) is a technique developed in the past decade to address what many researchers interested in studying rare populations for which

CHAPTER 10

The Need for Connection: The Role of Groups in the Lives of Older Women

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Abstract: Group connections are powerful tools to help older women to sustain a sense of well-being and health. The healing qualities of groups have the potential to mitigate issues of social isolation and loneliness. Women find support, camaraderie and hope through group membership. This chapter describes common challenges faced by older women and explains the healing quality of belonging to diverse types of groups.

Keywords: Connections, Groups, Older women, Relationships.

INTRODUCTION

The following case example identifies and highlights common challenges experienced by older women in today's society.

Jane Harris is a 75 year old woman who states that she generally enjoys good physical and cognitive health. Her main concern is that she experiences periods of sadness, lethargy and fatigue that she believes come from loneliness. Ms. Harris was widowed five years ago. She spent the last five years of her husband's life caring for him through his battle with lung cancer. She has three children who live out of state, two of whom are married, one of whom has two children. Ms. Harris speaks with great pride about her grandchildren but is disappointed that she does not see them very frequently.

Ms. Harris was married for 42 years and describes her "total dedication" to her

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husband and children during that time. She finished a teaching program in a local college, but never worked because she thought it would take too much time from her family.. She describes herself as not religiously observant but grounded in a spiritual belief in "a higher power." She is financially stretched, but determined to keep "food on the table and a roof over my head." She lives in the house that she and her husband built, and has contemplated a future decision to obtain a reverse mortgage to make ends meet. She relies on income of about $28,000 a year from a combination of Social Security benefits and a small investment fund. She worries that if she has health needs her money won't last. Now alone, Ms. Harris feels isolated and "out of touch" with the rest of the world.

Ms. Harris is typical of many women over the age of 65. Her life had once been organized around the care of her family, but now at a stage of life during which she still has health and the capacity to care for herself independently, she feels alone and disconnected from the world. The problem for Ms. Harris, and for other older women, is substantiated by statistics. In 2011, the Administration on Aging reported that older women outnumbered older men, 23 million to 17.5 million [1]. Also, the same report from the Administration on Aging reports that almost half of women over the age of 75 lived alone, with 40 percent of that group being widowed. Like Jane Harris, many older women live alone in our society and face significant physical, economic, social and psychological challenges.

Although a report by the National Center for Health Statistics [2] demonstrates that 44 percent of non-institutionalized older persons, defined as over 65 years old, assess their health as excellent or very good, most older persons have one or more chronic conditions. However, since women live longer, they are likely to experience the challenges associated with chronic illness and potential disability for an extended period of time. This is exacerbated by the natural decline of biological systemic factors inherent in the aging process [1, 2].

Older women also face financial challenges and are likely to be poor. Older women had a higher poverty rate (10.7%) than older men (6.2%) in 2011 [1]. The overall rate of poverty increases with age [1], with 70 percent of all older women having fallen below the poverty line. Older women who live alone are even more likely to live in poverty. This is especially true among older women of color who

live alone, with the highest rate of poverty (38.8%) among Hispanic women and the next highest rate of poverty (32.2%) among African American women [1].

Often, poverty occurs after, not before, the death of a spouse. The median income of older persons in 2011 was $27,707 for males and $15,362 for females. The main source of income for women is Social Security, and the disparities in earned income result in lower benefits for women than for men. Women often have more sporadic work histories, with absences taken for family responsibilities and caregiving, denying them the opportunity to receive pension income [3].

SOCIAL RELATIONSHIPS

Social relationships have been clearly recognized as instrumental in the ongoing health and well-being of older people [4]. Transitions in the social lives of older women can be particularly challenging. In her groundbreaking work, *In a Different Voice* [5], Carol Gilligan discusses how life transitions impact women's experiences in distinct ways. Women are likely to organize their social identities around an "ethic of care," which Gilligan defines as relationships based upon mutual concern and support. Since almost half of women (46%) over the age of 75 live alone [6], many lack sufficient opportunities for meaningful social connections. The accessibility of earlier connections *via* employment, education, and community activities are likely to be diminished. Important connections with children and extended family may be challenged by mobility and geography as adult children move on with their own progression through the life cycle. Also, women who live alone are often hesitant or unwelcome to participate in social activities with people who are partnered. They may feel abandoned by friends [7]. The absence of these previously experienced daily opportunities for social relationships may therefore diminish older women's perceptions of well-being and sense of self.

Despite the recognition of the continued significance of connection in their older years, women are often reluctant to acknowledge their relational needs. In fact, older women tend to view dependency as a sign of deficit or weakness [8]. However, as life progresses and the relationships by which women have defined themselves are lost, new means of connection must become available.

CHAPTER 11

Well-Being and Health Considerations for the Aging Lesbian Community: Understanding Age Cohorts, Partnerships, Caregiving and Other Unique Needs

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Abstract: Effectively exploring the well-being, health and mental health needs of the aging lesbian community can often be difficult and multi-leveled, while insuring a competent and comprehensive assessment of needs. A limited amount of research has specifically attended to the lives and unique experiences of aging lesbians, along with those of the larger LGBT community, therefore such matters remain poorly understood. Regardless, insuring any dialogue surrounding the needs of older lesbians must underscore their resilience - which for many has included becoming actively engaged as advocates for visibility and change - especially during the late 1960s and Stonewall Inn revolution, as well as the early 1980s and beginning of the HIV/AIDS epidemic - despite ongoing discrimination and prejudice. This chapter examines some of the background statistics on the older lesbian population, exploring lifespan and developmental topics including: coming out; relationships and marriage; parenting; and age cohort differences along with caregiving, death and dying, and risk/protective factors related to sex and sexuality. The chapter concludes with implications for social workers, counselors, and others health practitioners, focusing on affirming approaches and models of practice.

Keywords: Aging, Caregivers, Lesbians, LGBT community.

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Teresa Kilbane & Marcia Spira (Eds.)

INTRODUCTION

Members of the widely diverse lesbian, gay, bisexual, transgender and queer (LGBTQ) community have unique needs when experiencing the aging process, needs which impact their long-term well-being, health and mental health when compared to other aging minority populations. Unfortunately, research has not adequately examined the social support and health requirements of older LGBTQ people (defined as those over the age of 65) and necessities specific to the population have largely "gone unidentified and unmet" [1] within research and social service contexts. Much of the research on LGBTQ older adults has typically examined varied samples of lesbian, gay and bisexual survey participants, commonly focusing on gay men in particular. Minimal research has specifically attended to the lives, concerns and unique experiences of older lesbians, a community that remains poorly understood at best [2]. Sample sizes of studies have also typically not been large, and have lacked specific attention to the impact and intersection of relevant socio-demographic factors, including: race/ethnicity, cultural diversity, urban/rural location, socioeconomic status and level of education [2, 3]. While much of the discourse surrounding the LGBTQ community focuses on risk factors, it should be underscored that this diverse community is notable for its resilience – which for many has included becoming actively engaged as advocates for visibility and change despite ongoing discrimination and prejudice [4]. Exploring and properly addressing the aging, health and wellness needs of all older LGBTQ adult sub-populations is critical to clarify the meaning of diversity within each sub-populations' lived experiences, and to more fully comprehend and understand the cumulative risks facing this aging community [5].

The aging process for lesbians specifically may differ from other members of the LGBTQ community in unique ways, necessitating specific attention. Despite recent advances in policy, advocacy and visibility for the LGBTQ community, lesbians continue to be stigmatized within society – perhaps suggesting why they do not typically participate in research efforts examining their lives [6]. The lives of all older LGBTQ adults have likely been impacted by some form of stigma or oppression [7]. While the impact of perceived or actualized stigma experienced by members of the LGBTQ community often facilitates opportunities for shared

understanding, important differences remain between LGBTQ sub-populations. The stigmatization experienced by these sub-groups is complex and contextual, affecting their health and well-being in unique ways [4]. One example may pertain to age cohort, as younger LGBTQ generations have embraced a more notable visibility while celebrating a LGBTQ sensibility and identity [8]. This celebration is in direct opposition to the projected, and often shared, sense of shame that many older members of the LGBTQ community have felt for decades – especially those among pre-Stonewall cohorts – as a result of being outsiders or having kept one's sexual identity a secret to avoid social stigma, bias and/or oppression [9]. Notably, while the term queer is increasingly popular among younger age cohorts [10, 11]; it may evoke a mostly pejorative meaning for many older members of the LGBTQ community [12].

A more nuanced, targeted discourse may be particularly helpful in discussions surrounding health promotion and service provision. While the health and mental health needs of bisexual women and queer women, as well as members of the widely diverse transgender community, are similarly important to consider, the particular needs of women identifying as lesbians still requires further elucidation. For such reasons, this chapter will focus specifically on the well-being, health and aging issues faced by older lesbians in the face of significant ongoing social stigma and oppression. Additionally, please note that the content presented in this chapter is not generalizable to all lesbians, nor indicative of all older lesbian experiences.

This chapter begins with some background statistics on the older LGBTQ population with a focus on lesbians, and then explores specific lifespan and developmental topics including: the coming out process; relationships, partnerships, and marriage; parenting; and age cohort differences (specifically comparing the pre-Stonewall and the post-Stonewall generations). To underscore the unique health and mental health needs of older lesbians, topics such as caregiving, death and dying will also be examined, as well as risk and protective factors related to sex and sexuality. We have specifically chosen to use the term lesbian for consistency throughout the chapter, yet this discussion is intended to be representative of aging and older lesbian, gay and other same-sex attracted women. Terminology has unique historical context, and using terms such as gay,

CHAPTER 12

Reducing Stigma of Aging and Dementia through Experiential Learning

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Abstract: Background: There is evidence that the stigma regarding older adults can be modified with experiential opportunities early in medical students' careers. The Buddy Program pairs first year medical students with persons with dementia to develop a mentoring relationship outside of the clinical setting. Methods: Using qualitative content analysis of journal entries kept over an academic year, this chapter examines the experience of a female medical student paired with a 74-year-old woman with Alzheimer's disease. Results: Emergent themes included - 1) recognition of the evolving nature of the students' thoughts about dementia over time, 2) the student's awareness of the subjective response of the person with dementia, 3) the student's own emotional reactions to the person with dementia, and 4) the student's understanding of the family experience. Conclusion: As a result of taking part in the program, this student experienced a more holistic view of the person with dementia and her family and a changed perception of dementia and what it is like to live with it.

Keywords: Attitudes, Dementia, Health care, Medical student.

INTRODUCTION

The United States population is aging rapidly and as a result there are an increasing number of persons living with dementia. Over the past ten years, there has been a significant focus on training the health care workforce to have the attitudes, knowledge and skills to provide care for older adults and the cognitively

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impaired. There is evidence that prevailing stigma regarding older adults can be modified with experiential opportunities early in students' careers. Few of these programs are aimed at persons with dementia.

This chapter describes the experience of a female medical student paired in an experiential learning and mentoring program with a 74-year old woman with Alzheimer's disease over an academic year.

SIGNIFICANCE AND BACKGROUND

Aging and Dementia

Those 65 and over represent 13.3% or 41.4 million of the U.S. population (an 18% increase since 2000) and are expected to grow to 21% of the population by 2040. Projections indicate that they will more than double to 92 million in 2060 [1]. The greatest increase in the U.S. population will be among those ages 85 and older. This cohort is at the highest risk for dementia, particularly dementia caused by Alzheimer's disease. The biggest risk factor for dementia is age and approximately half of those over age 85 are estimated to have the disease [2].

Dementia is a description of symptoms that can be caused by different brain disorders. It has an insidious onset and a gradually progressive loss of cognitive function such as thinking, remembering, and reasoning and/or changes in behavior, emotion, and personality. Dementia symptoms affect the person's ability to manage their daily life and activities compared to their prior functioning. Dementia ranges in severity from the mildest stage, when it is just beginning to affect a person's abilities, to the most severe stage, when the person must depend completely on others for basic activities of daily living [3]. Among people over age 65, Alzheimer's disease (AD) is the most common form of dementia.

Over the last 25 years, health and social service professionals, researchers, policy makers, and society as a whole have become more aware of dementia, particularly Alzheimer's disease. The National Institute on Aging estimates [3], over 5 million Americans have Alzheimer's disease as a cause of their dementia and others have related neurodegenerative diseases. The Alzheimer's Association reports Alzheimer's is the sixth cause of death in the country [4]. Based on mortality data

from 2000-2008, deaths have risen 66% for Alzheimer's disease while the cause of death for most major diseases has declined [4]. As a consequence of increased longevity and expansion of the older adult population, it is projected that by 2050, AD will affect 13.2 to 16 million United States citizens [2].

These facts contribute to a growing demand for health care professionals trained and committed to working with persons with dementia [5, 6]. Currently, less than one in four people with dementia receive a formal diagnosis [7 - 9]; therefore, they are not receiving appropriate care, treatment and support. The number of geriatricians is few and declining, leaving general internists and primary care physicians along with other health care professionals the task of providing the majority of health care for older people and those with dementia [10]. It is important that these clinicians have the attitudes, knowledge and skills to best care for older adults and the cognitively impaired.

Education and Training in Aging and Dementia

On January 4, 2011, President Barack Obama signed the National Alzheimer's Project Act (NAPA) (Public Law 111-375) [11]. One of the five concrete goals to achieve the vision of NAPA is to enhance care quality and efficiency by building a workforce that can give high-quality care for people with Alzheimer's disease [12]. Although assessment and management of Alzheimer's disease and related dementias has been widely disseminated among healthcare professionals, many have not acquired the knowledge and skills [7, 13, 14]. Medical professionals, both in the hospital and in the community find it challenging to provide competent care for patients with dementia [15, 16]. One of the major challenges is the negative attitude that healthcare professionals historically have had toward older adults leading to limited knowledge and interest in pursuing geriatrics or dementia [17 - 29]. While there is evidence that teaching geriatrics in general can impact medical students' acquisition of knowledge, skills and attitudes [20, 30 - 33] few learning outcomes focus on dementia and the majority have not addressed the lack of trained healthcare professionals who simultaneously understand the strengths, limitations, and needs of persons with memory impairment and dementia. A survey of more than 500 hospital and community physicians in the USA cited better understanding of dementia as the most commonly identified learning need

SUBJECT INDEX

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