

SPECIAL ISSUE

# Indian Journal of GERONTOLOGY

*a quarterly journal devoted to research on ageing*

**Vol. 26 No. 1, 2012**

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# Indian Journal of GERONTOLOGY

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**Vol. 26 No. 1, 2012**

*Special Issue on*

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**SOCIAL WORK**

**Part - 2**

*Guest Editors :*

**Barbara Berknan**

and

**Daniel B. Kaplan**

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## FOR OUR READERS

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### **CORRIGENDUM**

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### **Book Received for Review :**

AGEISM AND ELDER ABUSE (Edited By ) Lynn McDonald and K.L.Sharma, Rawat Publications, Satyam Apartments, Sector 3, Jawahar Nagar, Jaipur-302004, India, also available at Delhi, Bangalore, Hyderabad and Guwahati. The Book contains total 26 research papers ( 10 on Ageism and 16 on Elder abuse) by Indian and foreign scholars. Price Rs. 895

## Editorial

### **International Social Work in Health and Aging: Lessons from a Global Perspective, Part 2**

This special issue of the *Indian Journal of Gerontology* is the second in a two-part series on social work in health and ageing. With this series we have aimed to highlight contemporary social perspectives on ageing and to celebrate the unique bio-psycho-social framework that guides social work practice and research. The six articles in this second issue offer social perspectives on two very important themes: older adults' participation in meaningful productivity; and the relevance of cultural views and practices related to health. Beginning with three articles presenting research on social engagement of older adults and workforce dynamics which impact older workers, we gain an understanding of the experiences of older, productive citizens who participate in the workforce and in community development efforts. The three subsequent articles address cultural relevance of health related practices and perspectives, which are paramount to our critical appraisal of how we design and deliver health services for older adults.

Carol Austin, Robert McClelland, Jackie Sieppert, and Ellen Perrault's article, "Engaging Older Adults in Community Development," presents research findings from a two-year qualitative examination of the social engagement of older residents during the initial stages of the Elder Friendly Communities Programme, a multi-cultural neighborhood community development initiative in Calgary, Alberta, Canada. Communities which are responsive to the needs of older adults recognize that the vast majority of older people can be vibrant, productive contributors to society. By creating opportunities for full participation

in the community, these authors demonstrate that older citizens can offer considerable and diverse personal resources while benefiting from meaningful social engagement.

Rita Jing-Ann Chou's article offers a thorough review of current cross-national literature related to discrimination against older adults in the workplace. Many older adults experience productive participation in society through paid employment, having not yet retired from the workforce or having re-entered it with renewed interests or out of necessity. The author frames workplace discrimination against older adults as an issue of social justice and individual rights, which can have negative impacts on employment outcomes and on the physical health and psychological well-being of older workers. Implications of this review include the opportunity for the social work profession to promote employment equity and combat workplace discrimination against older workers.

Even when outright discrimination in the workplace is not observed, the subtleties of workplace relationships and coworker dynamics have a considerable impact on the older person's experience of working in late life. These dynamics are increasingly important as workforces become more diverse in terms of age, with older adults remaining on work teams comprised of colleagues from different age cohorts. Christina Matz-Costa, Rene Carapinha, and Marcie Pitt-Catsouphes examine these issues in their research on relational age among work teams and its effects on older workers' perceptions of inclusion in decision-making and information sharing. The authors suggest that those concerned with the well-being of older adults should consider the different social and physical environmental contexts in which people age and construct their realities, including their places of work.

The rapidly growing older adult population is not a homogeneous group. In fact, older adult groups are increasingly diverse globally. The importance of accounting for culture when trying to understand the health beliefs and practices of older adults cannot be overstated.

Culture can create both health benefits and health risks by influencing lifestyles, attention to disease prevention programme, engagement with health services, and responses to medical intervention efforts. In the fourth article in this issue, Halaevalu Vakalahi examines the cultural context of biological health and psycho-social-spiritual well-being among Samoan and Tongan American elders. This qualitative research study found that commitment to numerous cultural practices in the family can have protective influences on an elder's health and well-being. Yet overemphasis on some of these cultural practices can contribute to negative impacts on health and well-being. The author recommends that policies reflect the cross-cultural backgrounds and ways of life of increasingly diverse citizens and proposes that future research studies explore the cultural conceptions of health and well-being among elders in immigrant and dual cultures.

Shadi Martin, in "The Right Not to Know," reports findings from her phenomenological cultural study of older Iranian immigrants' attitudes about their views on medical disclosure of terminal illness. Study participants were asked about medical disclosure of terminal illness as well as their opinions on the ideal method for health care providers to inform patients about terminal illness. The growing numbers of older immigrants in most countries presents us with the need to address culture-specific attitudes about medical disclosure. Gaining understanding of cultural beliefs and attitudes can help health and social service professionals provide better care for patients and family members facing terminal illnesses.

The targeting of culturally relevant prevention and intervention efforts to those health and mental health conditions of greatest prevalence and detriment to the people we aim to help is exemplified in Peter Marmaladi and Tamara Cadet's article, "Ageing and cancer: A global concern for social work." Cancer is the second leading cause of death globally and significant increases in cancer rates and cancer-related deaths can be expected as the world's population ages. The

authors offer a comprehensive review of trends in the incidence of cancer around the world, well-established approaches to cancer control, and exemplary models of feasible cancer screening approaches. They strongly advocate that cancer control efforts be framed in appropriate psychosocial contexts and have cultural and linguistic relevance to the target populations. Older adults are now living longer with cancer, and health and social service providers must now translate cancer control advances into models appropriate for diverse populations around the world.

Taken together, the two special issues on social work in health and ageing help to illuminate the multidimensionality of ageing and the interrelated domains of biological, psychological and social forces that shape, and are shaped by, our living into old age. For citizens of every nation and culture, the challenges that may arise in late life are best understood and addressed through a multidimensional, culturally relevant lens. Gerontological social workers offer this perspective in their work as scholars, practitioners and policy makers. It has been our great pleasure to review and organize the articles submitted for these issues of the *Indian Journal of Gerontology*, and we hope the readers will find these materials to be as relevant as we have found them to be.

**Guest Editors :**

Barbara Berkman  
and  
Daniel B. Kaplan

## Engaging Older Adults in Community Development

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Ellen Perrault*

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### ABSTRACT

*In its Global Age Friendly Cities project, The World Health Organization identifies social engagement as one indicator of an Age Friendly Community. Such engagement can take many forms. The Elder Friendly Communities Programme, located in Calgary, Alberta, Canada, examined the practice of community development with older adults in their neighbourhoods. While community development is an historic social work practice modality, social work researchers and practitioners have not focused their attention on the nature of community development with an older population. Elder Friendly Communities was a seven year demonstration effort, which included a two year qualitative research study, focused on how the neighbourhood based community development effort unfolded. This article reports research findings specifically examining the critical initial stage of engaging older residents in community development activities and the practice of community development with older adults in multi-cultural settings.*

**Key words :** Ageing, Community development, Social participation, Capacity building

Population ageing is a global phenomenon. The United Nations projects older adults, over age 65, will comprise 13 per cent of the world population by 2030. In developing countries, the older population will increase by up to 140 per cent, and developed countries on average will experience a 51 per cent increase by 2030. By 2045, the number of older adults over age 60 will surpass the number of children under age 15, a demographic first (Lopez, *et al.*, 2006; World Health Organization, 2003; Chan Cheung Ming *et al.*, 2007).

These projections pose significant challenges to governments, non-governmental organizations and the private sector around the world (Derricourt & Miller, 1992; Desai & Tye, 2009). The United Nations convened the Second World Assembly on Ageing in Madrid in 2002. Representatives from 151 countries endorsed the Madrid International Plan of Action on Ageing (MIPAA) that specified three areas requiring determined and sustained attention by policy makers: 1.) older persons and development, 2.) advancing health and well being and 3.) ensuring and enabling supportive environments (United Nations, 2002).

Older adults are at substantial risk of marginalization in many different cultural, political and economic contexts (Tout, 1992; Gilchrist, 1992). "People live longer and healthier lives than ever before and have also the potential to make important contributions to society at old age. However, older persons are often vulnerable to exclusion, marginalization and discrimination" (UNECE, 2009). The MIPAA also recognized that poverty in old age is a significant reality in both developed and developing countries, as well as those with transitioning economies. Unfortunately, public pension systems, where they exist, do not ensure economic security for elders. In multi-ethnic societies, elders who do not belong to the majority cultural group can confront serious barriers in their efforts to access economic benefits, as well as health and social services. Representatives at the Madrid World Assembly noted that many countries are not adequately prepared to meet the health and social service needs of their ageing populations. Insufficient planning, funding, staffing, policy and programme development undermine healthy ageing at the individual and population levels.

The Madrid World Assembly also recognized that global population ageing presents an opportunity for older adults to become more influential. However, this requires a level of organization (local, regional and national) that is not consistently present around the globe. The MIPAA's focus on ensuring and enabling supportive environments for older persons, is echoed in the World Health Organization's Global Age Friendly Cities Initiative. The World Health Organization has identified social participation, respect, social inclusion and civic participation as indicators of urban environments that promote healthy and active ageing (WHO, 2003). Older adults are viewed as full, contributing members of the community, whose participation and contributions are sought and

valued. Elder rich societies have the potential to draw upon this frequently overlooked and untapped resource, their older population. How can this be accomplished? One approach is community development with older adults in their neighbourhoods.

This paper reports on the experience of engaging older adults in the early stages of community development in their neighbourhoods. The Elder Friendly Communities Program was a research and demonstration effort in Calgary, Alberta, a large urban centre in Western Canada. This article addresses the historical significance of community development in social work and continues with a description of the programme. It presents the qualitative research methods used in the study and reports findings and implications for practice.

In brief, older adult participants and community development workers in this study identified the initial obstacles they confronted in starting neighbourhood based community development efforts including, challenges in forming neighbourhood groups, relationship building and mobilizing leadership. Community development workers stressed the need to position themselves to facilitate rather than control. They called this leadership from behind. Both groups identified the pivotal role played by community associations in their neighbourhood based community development activities. The Elder Friendly Communities Program involved culturally diverse participants whose responses shaped insights regarding the practice of multicultural community practice with older adults. The article includes a discussion of practice implications for social workers potentially interested in engaging older adults in community development in diverse locations around the world.

### **Back to the Future : Community Development in Neighborhoods**

Community development (CD) is a familiar social work practice approach designed to enhance community capacity and to address local concerns. Historically, proximate local environments, neighbourhoods, have been important targets of social work intervention. However, older adults may have been overlooked as participants in community development efforts because of their age. Why is this the case? Perhaps one explanation is found in ageist stereotypes embedded in many cultures that may influence professional practice. We often encounter such views as: ageing is largely about decreasing energy and failing health; elders

do not have much to contribute; older adults only want recreational activities; seniors' attitudes are narrowly conservative; and elders are not capable of learning new skills and roles (Butler, 1975). Such stereotypes devalue the talents, experience, expertise, capacities and contributions elders make to their communities. Community development is one way to engage this rich, frequently untapped, community resource.

Community development starts with the conviction that older adults contribute to their communities and will benefit from this involvement. "Fundamental to this approach is the belief that members of the community have the primary responsibility for decision making and action. Community development produces self-reliant, self-sustaining communities that mobilize resources for the benefit of the whole" (Homan, 2004).

Why are neighbourhoods important in community development? People spend most of their time living and interacting in proximate environments, locations that profoundly affect their daily experience (South Vancouver Neighbourhood House, 2009). In urban settings neighbourhoods are the ongoing and dynamic contexts for daily life (Saleebey, 2004). Neighbourhoods are also important because they are recognizable and easily identified geographic areas. Each neighbourhood has a complex network of relationships (Chaskin, 1997). Furthermore, neighbourhoods are viable units of identity and action (Wellman, 1979). This is particularly significant for elders, given policy and programmatic initiatives designed to promote ageing in place. Rowles (1993) distinguishes between "aging in place" and "place in aging," noting the importance of "social affinity with our neighbourhoods as a result of patterns of interactions with neighbours and friends".

Consequently, neighbourhoods are important targets for community development initiatives, aiming to engage older adults in creating supportive environments. However, little research has focused on understanding the practice of community development with older adults at the neighbourhood level (Mairs, 1993; St Christopher House, 2004). The Elder Friendly Communities Program in Calgary, Alberta Canada sought to examine the nature of grassroots community development as an approach to promoting civic engagement of older adults, enhancing their ownership of local initiatives and generating sustainable social changes in their neighbourhoods. The neighbourhoods in this project

ranged in population from 6,669 to 18,361, and the proportion of seniors ranged from 18.4 per cent to 5.7 per cent respectively (see Table 1).

### Elder Friendly Communities Programme

Predating the Madrid World Assembly and the Global Age Friendly Cities Project, the Elder Friendly Communities Program originated in 2000 with the goal of engaging and empowering older adults in their neighborhoods, using community development to build skills, leadership, advocacy and organization. It was seen as a vehicle for fostering vital involvement of seniors in their communities, improving the quality of life for older adults and supporting seniors in their own homes and neighbourhoods. These community development activities were funded by public sources at the municipal, provincial and federal levels, as well as support from not for profit agencies and foundations. The research reported here was funded by the Alberta Heritage Foundation for Medical Research (Austin, *et al.*, 2006).

The programme developed using a phased approach. An extensive needs assessment was initially conducted in four, geographically defined Calgary neighbourhoods, selected for variation in density of older population, income levels and cultural diversity (see Table 1).

**Table 1. Neighbourhood Characteristics in the EFCP**

Calgary Neighbourhood	Total Population	% Seniors in neighbourhood population	% Seniors 85+	Average Senior's Income (CA \$)	% Low Income Seniors	% Population Non-English & Non-French Mother Tongue*
1	9,365	13.3	10.8	\$14,906	35.0	15.6
2	6,669	18.4	3.7	\$20,832	20.6	11.0
3	18,361	5.7	3.8	\$14,974	51.4	30.0
4	12,634	15.0	6.9	\$30,464	16.9	23.5

Source: Statistics Canada. 1996 Census of Canada: Profile Data. E-STAT ed. 2004.

\* Canada's two official languages are English & French. This census data was used as a measure of ethnic/cultural diversity.

The needs assessment sought to develop a solid understanding of the assets, capacities and needs of older adults and their families in these neighbourhoods, and to engage seniors in a community development process to address some of the concerns that they had themselves identified. The needs assessment report entitled, A Place to Call Home (Austin, *et al.*, 2001) captured the voices of seniors, identifying eight themes: being valued and respected, staying active, building community, feeling safe, having a place to call home, getting what you need, making ends meet, and getting around. Subsequently, participants developed work plans and took action to address their concerns. After the initial start up period, a two year qualitative research project was undertaken to identify promising community development practices with older adults in their neighbourhoods. The research findings reported below and the practice implications offered later in this article, applied a process model as an organizing framework in the analysis and interpretation of the Elder Friendly Communities project experience (Henderson & Thomas, 2011). The final report of this research (Austin, *et al.*, 2006) presents these findings in greater detail. We believe that the observations and insights found in this research may be relevant to practitioners in other countries. It will be necessary to carefully develop cultural adaptations that reflect the specific realities of local communities around the world.

### Methods

The multi method, qualitative research included direct observation, focus groups, individual and group interviews. Respondents included older adults involved in neighbourhood based community development activities, community development workers and community leaders. Detailed demographic data were not collected directly from programme participants as this was viewed as intrusive and potentially negatively affecting elders' willingness to remain involved in the programme and participate in the research. All programme participants were self identified as over age 65. By observation, participants were Caucasian, Chinese and Vietnamese. There was a mix of genders in all groups. Translation and interpretation services were used in data collection involving Chinese and Vietnamese elders. Focus group respondents were active members in their neighbourhood groups. Individual interviews were also conducted with elders who had assumed leadership roles. A semi-structured interview schedule was used in interviews with



programme participants. Community development workers were interviewed using an unstructured interview schedule.

Data were collected at two points (T1 & T2) over a two year period. At T1, 68 older adults were interviewed in 6 focus groups. Individual interviews (T1) were also conducted with 11 community development workers. At T2, 64 of the 68 older adults previously interviewed at T1 participated in 5 focus groups. Individual semi-structured interviews (T2) were conducted with 10 participants who were leaders in their neighbourhood groups. Additionally, 12 in-depth, unstructured interviews were conducted with community development workers most involved over the 2 year research period. Member checking was conducted in all group interviews. Some respondents were both individual interview respondents and focus group participants. A total of one hundred sixty-five respondents were interviewed in T1 and T2 data collection.

A systematic data analysis strategy was implemented to examine the community development database. Audio-recorded data were reviewed to double-check that the transcripts matched the audio recording for each interview, focus group, and meeting observation. ATLAS.ti (4.1 for Windows 95) was selected as a tool for storing and organizing the database. The multi-phase coding and interpretational analysis was conducted by four coders. Three coders were social work faculty members and one was the project research coordinator, a doctoral student. This process included analytic induction, categorical aggregation, identifying relative patterns, and assessing frequency of similar statements. Simultaneously drawing on all forms of data collection to uncover the common themes, all data were analyzed continuously to give the “convergence of evidence” required for triangulation. This uncovered important dynamics, behaviours, and influential incidents. The four coders met every two weeks over six months to discuss the analytic process and emerging findings.

This paper presents findings about the critical initial stages of grassroots community development. We included respondents’ quotations, from both elders and community development workers, to highlight their diverse perspectives and to show points of convergence. These quotations are presented in bold single spaced italics. The following

discussion begins with the need to confront initial barriers in two important areas: stimulating confidence and achieving a common vision of community development. This discussion is followed with observations concerning, engagement, relationship building, leadership, forming neighbourhood groups, the role of community associations and multicultural community development. We close with a discussion of implications for practice.

### **Confronting Initial Barriers: Lack of Confidence**

In community development, there is a strong commitment to enhancing community capacity and social capital by establishing and maintaining interpersonal relationships. The approach adopted by in the programme stressed that older adults’ talents, assets, skills and experience are untapped community resources that should be mobilized. The emphasis was on skill development, the capacity of participants to understand and resolve issues and the development of initiatives led by older neighbourhood residents. From the beginning, elders were asked to lead the local community development process. This approach was foreign to some older adults whose experience in society generally, and specifically with helping professionals, often occurred in environments where elders were viewed as passive recipients of services, rather than assertive leaders and decision makers.

The most profound barrier confronted by community development workers was ageist attitudes held by both seniors and professionals. Some seniors had internalized the stereotypes.

*Something we fight, as a hidden enemy, is that people think when your hair gets grey, your mind gets dead. (Senior)*

*It is a psychological thing – people are scared of getting old – people say, “I’m not old enough to be in there”. (Senior)*

*Perhaps the seniors attending the groups may be those that have not internalized the negative stereotypes of seniors. (Community development worker)*

Professional expertise is powerful and older adults may defer to it. For example, at an early community meeting in one neighborhood, two community development workers described the importance of senior

led initiatives, stressing empowerment, self-determination and owning the process. They emphasized that community development workers were there to facilitate the process and not lead it. When they finished, a voice came from one of the seniors in the back of the room asking, “Okay, what do you want us to do first?”

Initially, the community development workers did not fully appreciate the power of perceived professional expertise and how it affected their efforts to engage participants. While community development workers sought to identify and build on the abilities of older residents, a common response from elders was to defer and expect professionals to be in charge. In essence, some of the elders were saying, “What do I know? You have all the answers.” Over time, this misconception dissipated and a facilitative working relationship developed between elders and community development workers.

### **Confronting Initial Barriers: Achieving a Common Vision of Community Development**

The programme involved staff (nurses and social workers) from a number of health and social service organizations, agencies that wanted their staff to learn more about community development with seniors. Often job expectations in the participating agencies lacked clarity. These organizations had different understandings of what community development involved. The community development workers noted that their agencies provided inadequate organizational supports for their work, undermining their ability to devote sufficient time and attention to the initial efforts to engage older residents. Respondents also identified the importance of collaboration skills in multidisciplinary, inter-agency community development practice.

*It is difficult to work together with other professionals if the definition of community development is different among these professions. (Community development worker)*

*The agencies must be flexible with the CD workers time, responsibilities and budget. (Community development worker)*

*The agencies also need to understand that CD work requires time and provide the worker with enough time to do the work. (Community development worker)*

*Collaboration is essential to community development. You must work in collaboration because one agency cannot be everything for people. Each person brings their own resources, talent, knowledge, and experience to the table. (Community development worker)*

*I think as we have worked together and struggled to look at different ways of doing things, there have been initiatives that have come out of that struggle and that dialogue. (Community development worker)*

### **Engaging Older Adults**

A catalytic event can be an effective strategy to facilitate the initial process of senior engagement. Seniors were initially engaged through a community needs and assets assessment designed to identify their issues and concerns about living in their respective neighborhoods. This assessment process was different than many previous needs assessments conducted by service organizations. It was not designed to identify service gaps. In the community assessment seniors were asked to identify aspects of community life that were important to support independent living. Seniors who participated in the process did not identify gaps in social and health services as prominent concerns.

Findings from the needs and assets assessment (Austin, *et al.*, 2001) provided the foundation for community capacity building. Elders were asked, “Are there any of the issues you identified that you want to work on with our help?” The response was positive in every neighbourhood. Participants and community development workers then shifted their attention from general concerns to identifying concrete actionable issues.

Although putting community expertise ahead of professional expertise was challenging for some of the community development workers. However, the expressed interests of seniors to drove community development initiatives. Seniors were not asked to devote their time and energy to initiatives that they had not identified. This promoted group cohesiveness. The most successful seniors’ groups organized practical initiatives that addressed their most significant concerns such as socialization, snow removal, information on benefits, advocacy and health improvement.

*The Elder Friendly process includes taking careful steps to measure and analyze the needs and problems of the community. (Community development worker)*

*We go in there saying “are there issues?” and people identify them and then we start to try and help the community mobilize to address them. (Community development worker)*

*Each community requires a different strategy because neighbourhoods aren't all alike. (Senior)*

*The size of the group has to be small enough to stay closely knit. (Senior)*

*You really need to establish credibility before you go and “make the ask”. (Community development worker)*

*Initially, it seemed like a long term goal that might not happen and as we worked more on it and people came together more, nobody would want to miss a meeting. (Community development worker)*

### **Relationship Building**

Paradoxically, in order to organize group initiatives, community development workers found that engaging older adults involved building relationships one person at a time. Seniors reported that building trust involved the community development workers being supportive, available, listening carefully and encouraging participation. This process enhanced the capacity of community development workers to identify individual senior's skills and assets that might contribute to group capacity.

*The CD worker must be supportive, friendly, knowledgeable, mature, helpful, genuine, smile, sympathetic and be a “real person”. (Senior)*

*CD workers have to be social oriented. They have to know how to approach people. (Community development worker)*

***...in order to do community development, you need to build relationships one at a time. It is not just bringing a whole big group of people together. I find it is more effective on a smaller scale because seniors feel very***

***powerless to affect change, even in their individual [lives], let alone on a community scale. (Community development worker)***

***...it is about developing relationships one on one with individuals, and the more that you can do that, it draws more people in. They need that first of all — knowledge of who you are. (Community development worker)***

*It takes time to engage in something meaningful with seniors. We do it with them, not for them. (Community development worker)*

*At the beginning of the process, the CD worker needs to demonstrate the CD worker's role by encouraging the seniors to take the reins. (Community development worker)*

Programme staff learned that participants joined the neighbourhood groups for a variety of reasons. Some wanted to improve social conditions in their neighbourhoods and others wanted to socialize. In order to engage and sustain involvement of a diverse group of participants, it was important to attend to the balance of task oriented activities and opportunities to socialize. Starting with a small group of elders who had many community connections and who were long standing neighbourhood residents, facilitated engagement of other participants.

*Some come for social aspects (Senior)*

*Some like to go to anything with food and then don't attend any other meetings. (Senior)*

*The [neighbourhood # 1] meeting structure seems to work really well. They have 10 minutes at the beginning for business and then they have a 20 minute information session, and then a one hour social. (Senior)*

*Start by getting a senior already experienced and skilled in being involved in the community to speak to others. These would be initial key contacts. (Senior)*

***Ideally, your seniors' group is developed in the area seniors grew up. Then you have connections to start from in developing the group, to build on existing community connections. (Senior)***

### Mobilizing Leadership and Leading From Behind

A participant identified a key skill required for effective community work. This was the ability to facilitate the group processes in order to mobilize and focus the interests and abilities of programme participants. They needed to be well organized and approachable.

*She [a community worker] listens, she is through, she follows through on what she says she is going to do, she lets people have a say and then pulls the group back together, and she is task oriented with a lot of common sense. (Senior)*

Mobilizing community leadership was one of the biggest challenges. In some neighbourhoods, leaders emerged quickly, but for other communities, the community development worker had to devise creative ways to build the confidence and capacity of local leadership. Only a small number of seniors were willing to assume key group leadership responsibilities at any point in time. In order to recruit leaders more effectively, the leadership role was reframed as “helping others out”. Sharing tasks and breaking big jobs into smaller components also worked well. This reframing of leadership was successful in enhancing the willingness of participants to undertake these important responsibilities. The need to plan for leader succession was evident in all of the neighbourhood groups.

*You really have to work to bring more people in. It works sometimes to ask them to do one little job. (Senior)*

*Some say they have “done that and been there” so don’t want the responsibility of leadership or responsibility of tasks within the group. (Community worker)*

*Although some seniors demonstrate lack of confidence (not comfortable speaking in public or taking on certain tasks), others are demonstrating confidence and sense of knowing self and demonstrate “awareness of others outside themselves”. (Community development worker)*

*I think that maybe the facilitator should be aware whether that senior will be capable to do that job and also may need some assistance too. (Community development worker)*

Programme staff struggled with the nature of their participation and the extent to which they should assume a leadership role. Most often, they adopted an approach to facilitation that was called “leadership from behind.” In this approach the worker assumed some leadership roles temporarily, while mentoring potential leaders to assume these responsibilities. The emphasis was on developing leadership capacity. In this process it also important for the community development workers to clarify their role.

*It is a fine balance of knowing when to offer things and when to respond to seniors requests. (Community development worker)*

*Sometimes the seniors need a break from the specific leadership and then the CD worker may need to step in to provide leadership for a short time. (Community development worker)*

*Very slow process! You really have got to be willing to not direct it. Just let it happen and accept whatever the outcome is. You can’t make it happen. (Community development worker)*

*What have I learned? To be quieter at the meetings. . . not to talk so much . . . sit back and you just have to listen and you will get all the ideas. Respecting their skills so that you [as the facilitator] are not always volunteering to do the work. (Community development worker)*

### Forming Neighbourhood Groups

Once community development workers have successfully entered the neighbourhood the next task is to focus on forming seniors groups. It was important that the group establish its identity in the neighbourhood. This was accomplished using a variety of strategies including publicity, advertising, putting up posters in visible locations, making contact information for key group members available to neighbourhood residents, developing pamphlets and through word of mouth. It was particularly important that neighbourhood seniors who were early participants in community development express positive feelings to others about the seniors’ role in the community and their involvement in the group.

*. . . to have a group get together and say, “yeah you are more than equal to this because you know your community. You are the roots of this community.” (Senior)*

*If we feel good about the group, we will introduce and promote it to others. (Senior)*

#### The Pivotal Role of Community Associations

One organization that proved to be essential to the program in its initial stages was the local community association. They proved to be important for forming neighbourhood groups. Some associations needed help in understanding and acknowledging the expressed needs of older community residents, but they eventually became a primary support. Local community associations in Calgary were already organized by geographic neighbourhood boundaries. They were well established community organizations and were a critical resource for group development, a place for groups to meet and a setting from which group initiatives were launched.

*Are we accepted in the community? Do they know about us? How does the community association look at us? Why are we treated differently? We want to help the community as a whole. We really looked at that very carefully and then determined how best [we] could get the [community association] board informed, keep them up to date with what was happening. It was kind of building that relationship with them and I think it was huge. (Senior)*

*Again, just being voted in as a [board] member, I think that was pretty significant. I also think the support we got administratively by the Board of Directors [helped us]... (Senior)*

It was necessary for programme staff to assess the readiness of community associations to support the developing seniors group. Some community associations focused most of their efforts and energy on programs for children and youth and had not engaged elder residents. In other neighbourhoods, community associations were already involved with senior programming. In these situations, it was imperative that initiatives undertaken by Elder Friendly Community groups were planned and implemented with full knowledge of other programs provided by or through the local community associations. Because community associations represented an ongoing presence in the neighbourhoods, this collaboration was important for the sustainability of the groups.

*This Elder Friendly [group] really needs the community backing because they (the community association) concentrate on*

*young people but now they have to start concentrating on us old plugs. And there is getting to be more of us. (Senior)*

*I was talking to a [community association] director in [community 3], because I live in [community 3], and she said, "Well, we do that! So why are you doing that as well?" Why are we doing the same as they are? (Senior)*

*The other factor that made the Elder Friendly group successful is that the community association had already expressed a genuine wish to reflect the needs of seniors in the activities of the community association. Not just cards but in some other ways which would affect the quality of life, other than just the card playing. So there was certainly support from the community association and a bit of impetus from one of the community members. (Community development worker)*

*Sustainability depends on the group receiving the necessary support to garner a stable place and finances. (Senior)*

*There is some connection now with the community association and that is very much a positive because I think that is how the support and sustainability has to come, is from the community at large. (Senior)*

One consistently useful communication tool for neighbourhood groups was the community newsletter. Since this publication was delivered to each home in the neighbourhood, it was a very efficient way to get the word out about the new seniors group to older residents who might be interested in joining, as well as to the community in general. Another successful approach to establish the group's identity was to organize and hold a highly visible event. Events that included a meal were particularly effective. A core group of senior participants was required to plan and hold the event. These events enhanced the visibility of the neighbourhood group, provided a way to gauge initial interest, to recruit new participants and to socialize.

*... they do write ups in the community newsletter and I think they are starting to know who Elder Friendly is and that the group exists. (Community development worker)*

*...have a launch that would really sort of let everybody know what was going on. It launched not only this on-going drop-in but it also launched the whole idea of [community group # 1]. It got a lot of attention from people in the community. (Senior)*

*Highly visible event and what impacted me was there were just a lot of people that showed up. It was inexpensive and so they had a chance to socialize in their community. The impact, what I see is just in terms of people coming so the word got out somehow. (Senior)*

*[Community group # 2] people made the pancakes, set everything up. We had [our Member of the Provincial Legislative Assembly] come in, and I believe [our alderman] came too. We had a bit of entertainment and we had a pretty good turnout. So I thought here is a very highly visible thing that is connected to Elder Friendly. (Senior)*

Community development workers reported that during the initial group formation phase, it was important for them to demonstrate their availability to seniors, particularly as an information resource. This took the form of responding directly to questions and generally served to improve access to information for participants.

*I acted as a resource for them. I don't know how many questions I have taken from people from the project, from the group, [they] phone me and ask me specific questions. They needed some way of getting information about what was out there to help them live a quality life. . . (Community development worker)*

### **Multicultural Community Development**

Grass roots community development with older adults can be an effective strategy in culturally diverse settings. The community development workers engaged Chinese and Vietnamese elders, along with other residents who lived in the most culturally diverse neighbourhood. Bilingual community development workers were hired to work with these groups. Program staff found that barriers to vital involvement in civic affairs were magnified for ethnically diverse seniors. These barriers had a number of root causes, but the most significant was linguistic isolation. Although ethnic minority seniors were interested in learning about other cultures, they found that most ongoing community

activities did not provide adequate translation, and they felt left out. In order to be inclusive, the community development effort with ethnically diverse seniors required extensive use of translation services. The translators quickly became community development workers in their own right. When meetings were held in more than one language, workers structured the meetings to ensure that everyone had a chance to hear, speak and understand what was being discussed. Community development workers modeled appropriate and respectful behaviors at meetings when translation was required. This became an important part of their role.

*[It] requires translation to be involved with the other groups. For example, if a festival [is organized], there can be lots of participation, but without proper translation, then only a few would attend. (Senior)*

*The ideal CD worker would know a few languages – the more languages the better. (Senior)*

The recruitment of participants from a diverse ethnic groups required community development workers to assist participants to identify what they wanted from their group. Often the motivation for participation involved a chance to socialize. They wanted contact with others from their own age cohort. Ethnic seniors were attracted to activities that promoted health, access to information about services and benefits, learning English and learning about the mainstream culture.

*The seniors would like more: information of government programs, more exercise like Tai Chi, more outing, dance lessons, pronunciation (a senior volunteer has been helping with this), singing lessons, and Quing. (Senior)*

### **Learning about Canadian culture brings seniors in. (Senior)**

Community development workers who were involved in facilitating ethnically diverse groups reported their own need to engage in self-reflection as they learned to respectfully engage these populations.

*...for me it brings up, again, the issue of respect and how culturally subtle it is, and that we just need to keep learning and trying and paying attention to those issues so we really can work effectively cross-culturally. (Community development worker)*

*It wasn't until later that I realized he was trying to instruct me on how I was to speak to the president of the organization. I realized it not through my own insight but because a person I'd brought with me, not on my staff, who knew what was going on told me, "We gotta have lunch cause I gotta explain to you what this guy was trying to do." (Community development worker)*

Engagement of ethnically diverse seniors required an understanding of how ageing is viewed in each culture, as well as recognizing the unique challenges experienced by older adults who live in a country with dramatically different cultural norms than their country of origin. As well, community development workers learned that it was not unusual for seniors from the same country to retain strongly held pre-emigration conflicts and stereotypes. While program staff attempted to identify and build upon commonalities, they also understood that ethnic groups were not homogeneous simply because they shared an immigration experience. Understanding these subtle but powerful differences required the building of personal relationships with each participant. This led to mutual trust and respect. The process was lengthy and time consuming. Working with diverse senior groups required cultural competence that included multifaceted knowledge, of participants traditions and their sensitivities. Demonstrating respect was essential.

*Very important to be able to trust the CD worker. (Senior)*

*Very important for the CD worker to connect with each senior one-on-one. (Senior)*

*What's interesting is that respect is so different in different communities, and you just don't know what you don't know. (Community development worker)*

*I have worked with [a specific ethnic group] before, and thought I kind of had it down, but the senior population is much more conservative, more traditional. (Community development worker)*

Fostering leadership proved to be a challenge in the ethnically diverse groups, as cultures differ in how leadership is understood. Often leadership was not viewed in Western terms. A useful approach was to describe group leadership as "helping others" rather than being in control or being responsible for others. Respondents expressed discomfort with

taking the risk of being responsible for an important aspect of the program because they lacked confidence in their language skills. Culturally ascribed gender roles also had to be considered in leadership development efforts. Senior respondents stated their preference for organizing small groups of participants that kept in touch with each other. This generated personal connectedness and helped to enhance individual confidence as well as group cohesion.

*To encourage senior leadership, the seniors recommend a focus on small groups calling and caring for each member (rather than the CD worker calling each senior). (Senior)*

*[We] voted on those that would like to see more structure within the group, such as having a president and treasurer [or having] less responsibility and less structure (Senior)*

*[Some community development workers] find that seniors do not want to take up the responsibility of leadership because these seniors do not speak English well, and to provide leadership, there are requirements to liaise with the outside. (CD worker)*

The goal of multicultural community development in the program was to facilitate both bonding and bridging outcomes (Putnam & Feldstein, 2003). Bonding community development activities built on similarities among group members that bind them together. Bridging community development activities focused on developing relationships among diverse ethnic and cultural groups.

Initially, the ethnically diverse elders lacked a vehicle for bridging their differences with their English speaking peers. Consequently, two types of community meetings were organized. One involved meetings held only in the first languages of each cultural groups and the other included all participants in the neighbourhood group where all languages were spoken and translation was provided. Bridging activities required developing new group process norms including the need for patience and quiet in order to allow the members who spoke different languages to hear translators. Inclusive neighbourhood seniors' events also made extensive use of activities that did not require verbal communication such as Tai Chi, pot luck dinners, crafts fairs, magic shows and mime theatre. This facilitated interaction without the language barrier. At one point, a bonding activity, Tai Chi for Chinese participants, became a bridging event when main stream seniors asked to join the class. A

new level of cross cultural engagement was clearly evident through this process.

*The seniors like to know about other cultures. (Senior)*

*Many celebrations and events can be done together, for example, the Canada Day celebration or a big multicultural event. We can do it together and share our experiences. (Senior)*

### **Implications for Practice**

The research reported in this article suggests that community development with older adults in their neighbourhoods is a promising way to enhance elders' social participation and civic engagement. A significant challenge, however, is the presence of ageist attitudes held by some seniors and community development workers. Older respondents initially expressed a lack of confidence in their abilities and capacity to engage in neighbourhood based community development activities, exhibiting over reliance on professional development workers for leadership and direction. For their part, professional community development workers had to pay careful attention to their own preconceived notions about elders' skills and capacities. Over time, program staff embraced a fundamental understanding of community practice that values community ownership and promotes collaboration over control by professionals. These issues were of particular significance in the early stages of engaging older adults in community development. This is when carefully designed strategies and awareness of clear communication are required to recruit and retain participants

This research raises important questions about the extent to which these findings, which were produced in geographically defined neighbourhoods in a Western urban setting, can be generalized to urban locations as well as rural towns and villages in the developing world. There is little disagreement that community development has proven to be an effective method for engaging residents in both rural and urban localities in developing countries. The question is whether this approach can be effective when specifically targeted to older adults, aimed at enhancing their social participation and reducing their marginalization. Furthermore, it is critical to unequivocally stress the cultural heterogeneity that exists across countries, within regions in the same country and within local communities. This heterogeneity demands very careful

attention to how community engagement efforts are designed and implemented. Linguistic and cultural diversity around the globe requires that community development workers have high levels of cultural competence, recognizing not only the current realities in the communities in which they are involved, but also having an in depth understanding of the history of interaction among diverse cultural groups that may affect current relationships and willingness to become involved in community development efforts. Both bonding and bridging activities should be considered when working with diverse cultural groups.

Although community work has deep roots in social work practice, community capacity building with elders may not be adequately taught in social work education programs. Even in programs with a significant emphasis on community work, the relevance of the community context for the well being of older adults may not receive sufficient emphasis. It would be valuable to assess the extent to which community development with elders is addressed in educational programs globally and more specifically in North American educational programs currently offering content in gerontology and community development. When recruiting staff for the program, it was very difficult to find candidates knowledge of both community development and gerontology.

Community work has historically focused on marginalized groups. Social work educators and practitioners should ensure that older adults are included as a population that can and should be engaged in community development as a way to address the social exclusion that elders often experience. The United Nations initiatives discussed at the beginning of this article and their focus on enhancing vital involvement and participation of older adults, suggests the need to further explore grass roots community development as a strategy to promote social inclusion of older adults worldwide.

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## Discrimination against Older Workers : Current Knowledge, Future Research Directions and Implications for Social Work

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### ABSTRACT

*Work is increasingly important for older adults in many societies, yet the workplace is one of the places where discrimination frequently occurs. Workplace discrimination is not only an issue of social justice and individual rights, but it also negatively affects employment outcomes and individuals' physical health and psychological well-being. Although there has been a growing body of literature on workplace discrimination against older workers, the need to review and integrate this body of knowledge remains. This article, first, provides a review of the major themes that have emerged in the cross-national literature, including the aspects related to workplace discrimination against older workers: types and prevalence; subjective experiences; theories; covariates; effects on employment outcomes and individual health and well-being; and older workers' strategies for combating discrimination. The article points out gaps in the existing literature and suggests directions for future research in the areas of micro-aggressions; theoretical perspectives; disability and ageism; older worker employment programmes; longitudinal approach or life course perspective and cohort effects; grievance resolution mechanisms, process, and results; best practices of employment equity; and cross-national or cross-cultural comparisons. Finally, the article highlights the role of social work in countering workplace discrimination against older workers and promoting employment equity.*

**Key words :** Older workers, Workplace discrimination, Prevalence, Types, Theories, Cross-national, Social work

Work has become an increasingly important aspect in old age for people in many countries, due to financial necessities or a desire to continue active engagement, or both. In the United States, the participation of older adults (age 65+) in the labour force has been rising since the late 1990s (U.S. Bureau of Labor Statistics, 2008). Although 17 per cent of men and 9 per cent of women age 65+ were in the workforce in 1995, 22 per cent of men and 13 per cent of women were in the workforce in 2009 (Shattuck, 2010). Similar trends have also been seen in other more-developed countries, such as France, Germany, United Kingdom, Finland, New Zealand, and Canada (Sigg, 2005; National Institute on Aging [NIA], 2007). Although data on less-developed countries are inconsistent, in general, older women's workforce participation rates are also increasing (NIA, 2007). Further, in many less-developed countries, such as China, Bangladesh, Peru, and Uganda, older people who are poor must work because of the lack of—or insufficient—pension coverage (Chou, 2010; Truelove, 2009).

The workplace is one of the settings where discrimination frequently occurs (De Castro *et al.*, 2008). Workplace discrimination involves treatment based upon individual attributes such as : age, gender, race, ethnicity, religion, disabilities, sexual orientation, political affiliation, and national or social origin (Colella & Stone, 2005; McMahon & Shaw, 2005; Ragins & Wiethoff, 2005; Tomei, 2003). Workplace discrimination can be manifested in hiring, training, promotion, firing, and other institutional or interpersonal treatment. Not only an issue of individual rights and social justice (Wood *et al.*, 2008), workplace discrimination also affects employment outcomes and individual physical and psychological well-being.

Although there is a steadily growing body of literature on various dimensions of workplace discrimination against older workers, the need to review and integrate these disparate literatures remains. This article aims to (a) provide a literature review focusing on the major themes that have emerged from studies from multiple nations on workplace discrimination against older workers; (b) discuss the gaps in extant literature and recommend directions for future research; and (c) highlight implications for social work.

Before going further, it is necessary to examine how older workers are defined in the existing literature. A review of the literature on the ageing workforce and older workers (including discrimination against older workers) indicated that the term “older workers” has been conceptualized differently in different contexts. In some industries, such as information technology (IT), an “older worker” can be someone over the age of 30 (BNET, 2009). In other contexts, older workers have been defined as those age 40+ (Hansson *et al.*, 1997), age 45+ (Berger, 2009; RoperASW, 2002), age 50+ (Chou & Choi, 2010; Malul, 2009; Mor-Barak, 1995; Smyer & Pitt-Catsouphes, 2007), or age 55+ (Kaye & Alexander, 1995; Noonan, 2005; Taylor, 2007). Typically, however, older workers are individuals age 50+ (International Labour Office, 2008). The literature reviewed in this article concerns workers aged 40+, with the majority focusing on those aged 50+ or 60+.

## Major Themes in Extant Literature

### A. Discrimination against Older Workers: Types and Prevalence

Ageism refers to the “systematic stereotyping of and discrimination against older people because they are old” (Butler, 1975). Although older workers are perceived positively in terms of stability, dependability, knowledge, experience, individual initiative, and mentoring (Berger, 2009; Gibson *et al.*, 1993; Marshall, 2001), they are perceived negatively in many other ways. Research indicates that employers view older workers as less flexible or creative, less alert, more prone to accidents, in poorer health, unfamiliar with new technologies, more resistant to innovation and technical change, harder to train, lacking in physical strength, less ambitious, less productive, and less financially beneficial (Berger, 2009; Johnson, 2009; Schulz, 2000; Shore & Goldberg, 2005). Older workers may also be regarded as less dependable due to health reasons, and their knowledge can be undervalued (Wood *et al.*, 2008). Negative stereotypes about older workers persist, despite decades of evidence to the contrary (Grossman, 2008; Hedge *et al.*, 2006; ReportAge, 1999).

Age discrimination has been reported in many countries: from developed nations or societies, such as the United States, Canada, the United Kingdom, Germany, Japan, Hong Kong, and Australia (Berger, 2009; Chiu *et al.*, 2001; Naegele & Walker, 2004; RoperASW, 2002; Weller, 2007) to underdeveloped nations, such as India, China, Peru,

Bangladesh, and Uganda (Chou, 2010; Newman, 2004; Truelove, 2009). For example, in a survey conducted by the American Association of Retired Persons (AARP), two-thirds of the 1,500 U.S. workers aged 45–74 reported that they have personally experienced or witnessed age discrimination at work, whereas 9 per cent, 6 per cent and 15 per cent of those surveyed indicated that they were passed up for a promotion, laid off, or not hired because of their age, respectively (RoperASW, 2002).

Although the Age Discrimination in Employment Act (ADEA) has been in place since 1967 in the United States, there are still mounting cases of workplace discrimination. As shown in the annual statistics of the U.S. Equal Employment Opportunity Commission (EEOC), the authority enforcing federal laws against employment discrimination for individuals over the age of 40, a total of 22,778 age discrimination complaints were filed with the EEOC in 2009 (EEOC, 2010). Based on the Anti-Ageism Taskforce (2006), such incidents are likely to be wildly underreported due to the difficulties in providing evidence for discrimination in the employment process.

Discrimination experienced by older workers extends beyond age discrimination. At the interpersonal level, workplace discrimination is shown in micro-aggressions, which includes prejudice and discriminatory behaviour in daily social interactions, e.g., sexual harassment, receiving unfair work assignments, and being monitored more closely on the job (Roberts *et al.*, 2004; Swim & Stangor, 1998). There has been little research on discrimination against older workers in daily social interactions. One of the rare exceptions is Chou and Choi (2010), which examined micro-aggressive behaviours among 420 older workers age 50+ in the United States. Findings indicate that about 80 per cent of the subjects experienced at least one instance from the following categories within a year: being unfairly given undesirable tasks; being watched more closely at job than others; receiving ethnic, racial, and sexual slurs from boss or coworkers; and being ignored or not taken seriously by boss.

### B. Older Workers’ Subjective Experiences of Discrimination

Although research on employers’ attitudes toward older workers is growing, less attention has been paid to older workers’ perceptions

and interpretations of workplace discrimination. Only a few studies provide information in these directions.

RoperASW (2002) reported that among the 1,500 U.S. older workers surveyed by AARP, 60 per cent viewed age as a liability in the workplace. On average, older workers believe that workers start to encounter age discrimination around age 49—specifically, African Americans, Whites, Latino(a)s, and Asian Americans report ages of 48.2, 48.9, 49, and 50.8, respectively, for when discrimination is first experienced. Likewise, based on 78 semi-structured interviews with men and women age 45 or over in Quebec, Zimmermann *et al.* (2007) reported that although 27 per cent of the respondents regard their age as a strength for labour market retention, 36 per cent think of their age as a constraint holding back new career plans, and 37 per cent see their age as a source of multiple liabilities and discrimination at work. Moreover, Kaye and Alexander (1995) studied 164 low-income elderly part-time workers (mean age = 67.1 years) placed by four senior employment programmes in Philadelphia. Older workers expressed the view that workplace discrimination was reflected in fewer promotions, reduced pay, and inadequacies in benefits. There was also a reluctance to disclose workplace discrimination due to the fear of job loss.

Based on interviews of 45 older adults aged 55+ in the United States, Noonan (2005) shows that in the job search process interviewees often felt discriminated against on the basis of their age. They reported that they received few responses from potential employers on their job applications and found it very difficult to obtain a job. They also reported that employers prefer younger workers, although the latter may have less work experience. Some individuals mentioned that the age discrimination they encountered in the job search came as a surprise, because they have always expected to be able to work beyond age 60. One indicated that he is unwilling to retire, because he has got more energy than a 35-year-old.

Based on a symbolic interactionist framework and using grounded theory techniques, Berger (2009) interviewed 30 adults aged 45–65 in Canada in order to examine the discrimination they encountered while seeking employment. She pointed out that the lengthy periods of unemployment experienced by older workers (aged 45–65) in Canada

was partly due to age discrimination in the employment context. To highlight individuals' subjective experiences, she focused on the changes in age identity that occurred during job search, using data from (a) interviews with 30 unemployed Canadians aged 45–65 who were searching for employment and (b) participant observation in three older worker employment programmes, funded by Human Resources Development Canada. Findings show that being considered “old” based on appearance was a stigma that the participants had difficulties to surmount. There were two pathways to identity degradation: (1) perceived age discrimination encountered from potential employers; and (2) attending older workers programmes, where age as a barrier in finding employment was heavily emphasized. Interviewees pointed out that once they were told to seek out assistance from older worker programmes, the label of being “old” made them vulnerable to identity degradation. Some participants indicated that the programmes' strong emphasis on age as an employment barrier, as shown in programme lectures and videos, was infuriating and depressing. Thus, ironically, although the programmes were intended to assist individuals in job search, the unintended consequence was the identity degradation experienced by some programme participants, which in some ways was similar to experiences encountered with discriminatory employers.

### C. Theoretical Perspectives on Workplace Discrimination

Multiple theoretical perspectives have been proposed or used for examining causes of workplace discrimination. Most of the theories concern age discrimination. Neoliberal literature on the underlying causes of age discrimination involves three perspectives (Wood *et al.*, 2008). First, the “rational choice and labour costs” perspective argues that older workers' higher pay renders them less attractive to employers, particularly if younger workers are deemed equally or more productive. Consequently, older workers are more likely to become redundant and to encounter obstacles in reacquiring employment (O'Boyle, 2001; Wood *et al.*, 2008). Second, the “lifestyle choice” perspective claims that older workers' inability to find work reflects poor life-style choices. If older workers are able to upgrade their skills and effectively market their “youthful qualities” in a youth-dominated labour market, more job opportunities would be available to them (Shen & Kleiner, 2001). Finally, the “imperfect information” perspective maintains that age discrimination

originates from employers' misinformation about the abilities and skills of older workers (Glover & Branine, 1997; Wood *et al.*, 2008).

In contrast, the political economy literature examines age discrimination in the wider context of industrial change, culture, and the disadvantages of old age (e.g., poverty, ill health). First, when the long economic boom ended in the 1970s, firms were compelled to reduce costs and adapt to changes in demand and technology, which worsened the conditions and terms of employment (Kelly, 1998; Wood *et al.*, 2008). The growing need for flexibility and leaner organizations has had negative consequences for older workers. Older employees may be subject to more discrimination because they were regarded as more compliant and less resistant to pressure to retire (Taylor & Walker, 1997; Wood *et al.*, 2008). Second, the youth-oriented culture in many Western or Westernized societies is characterized by a strong emphasis on the value of beauty, youth, and innovation. Such cultural ideas, which are also found in the workplace, undervalue older employees (Glover & Branine, 1997; Wood *et al.*, 2008). Third, in many societies, older adults are often among the poorest, and poverty often worsens their employment prospects. Because of poverty, they may be more dependent on public transportation to get to work, and their employment prospects may be jeopardized if such transportation is costly or unavailable. Further, older employees in manual jobs are more likely to be less healthy and thus may be more likely to be considered redundant (Wood *et al.*, 2008).

Scholars have also used other perspectives to study age discrimination at work, such as the human capital and institutional perspectives. Somewhat echoing the lifestyle choice perspective, the human capital perspective postulates that because stocks of human capital (i.e., knowledge, skills, and experience) increase with age, older workers should be appealing to employers. However, changes in technology and work demands may also make their human capital obsolete, and result in a mismatch between older workers' skills and market demands (Organization for Economic Cooperation & Development [OECD], 1990; Weller, 2007). The institutional perspective, on the other hand, views the labour market as a social institution with values and norms influenced by mutually reinforcing institutions. According to this view, the labour market is divided into semi-independent submarkets, regulated by a unique set of rules under the

influence of multiple technological, social, and regulatory forces. Consequently, based on specific job-related intersections of knowledge, skill, physical demands, and authority, age discrimination will be more evident in some industries and occupations than others (Duncan & Loretto, 2004; Weller, 2007).

Finally, theories have been proposed for examining the relationship between perceived discrimination and minority/majority status. For example, the social barriers theory suggests that, compared with their counterparts in the majority groups, members of minority groups (e.g., racial minority) would perceive more discrimination because overall they experience more social barriers (i.e., prejudice and discriminatory behaviors) in their lives (Rodriguez, 2008). In contrast, the attributional ambiguity theory maintains that when low-status group members are uncertain about whether discrimination is the cause of negative performance feedback at work, they are less likely to attribute their failures to discrimination because they are used to negative reactions. Instead, members of higher-status groups, such as men and individuals of higher socioeconomic status, would be more inclined to attribute personal failures to external factors, including discrimination (Rodriguez, 2008; Ruggiero & Major, 1998).

#### **D. Covariates of Workplace Discrimination**

What are the institutional, occupational, and sociodemographic characteristics associated with workplace discrimination? Although research suggests that different occupations are differentially associated with workplace discrimination in the general (non-age specific) populations (DeBeaumont, 2009; Masser *et al.*, 2007), little attention has been given to older workers in this regard, except by Chou and Choi (2010). In their study, they included three occupational categories (executive, managerial, and professional; technical, clerical, service, and sales; and crafts, labour, and military) and six types of workplace discrimination (being unfairly given undesirable jobs; being subject to closer surveillance at the job than others; receiving ethnic/racial/sexual slurs from supervisors; receiving ethnic/racial/sexual slurs from coworkers; being ignored or not taken seriously by supervisor; and coworkers with less experience and fewer qualifications being promoted before the respondent). Results show that the occupational category affects the prevalence of "boss uses ethnic/racial/ sexual slurs."

Although the crafts, labour, and military category has the highest prevalence, the executive, managerial, and professional category has the lowest.

Several studies examined the institutional, job, and sociodemographic covariates of workplace discrimination. Chou and Choi (2010) discovered that prevalence of perceived workplace discrimination (as described above) varied with age, gender, education, and wage. RoperASW (2002) also reported that age, gender, and education exert the strongest impact on the treatment towards older workers at work, followed by ethnicity and race. In addition, African Americans, Latino(a)s, and blue-collar workers are more likely to feel that “age makes workers more vulnerable to job losses during an economic downturn” (RoperASW, 2002). Taylor and Walker (1998) shows that both work positions and gender affect how older workers are treated at work in the United Kingdom. Older managers are more likely to receive training than other older employees, whereas women are considered to be old at an earlier age than men. The study by Chou and Choi (2010) further shows that individuals with higher supervisor support experience less workplace micro-aggressions; coworker support made no difference.

### **E. Effects of Discrimination on Employment Outcomes and Individual Well-Being**

A review of the literature indicates that most studies on effects of workplace discrimination were non-age specific, involving younger and older workers. Moreover, the effects of discrimination have been examined mainly in two aspects only: (a) employment outcomes and (b) individual physical health and psychological well-being.

Multiple studies have examined the effects of discrimination on employment outcomes. For example, Cunningham and Sagas (2007) studied 200 head coaches of athletic teams in the National Collegiate Athletic Association (NCAA) and found that discrimination from employers negatively affected their career satisfaction and positively correlated with higher turnover intentions. The study also shows that these relationships were more pronounced in men than women. Ensher *et al.* (2001) studied 366 ethnically diverse employees working at operations level and found that discrimination from supervisors, coworkers, and the organization caused adverse effects on employees’

level of job satisfaction, organizational citizenship behaviour, and organizational commitment. Likewise, researchers have reported that workplace discrimination is associated with higher work stress (Landrine & Klonoff, 1996; Moeser, 2008) and lower job satisfaction (Landrum, 2000; Yamini-Benjamin, 2006).

The adverse effects of workplace discrimination on individual physical health and psychological well-being have been documented in the general literature (including both younger and older workers). For example, DeCastro *et al.* (2008) found that exposure to racial discrimination in the workplace was associated with health conditions among Filipino Americans. Jackson *et al.* (1995) discovered that workplace discrimination was related to anxiety and depression among African Americans. Krieger *et al.* (2005) noted that racial discrimination was associated with psychological distress and cigarette smoking among low-income workers. Likewise, based on a study of 1,977 Asian Americans, Chae *et al.* (2008) discovered that individuals experiencing higher levels of general unfair treatment or higher levels of racial or ethnic *discrimination* were more likely to smoke. Krieger *et al.* (2008) found that sexual harassment was associated with elevated systolic blood pressure among low-income working women. Based on a national sample, Rospenda *et al.* (2009) showed that discrimination and harassment in the workplace was associated with problem drinking and poor mental health.

In contrast with the above studies, which included both younger and older workers, a few studies focused solely on older workers. Drawing on data from 1966–1980 from the National Longitudinal Survey of Older Men (NLSOM), which provide 19,270 observations on 3,100 older workers, Johnson and Neumark (1997) tracked the employment behaviour following a self-report of discrimination. Results indicated that older employees who reported age discrimination from their employer tended to leave their employer and were less likely to remain employed compared with those who did not report discrimination but were otherwise similar. Based on a field study of 179 older workers, Hassell (1991) discovered that age discrimination had a negative impact on self-esteem and perceived personal control. Landrum (2000) found that older workers receive subtle messages, causing them to reevaluate their abilities to perform and learn. Moreover, the perception of being

treated differently due to age predicts lower levels of job satisfaction and higher levels of anxiety and depression. In a study of 164 low-income elderly part-time workers (mean age = 67.1 years) placed by four senior employment programmes in Philadelphia, Kaye and Alexander (1995) discovered that discrimination at work substantially reduced the quality of the work experience.

### **F. Older Workers' Strategies to Counter Discrimination in Seeking Employment**

Berger (2009) examined the strategies used by older workers to counter discrimination in seeking employment. Participants in the study reported that prospective employers applied various tactics to discriminate against them. According to the participants, potential employers scrutinized their résumés for the year they received their degree and used that information for selecting younger interviewees. Further, prospective employers not only used the job interview as a device to appraise job candidates' age, but also used ageist language during the process of hiring. These tactics reflected negative stereotypes towards older workers regarding skills, training, flexibility, adaptability, and financial costs.

Berger (2009) also reported the strategies used by the participants to manage age discrimination in the job-seeking process. First, the participants kept their skills up to date to avoid being categorized as "out of touch" by prospective employers. They signed up for training classes in universities, older worker programmes, or other venues. Some used volunteer work as a way to enhance their skills. The second strategy involves changing expectations. Most participants adjusted their employment expectations regarding (a) employment goals (e.g., some participants listed job satisfaction as more important than monetary compensation), (b) type of employment, in terms of employment status (e.g., full-time, part-time, or work on a contract), monetary remuneration, and career change, or (c) the geographical location of employment. Finally, the third strategy involved concealing one's actual age by (a) modifying one's resume (e.g., eliminating some of their work experience and the year a degree was conferred), (b) changing into a youthful

appearance, and (c) adopting youth-oriented talk or language in the interview (e.g., mentioning currently popular sports or social groups and using current lingo).

### **Gaps in the Extant Literature and Recommendations for Future Research**

Given the above-mentioned themes in literature, several gaps exist in current knowledge. To advance this field, the following presents recommendations for future research.

#### **A. Micro-aggressions**

Most studies on discrimination against older workers address discrimination at the institutional level, i.e., hiring, training, and retention. Relatively little research has examined micro-aggressions at the interpersonal level, such as subtle derogatory comments (e.g., negative and unfair comments on one's performance or ability) or condescending treatments (e.g., being watched more closely on the job than others or being assigned tasks that no one else wants). To obtain a comprehensive understanding of workplace discrimination against older workers, it is also imperative to look into the prevalence and patterns of micro-aggressions inflicted on older workers.

#### **B. Theoretical Perspectives**

Although research on workplace discrimination against older workers has included multiple theories (see above), future studies would benefit from other theoretical paradigms from the general (i.e., non-age specific) literature on workplace discrimination. For example, the "global competition" thesis of work discrimination maintains that the rise of global competition brings substantial concerns about cost reduction among employers and causes them to shift away from the postwar social contract of lifetime employment (Stone, 2007) to conditional, temporary, or part-time work arrangements (Kalleberg, 2009; Scott, 2004). Consequently, global competition provides a rationale for replacing more costly workers, who tend to be older. To what extent does global competition affect the employment and reemployment of older workers and their experience of workplace discrimination? Do occupational and industrial categories matter in this regard? What can be done to lessen

the impact of the global competition on discrimination against older workers? These may be fruitful avenues for future research. Other theories, such as social closure theory (Tomaskovic-Devey *et al.*, 1993) and exchange theory (Robbins *et al.*, 1998; Dowd, 1975) may also provide important insights into workplace discrimination against older workers.

### **C. Socio-demographics and Positions at Work**

Previous research (e.g., Taylor & Walker, 1998) shows the importance of avoiding treating older adults as a homogeneous group, because, in addition to age, individual socio-demographics as well as positions at work play a role in workplace discrimination. There is a need for a more systematic examination of workplace discrimination that focuses on the intersections of multiple characteristics, e.g., gender, race, ethnicity, education, immigration status, and occupational position. One interesting endeavor would be to apply the theses of “multiple jeopardy” or “age as a leveler” (Chou, 1992; Ferraro & Farmer, 1996) to workplace discrimination against older adults to see whether old age becomes an obstacle for older minority workers in addition to other barriers (e.g., racism), or if old age equalizes the extent of workplace discrimination encountered by majority and minority older workers.

### **D. Disability**

Disability may be perceived in various ways, depending on the position of the individual with the disability in the social structure. Ageism not only may place older workers at a disadvantage, it may compound negative attitudes toward disability and situate these workers at even worse positions (McMullin & Shuey, 2006). The work experience of older adults with disabilities and how current laws protect (or fail to protect) the employment rights of older adults with disabilities merit further investigation.

### **E. Older Worker Employment Programmes**

Previous research shows that although older worker employment programmes in Canada attempted to assist individuals with job searches and training, they led to the unintended consequence of identity

degradation amongst their participants (Berger, 2006). Are similar consequences experienced by participants of older worker programmes in other countries (e.g., the Senior Community Service Employment Programme in the United States or the Silver Human Resource Center in Japan)? What can be done (or has been done) to address such issues? Future research should look into these questions.

### **F. Longitudinal Design or Life Course Perspective and Cohort Effects**

Much of the research on the effects of workplace discrimination (e.g., job satisfaction, individual health and well-being, and work-family conflict) is cross-sectional in design. To acquire a better understanding of causal relationships, studies using longitudinal research design or a life-course perspective are essential. Moreover, the different expectations and life experiences of different cohorts may also play a role in mediating or moderating the effects of workplace discrimination on older workers. Such potential cohort influences should be taken into consideration in future research.

### **G. Grievance Resolution Mechanisms, Processes, and Results**

As a means for governmental intervention on age discrimination at work, in the United States the ADEA has helped enhance employment of older workers. However, the lack of effective processing and enforcement remains. For instance, out of 19,921 age discrimination charges brought in 2002, only 29 lawsuits were filed by the EEOC (Dennis & Thomas, 2007). An examination of the annual statistics of EEOC further shows that 52% to 63% of the complaints of age discrimination filed each year with EEOC between 1997 and 2009 were dismissed due to “no reasonable cause” (EEOC, 2010). Although the high dismissal rates could be a sign that complaints are hard to justify, they may also reflect the discrepancies in the resolution mechanisms and process. As noted by Stalcup (2009), long-standing concerns with the EEOC complaint process include delays in processing complaints, lack of fairness in complaint processing, and fear of retribution at work. Studies are needed to address these concerns.



## H. Best Practices

Although discrimination against older workers seems to be rampant across industries and countries, there are also exemplary practices. The AARP's annual selection of "Best Employers for Workers over 50 in the U.S." provides a window to some of the best practices that benefit older workers. The criteria of the selection includes recruiting practices, training and development, health benefits, pension plans, and alternative work arrangements (AARP, 2007). To achieve a better understanding of the factors contributing to the success of the awardees, it is imperative to conduct in-depth investigations on their operational, monitoring, and control mechanisms in financial resource allocation and human resource management. The framework proposed for identifying best practices and measuring employment equity provided by Jain *et al.* (2003) may serve as a starting point.

## I. Cross-National or Cross-Cultural Comparisons

Although workplace discrimination against older workers is a global issue, there has been a lack of systematic cross-national or cross-cultural comparisons. Much of the aforementioned research will benefit from comparing and contrasting targeted issues in different societies and cultures. Cross-national or cross-cultural comparisons will also enhance the possibility of mutual learning and cooperation in the international community in countering workplace discrimination against older workers.

## Conclusion and Implications for Social Work

Although older adults expect to have prolonged work lives in many societies, the workplace is one of the places where discrimination frequently occurs. Workplace discrimination not only concerns individual rights and social justice, but also negatively affects employment outcomes and individuals' physical and psychological well-being. This article focused on major themes in the literature on discrimination against older workers in various societies and pointed out directions for future research.

With the ageing of the workforce occurring across Europe, Asia, North America, and Oceania (notably, Australia and New Zealand)

(Barnett *et al.*, 2008; IBM Business Consulting Services, 2004; Taylor, 2007), how to accommodate older workers is a challenge for the 21<sup>st</sup> century. Social workers with training in both gerontology and occupational social work are especially well equipped to respond to workplace discrimination encountered by older adults (Mor-Barak & Tynan, 1993). At the micro and macro levels, they play important roles not only in linking older job seekers with potential employers and counselling older workers and their families, but also in combating age-related stereotypes within organizations (Hedge, 2008). Solutions for the latter include developing and conducting training to counter ageism among employers and employees; encouraging the use of age as an additional component in diversity training; advising companies on work arrangements for older workers; and engaging in team-building and enhancing organizational climate in employment equity (Kurzman, 2008; Mor-Barak & Tynan, 1993). In such endeavors, the plight of minority older workers who are likely to face multiple types of workplace discrimination deserves special attention.

Although traditional social work approaches in the area of ageing have primarily focused on interventions addressing individual difficulties and needs, social workers serving older workers also need to intervene at the macro level. They should examine the larger social, economic, cultural, and legal contexts of the ageing society that influence ideas about old age and older workers and shape social policies affecting older adults' workforce participation. They need to engage in policy advocacy for funds, programmes, and beneficial legislation for older workers and older adults seeking employment. In short, they need to be "agents of change" to ensure social justice for older workers.

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## Putting Age in Context: Relational Age and Inclusion at the Workplace

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### ABSTRACT

*To date, there have been few empirical tests of the effects of relational age on work team members' assessments of their inclusion in team decision-making and information sharing. Relational age is the employee's perception of personal age relative to the age distribution of their work team. This study used a multi-worksite sample of 1,778 employees (aged 17 to 77 years) to examine the impact of relational age on perceived inclusion in decision-making and information sharing. Our results indicate that employees who felt they were age dissimilar from their work teams—where the majority of their team members are in a different age cohort—reported being less included in both decision-making and information sharing than those on age diverse work teams—where the work team is heterogeneous in terms of age without a clear age majority. We found variation across age groups; older workers perceived the highest levels of inclusion when they were in age diverse teams, whereas younger workers perceived the highest levels of inclusion when they were on age similar teams. Implications for social work are discussed.*

**Key words:** Aging of the workforce, Age diversity, Inclusion, Relational demography

It is widely recognized that the global workforce is ageing (e.g., Bloom *et al.*, 2009; Ilmarinen, 2009; Maestas & Zissimopoulos, 2009). The increased presence of older adults in the workplace has fostered

interest in the effects of work team age diversity on workplace outcomes (Riach, 2009; Wegge *et al.*, 2008). Research on diversity in the workforce shows that problems arising from diversity are caused not only by the changing composition of the workforce itself, but also by the inability of employers to truly integrate and utilize a heterogeneous workforce at all levels of the organization (Mor Barak, 1999). In fact, Mor Barak (1999) suggests that “exclusion from organizational information networks and from important decision-making processes is one of the most significant problems facing today’s diverse workforce”.

The ageing of the workforce not only results in increased numbers of older workers but also increases the diversity of work teams’ age composition. The interests of both employers and employees are served when all employees are included in circles of influence and information sharing that enable them to fully contribute and benefit from work experiences. Age dissimilar employees—or employees working in teams where the majority of their team members are, or seem to be, in a different age cohort—may be at particular risk for feeling excluded. These issues are especially relevant to social work practitioners and researchers since understanding and addressing factors that lead to social exclusion have long been central to the profession’s mission.

To date, there have been few empirical tests of the effects of such dissimilarity on work team members’ assessments of their inclusion in team decision making and information sharing. Insights from relational demography suggest that individuals may feel themselves either ‘in the majority,’ (age similar compared to most of the others in the group) or ‘in the minority,’ (age dissimilar compared to most of the others in the group). Those who consider themselves in the minority will be less likely to feel that they are integrated group members (Riordan, 2000). The current study examined the impact of relational age on perceived inclusion in decision-making and information sharing. Relational age is conceptualized in this study as a team member’s perception of personal age relative to the age distribution of their work team. Employees could describe themselves as: 1) age similar to the majority of their team, 2) age dissimilar from the majority of their team, or 3) neither age similar nor dissimilar because of the age diversity in their work team. We also

explored whether this relationship varied for employees of different ages.

## **Theoretical Framework and Literature**

### **Perception of Work Team Inclusion**

The continuum of inclusion–exclusion refers to “the degree to which individuals feel a part of critical organizational processes such as access to information...and ... [the] ability to influence the decision making process” (Mor Barak & Cherin, 1998). In contrast to ‘diversity,’ which refers to characteristics that depict the homogeneity and heterogeneity of work groups, inclusion focuses on the extent to which individuals feel that they are treated like full members of a group with regard to opportunities for participation in formal and informal processes, as well as having access to job-related resources, such as information (Mor Barak, 1999).

Despite its currency in the diversity literature, the conceptualization of inclusion varies and there is little consensus about its theoretical underpinnings (Roberson, 2006; Shore *et al.*, 2010). In broad terms, however, it is possible to identify three core themes related to perceptions of inclusion: 1) feeling a sense of belonging or being part of a group, 2) feeling one’s uniqueness is respected, and 3) having unobstructed opportunities to participate and contribute to achieving communal goals.

Shore *et al.* (2010) emphasize that recognition of uniqueness is an important aspect of inclusion in addition to the feeling of belonging to a group. They define inclusion as “the degree to which an employee perceives that he or she is an esteemed member of the work group through experiencing treatment that satisfies his or her needs for belongingness and uniqueness”. An individual who perceives inclusion would therefore be treated and accepted as “an insider,” (Pelled, Eisenhardt *et al.*, 1999) and be allowed or encouraged to retain his or her uniqueness within the work group (Shore *et al.*, 2010). Perceived inclusion also refers to a sense of unobstructed opportunity to fully participate in and contribute to the organization (Roberson, 2006; Miller, 1998). Inclusion entails eliciting and valuing the contributions of all employees regardless of their socio-demographic characteristics or work status (Lirio *et al.*, 2008).

Research conducted over the past few decades indicate that greater perceived inclusion can be associated with various positive personal outcomes, including greater psychological well-being, social support, job opportunities and career advancement, as well as lower work related stress (Findler *et al.*, Wind & Mor Barak, 2007; Mor Barak & Cherin, 1998). Previous studies have also found that inclusion is positively associated with a variety of outcomes of interest to employers, such as organizational commitment, job performance, job satisfaction, and work engagement (Avery *et al.*, 2007; Cho & Mor Barak, 2008; Findler *et al.*, 2007). Inclusion is believed to provide a “bridge between interpersonal differences and a person’s ability to contribute effectively to the organization” (Mor Barak & Cherin, 1998). For this reason, practitioners often view policies and practices that promote inclusion as having the potential to integrate diverse people into work teams and organizations, thereby helping teams to work more effectively and, promoting positive individual and organizational outcomes (Roberson, 2006; Thomas & Ely, 1996; Wentling & Palma-Rivas, 2000).

### Theory of Relational Demography

Riordan and Wayne (2008) propose that “it is the degree of relative demographic similarity” between the individual and the referent group “that influences work-related attitudes and behavior”. Relational demography focuses on differences between the individual and the overall composition of the group to determine dissimilarity (Riordan, 2000; Tsui & O’Reilly, 1989) and builds on social psychological theories, such as the similarity-attraction paradigm, social categorization theory, and social identity theory (Riordan, 2000; Riordan & Wayne, 2008; Shore *et al.*, 2010). The similarity-attraction paradigm (Byrne, 1971; Newcomb, 1956) is based on the assumption that individuals who have similar attitudes or personal characteristics will be attracted to each other (Riordan, 2000), leading to increased social interaction and behavioral integration. However, this can have deleterious consequences for those in the minority and “can lead to exclusion from social networks and feelings of isolation or alienation” (Avery *et al.*, 2008).

Taken together, self-categorization theory (Turner, 1987) and social identity theory of intergroup behavior (Tajfel & Turner, 1979, 1985) explain the construction and meaning of an individual’s total identity

(personal and social identities combined) (Riordan, 2000). These theories propose that individuals classify themselves and others into social categories based on their personal identity (derived from observable characteristics such as age, race and sex, among other factors), and their social identity (derived from salient information about the groups to which they belong) (Schneider *et al.*, 1971; Adler & Adler, 1987; Ashforth & Mael, 1989). Membership in social categories forms the basis for distinctions that people make between similar and dissimilar others (Riordan, 2000; Mor Barak & Levin, 2002). Membership provides meaning, enhances the self-esteem and determines interaction with others from similar or different identity groups (Tajfel, 1982; Tajfel & Turner, 1986; Turner, 1987).

### Relational Age

Demographic dissimilarity can be measured objectively and subjectively (Riordan, 2000; Riordan & Wayne, 2008). Objective measures capture *actual* dissimilarity by estimating the degree to which a person differs from a larger group with respect to demographic variables (e.g., gender, age). The most common measure of actual demographic dissimilarity is Euclidean distance measure (Wagner *et al.* (1984). Research using actual measures of dissimilarity assumes that differences are recognizable by team members (Riordan, 2000; Riordan & Wayne, 2008). In contrast, the subjective measure of dissimilarity focuses on perceived similarities and differences, thereby capturing individuals’ perceptions of how different they perceive themselves to be from other team members (Riordan & Wayne, 2008). Given our theoretical focus on understanding perceptions of inclusion-exclusion, we rely on a subjective measure of dissimilarity.

Studies exploring perceived age dissimilarity have typically used questions similar to the following: “Think of those on your work team. How similar are you to them in terms of age?,” with a response scale of: (0) “very similar” to (4) “very dissimilar” (Kirchmeyer, 1995; Riordan & Weatherly 1999; Williams *et al.*, 2007). The problem with such a measure is that it is unclear how individuals in teams without a discernable age majority would respond. Would a member of such a team perceive themselves as age similar or dissimilar; and, similar/dissimilar to whom?



The measure used by Avery *et al.* (2007) allows for three types of referent group situations: perceptions of being in the age minority (respondent dissimilar compared to the majority); perceptions of being in the age majority (respondent similar to the majority); and perceptions of belonging to a group which is balanced with regard to age (making the respondent neither similar nor dissimilar to the majority). We examine the outcomes associated with membership in these three different types of groups.

### Hypotheses

This study explored the effects of relational age on perceptions of work team inclusion in decision-making and information sharing. Since dissimilar individuals will feel less integrated or feel excluded due to the effects of similarity-attraction, social categorization, and social identity formation, it is hypothesized that:

*Hypothesis 1.* Employees who perceive that they are age dissimilar to the majority of those in their work team will perceive less inclusion in team decision-making and information sharing compared to employees who perceive themselves as age similar to the majority in their teams.

Relational demography theories do not provide guidance about perceptions of inclusion in heterogeneous groups in which there is no perceptible 'in-group' or 'out-group.' However, studies that focus on strategies to reduce in-group/out-group boundaries provide insight into the intergroup consequences of "de-categorization," or separate individuals who are not members of any particular social category (Gaertner *et al.*, 1989). From these studies we learn that de-categorization diminishes perceived boundaries and intergroup bias (Ibid.). We could argue then that the lack of discernable social categories associated with team heterogeneity might create conditions whereby those demographic attributes which create diversity within the team (i.e., age) become less salient. It is therefore possible that in diverse teams, the effects of perceived dissimilarity on inclusion are minimized.

Accordingly, it is hypothesized that:

*Hypothesis 2.* Employees who perceive that they are age dissimilar to the majority of those in their work team will perceive less inclusion

in team decision-making and information sharing compared to employees who are in age diverse teams.

Extending this reasoning, differences may become so de-emphasized in diverse teams that individuals on such teams may feel just as included in decision-making and information sharing as individuals who are similar to the majority of their team members. Therefore, it is hypothesized that:

*Hypothesis 3.* Employees who perceive that they are age similar to the majority of those in their work team will perceive similar levels of inclusion in team decision-making and information sharing compared to employees who are in age diverse teams.

Several studies on relational demography have focused on potential moderators (e.g. gender, age, race) of the relationship between demographic dissimilarity and outcomes of interest, or "asymmetrical effects" (Tsui *et al.*, 1992; Chattopadhyay, 1999; Pelled, *et al.*, 1999; Lichtenstein & Alexander, 2000; Bacharach & Bamberger, 2004; Williams *et al.*, 2007). Tsui *et al.*, (1992) found, for example, that racial dissimilarity was negatively associated with psychological commitment, attendance, and intentions to stay with the employer, but that these effects were stronger for whites, as opposed to minorities, concluding that minorities could be desensitized to dissimilarity (relative to non-minorities) because they are accustomed to being underrepresented in most settings. With age, there is no clear underrepresented or minority group, however. Further, the literature is inconclusive with regard to whether the age dissimilarity-outcome relationship differs with age (i.e., an age-asymmetrical effect). For example, Chattopadhyay (1999) found that age dissimilarity had a negative effect on citizenship behavior among older workers, but a positive effect on citizenship behavior among younger workers. Williams *et al.* (2007), however, found no age differences in the relationship between age dissimilarity and within-team perspective taking (i.e., lower positive attributions and empathy). It is unclear whether relational age has a differential impact on perceptions of inclusion depending on an employee's age. In the absence of consistent findings to guide hypotheses in this area, the following research question is proposed:

*Research question 1.* Does chronological age moderate the relationship between relational age and perceptions of inclusion in decision-making and information sharing?

## Methods

### Data and Sample:

We used data from the Age & Generations Study, a study conducted by the Sloan Center on Aging & Work at Boston College in 2007-2008, to test our hypotheses. The nine organizations participating in the study were affiliated with a range of industry sectors: education (2 organizations); health care (2); retail (1); finance and insurance (2); professional, scientific and technical services (1); and pharmaceuticals (1). All of the respondents worked in U.S. locations; all organizations had over 1,000 employees. Participating organizations selected one or two of its departments to take part in the study; employees were then invited to complete a survey during company time. In total, we collected responses from 2,210 employees from 13 departments within the nine organizations. Within-department response rates ranged from a low of 28.5 per cent to a high of 88.8 per cent, with an average response rate of 55.3 per cent. The analysis reported in this paper, however, was restricted to employees who had tenure at the organization of at least two months ( $N=2,102$ ), to avoid low inclusion scores attributable to being 'very new' to the organization.

Employees in the sample were 60 per cent female, 40 per cent male, and 41 years old on average. Seventy-three percent were married or cohabiting; 43 per cent had children under age 19. Eighty-six percent worked full time and 14 per cent worked part time. The average organizational tenure was 8.5 years. Fifty-one percent of the employees were hourly; these workers earned \$22 per hour on average. Forty-nine percent were salaried employees earning an average of \$80,000 per year.

## Measures

### Perceived inclusion

The survey included seven items that were adapted from Mor Barak's (2005) Perception of Inclusion-Exclusion Scale. This scale

was reduced from its original length to take into account the limited time and resources that organizations could devote to the data collection effort. Respondents were asked to indicate the extent to which they agreed with each statement on a scale of (1) "strongly disagree" to (6) "strongly agree." These items were subjected to an exploratory factor analysis using principal factors extraction and varimax rotation to assess their factorial structure in this sample. Results revealed two factors: three items related to inclusion in the decision-making process loaded together, (e.g., "I am able to influence decisions that affect my work group."), as did two items related to inclusion in information sharing (e.g., "My coworkers openly share work-related information with me."). All factor loadings of the items to their respective factors were greater than .52, and taken together the factors explained 72.8 per cent of the variance. The remaining two items did not load well onto any factor and were discarded from the measure. The items were averaged, and then squared to reduce skew. The alpha reliability coefficient for the inclusion in decision-making and inclusion in information sharing scales were .81 and .84, respectively.

### Relational age

Employees were asked which of the following statements best describes the composition of their work team with respect to the similarities/differences in employees' ages: 1) "The members of my work team are all about the same age as I am"; 2) "The members of my work team are different ages; however, most of them are young adults"; 3) "The members of my work team are different ages; however, most of them are midlife adults"; 4) "The members of my work team are different ages; however, most of them are older adults"; and 5) "The members of my work team are different ages, with a fairly balanced mix of employees of different ages." Avery *et al.* (2007) found evidence to suggest that respondents did indeed interpret the word "mostly" to mean the majority, or roughly 65 per cent or more of the team. Using employees' responses about the age composition of their work group in conjunction with a question that asked respondents whether they consider themselves a young adult, adult at midlife, or an older adult, we created a series of dummy variables representing the following three groups: team is age similar to self, team is age dissimilar to self, and team is age diverse (reference group).

**Control variables**

A range of personal and job-related characteristics that could potentially affect individuals' perceptions of inclusion were included in analyses as control variables. Personal characteristics included whether the worker was female; white; married or cohabitating; had a high school degree or less, a bachelor's or 2-year degree, or graduate degree (reference group); their chronological age at the time of survey; whether the worker had children age 18 or under; and whether the worker provided support to an elderly family member on a weekly basis. Job characteristics included whether the worker had supervisory responsibilities; was paid on a salary (as opposed to on an hourly basis); was full-time; and the logarithm of tenure, used to reduce skew.

Work team size was also included as a job characteristic, as previous studies have found that size affects the extent to which members communicate with one another (Zenger & Lawrence, 1989) and thus influences inclusion in information sharing and decision-making (Chattopadhyay, 1999; Pelled *et al.*, 1999). Workers were asked how many people were on their work team. The distribution of responses was heavily positively skewed (80.9% of workers reported team sizes of 20 or less). To remedy this, responses were collapsed into five categories using cut-off points consistent with findings from the span of control literature (Cathcart *et al.*, 2004): 1 to 3 team members, 4 to 7, 8 to 15, 16 to 40, and 40 or more. This new variable was then squared to correct for skew. Means, standard deviations, and ranges for all variables included in analyses are presented in Table 1.

Table 1. Means, Standard Deviations, and Ranges for Study Variables (N=1,778)

	Mean	SD	Range
Inclusion in decision-making	4.15	1.12	1-6
Inclusion in information sharing	4.86	0.92	1-6
Female <sup>a</sup>	0.59	0.49	0-1
White <sup>b</sup>	0.84	0.36	0-1
Married/cohabitating <sup>c</sup>	0.72	0.45	0-1
High school degree or less	0.18	0.38	0-1
Bachelor's or 2 year degree	0.5	0.5	0-1
Graduate degree	0.32	0.47	0-1

Age	40.88	11.99	17-77
Has no children d" age 18 <sup>d</sup>	0.57	0.50	0-1
Provides elder care <sup>e</sup>	0.16	0.37	0-1
Supervisory responsibilities <sup>f</sup>	0.36	0.48	0-1
Salaried <sup>g</sup>	0.48	0.5	0-1
Full-time <sup>h</sup>	0.87	0.33	0-1
Tenure	8.59	8.4	0.22-45
Work team size	2.94	1.09	1-5
Team is age similar to self	0.34	0.48	0-1
Team is age dissimilar to self	0.27	0.45	0-1
Team is age diverse	0.38	0.49	0-1

<sup>a</sup>Reference = male; <sup>b</sup> Reference= non-white; <sup>c</sup> Reference = not married or cohabitating; <sup>d</sup> Reference = does not have children d" age 18; <sup>e</sup> Reference = does not provide elder care; <sup>f</sup> Reference = does not have supervisory responsibilities; <sup>g</sup> Reference = non-salaried; <sup>h</sup> Reference = part-time.

**Analyses**

**Accommodating the nested data structure**

A key assumption underlying standard regression techniques, such as OLS regression and path analysis, is that observations are independent. If non-independence of observations is present due to groups, such as departments or organizations, but not controlled for in appropriate statistical models, it can lead to biased results (Hox, 2002; Kreft & de Leeuw, 1998; Raudenbush & Bryk, 2002). Random effects models are the preferred method for dealing with nested data structures, as they take into account unit-specific effects in the estimation of coefficients and standard errors (de Leeuw & Kreft, 1995). Thus, similar to Civian *et al.*(2008), we used the software, Hierarchical Linear Modeling (HLM) Version 6, (Raudenbush *et al.*, 2004) to control for clustering, using a 2-level random effects model in which the employee-level intercept is allowed to vary freely across higher level units. All multivariate analyses were conducted using organization as the higher level unit and then replicated using department as the higher level unit<sup>1</sup>. There were no substantive differences between the results of these models, so estimates presented here are those that control for organization level effects.

### Missing data

In several instances the number of responses to a given item decreased because of the participants' failure to respond to all items in the survey. Using listwise deletion for the analyses in this paper would have resulted in a loss of 657 cases or 31.2 per cent of the sample. To address concerns about missing values, we used Stata IC, 10.1 (the ICE package, Royston, 2005) to implement the multivariate imputation by chained equations (MICE) method (van Buuren *et al.*, 1999) of multiple multivariate data imputation. In this approach, a series of conditional distributions are generated using models appropriate to the distributional assumptions of each variable being imputed (e.g., linear, Poisson, logistic, etc.). von Hippel (2007) advises that values imputed for the dependent variable during the process of multiple imputation be restored back to missing before proceeding with analyses. Therefore, those respondents who did not have complete data on the dependent variables were omitted from this analysis, resulting in a final N of 1,778 (84.6% of the original sample). The estimates presented for multivariate analyses have been averaged across the ten complete datasets using HLM's multiple imputation feature (see Raudenbush *et al.*, 2004, p. 180-182, for specific calculations).

### Model-building strategy

Our models for inclusion in decision-making and information sharing were built in a series of steps, beginning with a null or empty model (unreported), followed by the addition of personal and job characteristics (Model 1), relational age (Model 2), and finally, interactions between age and relational age to assess age-asymmetrical effects (Model 3). All models were estimated using full maximum likelihood methods. Independent variables, with the exception of 0/1-coded dummy variables, were grand mean centered for analysis, a practice that produces more stable estimates, helps to reduce multicollinearity, and provides consistency across models (Field, 2009).

### Results

The results of hierarchical linear models appear in Table 2. Models 1a and 1b indicate that while none of the personal characteristics were significantly related to inclusion in decision-making or information sharing, several of the job characteristics were<sup>2</sup>. Being a supervisor, salary-paid, full-time, having a longer tenure, and having a smaller work team

was found to be associated with greater perceptions of inclusion in decision-making, while only being a supervisor and having a smaller work team was found to be associated with greater perceptions of inclusion in information sharing. In Models 2a and 2b, relational age is introduced.

Hypothesis 1—that employees who perceive that they are age dissimilar to the majority of those in their work team will perceive less inclusion in team decision-making and information sharing compared to employees who are age similar to their teams—was not supported. However, hypotheses 2—that employees who perceive that they are age dissimilar to the majority of those in their work team will perceive less inclusion in team decision-making and information sharing compared to employees who are on age diverse teams—was, in fact, supported. Hypothesis 3 was supported as well. Employees who perceived that they are age similar to the majority of those in their work team reported similar levels of inclusion in team decision-making and information sharing compared to employees on age diverse teams. A likelihood ratio test based on the deviance values of Model 1a/1b compared to Model 2a/2b suggested that there was a significant improvement in model fit that can be attributed to the addition of relational age to the model for inclusion in decision-making ( $\Delta^2 = 6.19$ ,  $df = 2$ ,  $p < .05$ ), however, there was no such improvement in model fit for information sharing ( $\Delta^2 = 3.67$ ,  $df = 2$ ,  $p > .05$ ) (Table 2).

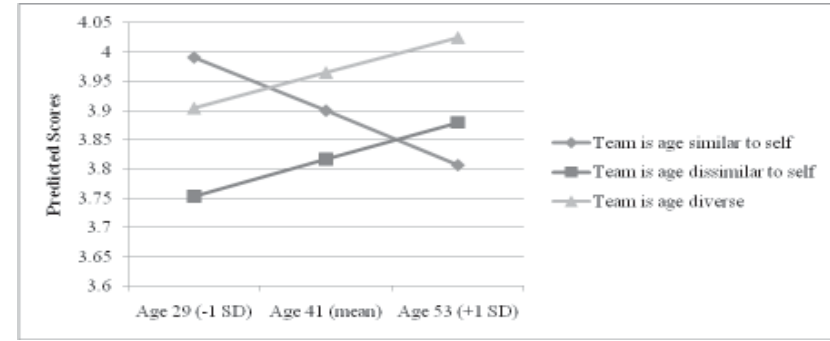
Finally, in Models 3a/3b interactions between relational age and chronological age were added. In response to research question 1, we did indeed find that chronological age moderated the relationship between relational age and inclusion in decision-making (see Figure 1). Specifically, among those who perceived that they were similar in age to the majority of their work team, there was a negative effect of age on inclusion in decision-making. In other words, young adults on a work team of mostly other young adults, felt more included in decision-making than older adults on a work team of mostly other older adults. An effect of age was not found within the age dissimilar or age diverse groups, however. The addition of these interaction terms represented a significant improvement in model fit over Model 2a ( $\Delta^2 = 10.84$ ,  $df = 2$ ,  $p < .01$ ). Overall, Model 3a explained 10.2% of the employee level variance and 74.8 per cent of the organization level variance in inclusion in decision-making, for a total of 31.1 per cent.

**Table 2.** Hierarchical Linear Model Results for Effects of Perceived Age Dissimilarity on Work Team Inclusion in Decision-Making and Information Sharing (Level-1 N = 1,778; Level-2 N = 9)

	Inclusion in Decision-Making			Inclusion in Information Sharing		
	Model 1a Coef.(SE)	Model 2a Coef.(SE)	Model 3a Coef.(SE)	Model 1b Coef.(SE)	Model 2b Coef.(SE)	Model 3b Coef.(SE)
Fixed Effects						
Intercept	15.20(1.28)**	15.67(1.32)**	15.72(1.31)**	23.84(1.42)**	24.25(1.44)**	24.27(1.43)**
Female <sup>a</sup>	-0.44(0.48)	-0.51(0.48)	-0.44(0.48)	-0.82(0.47)±	-0.87(0.47)±	-0.80(0.47)±
White <sup>b</sup>	-0.32(0.57)	-0.27(0.57)	-0.31(0.57)	0.37(0.54)	0.41(0.54)	0.38(0.54)
Married/cohabitating <sup>c</sup>	0.47(0.43)	0.44(0.43)	0.48(0.44)	0.44(0.45)	0.41(0.45)	0.45(0.44)
High school degree or less <sup>d</sup>	-0.93(0.78)	-0.99(0.78)	-1.04(0.78)	-0.97(0.78)	-1.03(0.77)	-1.09(0.77)
Bachelor's or 2 year degree <sup>d</sup>	-0.36(0.54)	-0.38(0.54)	-0.40(0.54)	-0.43(0.52)	-0.45(0.52)	-0.46(0.52)
Age	0.01(0.02)	0.01(0.02)	0.04(0.03)	0.03(0.02)	0.03(0.02)	0.03(0.02)
Has no children ? age 18 <sup>e</sup>	-0.16(0.41)	-0.10(0.42)	-0.17(0.41)	0.61(0.44)	0.65(0.44)	0.59(0.44)
Provides elder care <sup>f</sup>	-0.69(0.51)	-0.67(0.51)	-0.69(0.51)	-0.78(0.54)	-0.77(0.53)	-0.78(0.53)±
Supervisory responsibilities <sup>g</sup>	3.82(0.43)**	3.83(0.43)**	3.81(0.43)**	1.09(0.43)*	1.09(0.43)*	1.08(0.43)*
Salaried <sup>h</sup>	2.99(0.68)**	2.97(0.68)**	2.90(0.68)**	0.02(0.68)	0.01(0.68)	-0.06(0.68)
Full-time <sup>i</sup>	1.19(0.60)*	1.19(0.60)*	1.21(0.60)*	0.40(0.60)	0.39(0.60)	0.43(0.60)
Tenure	0.70(0.21)**	0.68(0.21)**	0.69(0.21)**	-0.10(0.20)	-0.12(0.20)	-0.11(0.20)
Work team size	-0.91(0.17)**	-0.93(0.17)**	-0.97(0.17)**	-0.41(0.17)*	-0.43(0.17)*	-0.46(0.17)**
Team is age dissimilar to self <sup>j</sup>						
Age similar X age						
Age dissimilar X age						
Random Effects	Var. Comp. (SD)	Var. Comp. (SD)	Var. Comp. (SD)	Var. Comp. (SD)	Var. Comp. (SD)	Var. Comp. (SD)
Employee-level variance ( $\sigma^2$ )	56.32(7.50)	56.12(7.49)	55.84(7.47)	55.27(7.43)	55.15(7.42)	54.93(7.41)
Organization-level variance ( $\epsilon_{00}$ )	3.55(1.88)**	3.56(1.89)**	3.48(1.87)**	7.19(2.68)**	7.43(2.68)**	6.96(2.64)**
Employee-level Pseudo-R <sup>2k</sup>	0.094	0.097	0.102	0.017	0.019	0.023
Organization-level Pseudo-R <sup>2k</sup>	0.245	0.243	0.248	0.161	0.163	0.188
Total Pseudo-R <sup>2k</sup>	0.306	0.308	0.311	0.258	0.259	0.259

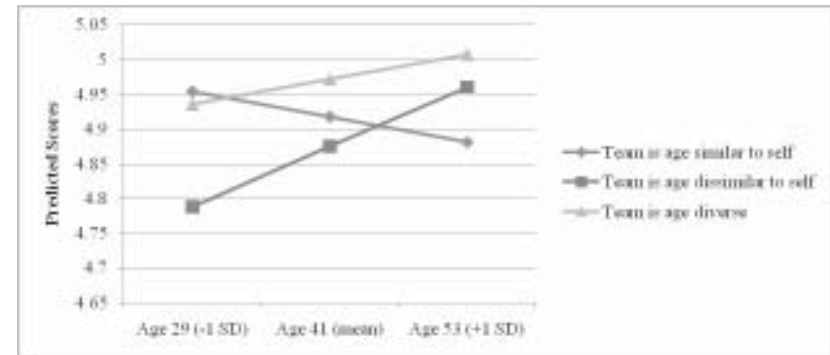
Note. All continuous variables in the model are centered on their grand means. <sup>a</sup> Reference = male; <sup>b</sup> Reference = non-white; <sup>c</sup> Reference = not married or cohabitating; <sup>d</sup> Reference = graduate degree; <sup>e</sup> Reference = does not have children  $d^{18}$  age 18; <sup>f</sup> Reference = does not provide elder care; <sup>g</sup> Reference = does not have supervisory responsibilities; <sup>h</sup> Reference = non-salaried; <sup>i</sup> Reference = part-time; <sup>j</sup> Reference = Team age diverse; <sup>k</sup> Compared to null model.

**Figure 1.** Interaction between Age and Relational Age Predicting Inclusion in Decision-Making



In Model 3b, age was found to moderate the relationship between relational age and inclusion in information sharing as well, but only at trend level ( $p > .10$ ), such that there was a negative effect of age within the age similar group and no effect of age in either the age diverse or age dissimilar groups (see Figure 2). However, the addition of these variables did significantly improve model fit over Model 2b ( $\Delta = 9.22$ ,  $df = 2$ ,  $p < .05$ ). Overall, these variables explained 2.3% of the employee level variance and 18.8% of the organization level variance in inclusion in information sharing, for a total of 25.9%.

**Figure 2.** Interaction between Age and Relational Age Predicting Inclusion in Information Sharing



## Discussion

This study explored the effects of relational age on perceptions of work team inclusion as measured by the extent to which individuals feel a part of the important organizational processes of decision-making (indicator of behavioral integration) and information sharing (social interaction). Results of our analyses indicate that after controlling for a variety of personal and job characteristics, employees who perceived themselves to be age dissimilar from their work teams felt less included in both decision-making and information sharing than those who were on an age diverse work team. Age dissimilar employees, however, did not feel significantly less included than age similar employees nor did age similar employees feel significantly less included than those in an age diverse work team. This effect was not consistent across age. In fact, we found that being age similar to one's work team had a differential impact on inclusion depending on employee age. The older age similar team members were, the less included they felt in decision-making and information sharing.

Interestingly, older workers perceived the highest levels of inclusion when they were in age diverse teams, whereas younger workers perceived the highest levels of inclusion when they were on teams that were made up mostly of other young adults. Conversely, younger workers felt the lowest levels of inclusion when they were on teams that were made up mostly of midlife or older adults, whereas older workers perceived the lowest levels of inclusion when they were on teams that were made up mostly of other older adults. Counter to previous research (Chattopadhyay, 1999) and theory, these findings suggest that while older adults benefit *most* from being on age diverse teams, they may benefit from being on teams with midlife or younger coworkers more than from being on teams that are mostly comprised of their age peers. Further, these results suggest that perceived age differences in the workplace might indeed become more salient when there is a clear age majority for part of a team (or organization), and that age differences may become deemphasized when there is age diversity within a team.

This study makes several important contributions to the literature. First, it suggests that there are important conceptual and measurement

distinctions to be made between teams where there is a perceived majority group and teams where there is no perceived majority group. In previous studies that have explored perceived age dissimilarity, it is not clear where individuals in age diverse teams would fall on a dissimilarity-similarity continuum (see Avery *et al.*, 2007 for an exception). This study addressed these distinctions and revealed important age asymmetries in the relational age-inclusion relationship that should be explored further in future studies. Secondly, some have criticized the literature on age-outcome relationships at the workplace, pointing out a variety of methodological and statistical issues that may contribute to conflicting findings, including: small or homogenous samples, the omission of potentially important statistical controls (e.g., tenure), and improperly modeling the form of the age-outcome relationship (Hochwarter *et al.*, 2001; Thomson, Griffiths & Davison, 2000). The current study addressed these concerns by: 1) employing a relatively large, heterogeneous sample of workers in the U.S. representing six different industry groups and a broad range of job types, 2) controlling for a variety of factors that could impact perceptions of inclusion, and 3) assessing the possibility of non-linear relationship between the continuous variables in the analyses and inclusion.

## Implications for Social Work Practitioners

As the very large Baby Boomer generation ages, an increasingly larger proportion of clinical social workers' caseloads will be comprised of older adults (National Association of Social Workers, 2009). Many of these clients will be in the paid workforce and work-related experiences will affect their quality of life. Social workers will need to have a comprehensive understanding of what constitutes a quality employment experience for these workers and of the age-related factors that may affect their clients' abilities to successfully engage in work roles. We found in this study that work team age composition in relation to employees' own age may be associated with an employee's sense of inclusion or exclusion from circles of influence and information sharing at the workplace. Given the link between inclusion and various positive individual, group, and organizational outcomes found in previous studies, these findings can have important ramifications for overall employee well-being.

Secondly, as the realities of an aging workforce become more salient at workplaces, there is an emerging role for social workers who work in organizations (e.g., Employee Assistance Professionals and occupational social workers) to advocate for programs and policies that will enhance the employment experiences of older workers (Bates & Thompson, 2007; Mor Barak, & Bargal, 2000). Findings from this study could be used by social workers to develop innovative policies and programmes that could leverage the talents and experience of the multi-generational workforce and promote more inclusive work teams which could, in turn, help teams to work more effectively. Ultimately, inclusion policies and programs could promote positive individual and organizational outcomes (Roberson, 2006; Thomas & Ely, 1996; Wentling & Palma-Rivas, 2000). Findings suggest that such policies and practices might include promoting age diversity within work teams and across the organization, developing mentorship models within teams where older adults are paired with midlife and younger workers, or implementing age diversity training to support such endeavors.

### Limitations

While our data have important strengths, there are also limitations. Due to employer-imposed limitations on the number of items permitted on the employee survey, only some items from Mor Barak's (2005) inclusion-exclusion scale could be included. While all three of the items referring to decision-making loaded well onto one factor, only two of the three items related to information sharing loaded well. An advantage of the items that factored out in our sample is that they were adapted to refer to the more proximal environment of work group only. We feel that this is a strength of the measure, as inclusion in the more proximal environments of supervisor and work group may be very different than inclusion in the more distal environments of higher management or the organization as a whole, especially in very large organizations, as were in this study. Although our measures did show strong internal consistency and factor loadings, future studies should seek to use more robust measures of inclusion and should assess whether inclusion within these various system levels differs in general and within different sized organizations. Additionally, the study relied on cross-sectional data. While a longitudinal design may have permitted stronger causal

inferences to be drawn about the existence of effects, sufficient longitudinal data was not available for this analysis.

### Conclusion

The aging of the workforce is likely to have an impact on the dynamics of work teams. Findings from this study and others suggest that many aspects of the aging experience unfold in a social context. For instance, cultural norms about age-appropriate and age-expected roles may affect how individuals and groups interpret the aging experience. At the workplace, the subjective experience of aging can be co-constructed as workers interact with one another. Working in a group increases the salience of 'relative or comparative age' where individuals' subjective understanding of their own age can be affected by the extent to which they feel they are similar to or different from others in terms of age. It is important that gerontological social workers and other professionals concerned with the well-being of older adults consider the multiple contexts within which individuals age and construct their realities, including individual and shared social environments (relational age) and the physical environment (work).

### Notes

- <sup>1</sup> We assessed the proportion of variance to be explained at the employee, department and organization levels assuming a 3-level structure and found that the proportion at the department level was negligible for both dependent variables (decision-making intra-class correlation (ICC)= .019,  $p=.007$ ; information sharing ICC= .002,  $p>.05$ .), indicating that a 2-level structure is more appropriate. ICCs for employees nested within organizations (decision-making ICC= .182,  $p<.000$ ; information sharing ICC= .132,  $p<.000$ ) and employees nested within departments (decision-making ICC= .170,  $p<.000$ ; information sharing ICC= .180,  $p<.000$ ) suggest that analytic adjustments were needed to account for nestedness at either the organization or department level to ensure that regression results were unbiased.
- <sup>2</sup> Possible non-linear relationships between the continuous variables (age, tenure and work team size) and inclusion were tested by adding squared and cubed terms to the models, but none were found to be statistically significant.

<sup>3</sup> In order to make this comparison, an identical unreported HLM regression analysis was run where the reference group for relational age was changed to represent the “team is age similar to self” group. For inclusion in decision-making,  $B = -.75$ ,  $t(1762) = -1.56$ ,  $p > .05$ , and for inclusion in information sharing,  $B = -.48$ ,  $t(1762) = -1.01$ ,  $p > .05$ .

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## Cultural Context of Health and Well-being among Samoan and Tongan American Elders

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### ABSTRACT

*This article examines cultural-related factors that may serve as sources of protection/benefits and risk for the health and well-being of Samoan and Tongan American elders. People from Oceania, in this case Samoans and Tongans, view health and well-being holistically, thus this study focused on biological health and psycho-social-spiritual well-being of participating elders. Study participants included 20 Samoan and Tongan American elderly immigrants living on the islands of Hawaii. For this exploratory qualitative research, data were collected via individual interviews. Findings indicate that commitment to cultural practices in the family such as respect for the elders, community and church leaders; reciprocity; spirituality; native language; use of traditional medicine, food, and music; and cultural expectations have protective influences on an elder's health and well-being. These cultural practices provided psychological encouragement and strength, social support systems, opportunities for reciprocity and strengthened relationships with God and others. On the other hand, over-giving and over-doing these cultural practices led to negative impacts on an elder's health and well-being. Cultural duality was identified as a source of both risk and protection for health and well-being. Implications for research and policy practice for the larger Pacific American group and other culturally similar groups are discussed.*

**Keywords:** Immigrant elders, Samoans and Tongans, Cultural practices, Health and well-being, Risk and protective factors

Immigration into the United States presents a complex and complicated context in which Samoan and Tongan Americans attempt to practice and perpetuate their traditional cultural lifeways. Although, traditional cultural lifeways are generally strong and deeply rooted across generations, Samoan and Tongan elders remain central to cultural survival, especially among immigrants. The significance of these elders to the survival of their cultures, and ultimately their people, has been recognized, however information on the influence of culturally related factors on the health and well-being of immigrant Samoan and Tongan elders is sparse and what is available does not accurately describe the experiences of these elders. The study presented in this paper attempts to initiate a meaningful discussion about the cultural context of health and well-being of immigrant Samoan and Tongan American elders. The research explored the consequences of strong connections and commitment to cultural values and beliefs on health and well-being. Specifically, what is the influence of culturally related factors as sources of risk or protection on the health and well-being of Samoan and Tongan American elders? In this study, culture is inclusive of family relations, connections to the land, church, respect for authority, and reciprocity. Understanding of the immigrant experience as the context in which the phenomenon of culture and its links to health and well-being exists frames this study. In this initial phase, qualitative research methods are appropriate for exploring the depth and complexity of this phenomenon which will contribute information on the health and well-being of immigrant Samoan and Tongan American elders.

### Literature Review

Samoan and Tongan elders are central to the daunting task of ensuring the transmission of traditional culture as well as assisting the young in negotiating cross-cultural identities such as a Samoan/Tongan American identity. The literature specific to Samoan and Tongan American elders is extremely limited, incomplete, and often subsumed within the general Pacific American literature which is also sparse. Available information regarding Pacific American immigrants, Samoan and Tongan cultural lifeways, and Pacific conceptualizations of health and well-being provides a foundation for further dialogue on the link of culture to health and well-being. Although brief, this review of the literature speaks to the significance of study which will contribute to

the existing knowledge by describing the experiences of Samoan and Tongan American elders in negotiating their cultures in a United States environment, the outcomes of such negotiation, and the accompanying challenges of the immigrant experience.

### **Pacific American Immigrants**

Currently, Pacific Americans<sup>1</sup> consist of over a million people, new and older generation immigrants, living primarily in Hawaii, California, Alaska, Utah, Washington, Texas, and Oregon (Population Reference Bureau, 2006). With population growth due to migration and birthrate comes both opportunities to achieve and contribute to the greater societal good, as well as challenges and difficulties. For instance, the average Pacific family size is reported as four, however, with the commonplace of intergenerational living, family household size can be as high as 10 individuals or more. The median Pacific family annual income is estimated at \$50,000 (Ibid.) with the lowest annual incomes among the Tongans at about \$27,000 and Hawaiians at about \$38,000. There are about 26 per cent of Samoans and 23 per cent of Tongans in the U.S. living below the poverty line. In terms of education, about 10 per cent of Pacific Americans have undergraduate degrees and 4 per cent have graduate degrees, compared to 27 per cent and 11 per cent of white Americans respectively. Specific to language barriers, 42 per cent of Pacific Americans speak a language other than English in the home (Population Reference Bureau, 2006; Vakalahi & Godinet, 2008).

In relation to health, Pacific Americans have high rates of obesity, alcohol use, and smoking, with the leading causes of death being diabetes. In Hawaii, Native Hawaiians are more than 5 times as likely as white Americans to die from this disease. Pacific Americans also suffer from cancer, heart disease, gout, accidents and stroke, with a high prevalence rate of hepatitis B, HIV/AIDS and tuberculosis (Population Reference Bureau, 2006). Pacific American elders are at particular risk given the combined challenges of these debilitating health problems, lifelong inadequate health care and lack of health insurance, likelihood of being employed in hard-labor jobs with low wages, language barriers, and living in a racist and ageist society that does not value the wisdom that comes with age. These factors are intimately linked to the

immigration experience (Braun *et al.*, 2004). The lack of access to and use of western health and social services by these elders are also major problems, either due to the lack of knowledge of available services, distance, or lack of financial resources (Braun *et al.*, 2004; Population Reference Bureau, 2006). Unfortunately, such health, social, and financial challenges faced by Pacific American elders can prove to be personally and culturally problematic (Australian Bureau of Statistics, 2004; Fitzpatrick, 2004; Linsk & Mason, 2004; Patton, 2003).

While the literature on Pacific American elders is sparse, information that exists indicates that elders are key to the survival of indigenous Pacific cultures in the countries of origin as well as the new countries of residence (Dodd, 1990). In an environment comprised of dual or multiple cultures such as the U.S., Pacific American elders play a crucial role in the preservation and transmission of cultural values, beliefs and practices for new and older generation immigrants. For Pacific Peoples, constant interaction with elders has significant meaning throughout the life course, with cultural practices such as respect for the elders, reciprocity and collectivity, and family and community responsibilities taught in the arms of the elders (William Wallace, Hawaiian cultural expert, personal communication, October 1, 2002). Pacific elders are the spiritual linkage between the past, present and future.

### **Traditional Samoan and Tongan Cultures**

Samoan and Tongan American elders include those in the U.S. with heritage and ancestry that are originally from the Pacific nations of Samoa and Tonga. The Samoans and Tongans belong to the Polynesian group of the people from Oceania<sup>2</sup> (Hau'ofa, 1994). Due to patterns of migration and exploration in the vast Pacific Ocean, cultures of people from Oceania are unique in their own rights; yet, they are familiar and similar to each other in so many ways (Taufe'ulungaki, 2008). Samoan and Tongan cultures share familiarity, a closeness that exists not only in terms of cultural values, beliefs, and practices but also proximity in the location of the two island nations and by virtue of living side by side in the U.S. in states such as Hawaii and California. Their immigration experiences in the U.S. have been quite similar particularly in terms of having to negotiate cultural duality. In

other words, they constantly deal with the reality of having to live simultaneously in their culture of origin and their new American culture.

In relation to the traditional Samoan culture, Autagavaia (2001) and Bell (1998) discuss key cultural values and practices taught and enforced by the elders, which includes familial connections; connection to the land; absolute respect for authority of the chiefs (matai) and ministers (faife'au); and a collective identity and worldview that is based on spirituality, physiology, and history. Also important is respect for the elders in speech and conduct, for example, when speaking to an elder one must not be standing.

The church and its ministers hold much power in the Samoan community. Mutual respect (vafealoaloa'i) and sacredness placed on human relations are core principles. For instance, in weddings, funerals, and other special occasions, Samoan families are expected to share the responsibilities and costs for the occasion. This sense of reciprocity and collectivity is facilitated by the fact that a Samoan person is rooted in the multiple aspects of culture including a family (aiga), village (nu'u), and ancestors. Children and grandchildren are customarily named after their grandparents/elders and are raised to respect their culture through participating in cultural ceremonies, retaining the Samoan language, and eating a traditional Samoan diet which includes breadfruit, taro, bananas, pineapples, coconuts, fresh pork and fish prepared in an underground oven (umu).

Similarly, the church plays a significant role in the lives of Tongans in and outside of Tonga, which is indicative in the strict observance of the Sabbath day and the inclusion of this protocol in the Tongan Constitution. Traditional Tongan culture emphasizes inclusiveness, reciprocity, extended family relationships, and respect for the elders as the basis for collectivity among Tongan people (Afeaki, 2001). Births and weddings are celebrated with families and communities who come to offer emotional and financial support, and include exchanges of gifts. There are roles in these gatherings that are elder, gender, and birth order specific. For instance, grandparents/elders name their grandchildren and such names are often the names of other elders in the family. Also, speeches given on behalf of a bride or groom are customarily given by the oldest elder from a family. Also similar to the

Samoan culture, traditional Tongan diet include mangos, oranges, melons, fish, and pork (Bell, 1998).

Relevant to both Samoan and Tongan cultures, Mulitalo (2001), Hereniko (1995), and Newport (2001) emphasize the fact that even in our transnational world of today, spirituality remains fundamental in all Pacific epistemology and regardless of where Pacific people reside, their sacred connection to the people and homelands remains strong. The elders play a key role in maintaining this sense of sacredness and connectedness in environments like the U.S. where immigrants must deal with dual or multiple cultural identities.

### **Traditional Conceptualization of Health and Well-being**

Pacific models of health and well-being vary yet are fundamentally similar in that, health and well-being are holistically inclusive of the physical, mental, social and spiritual dimensions as well as other cultural and environmental factors (Aanae *et al.*, 2001; Durie, 1985). For instance, according to the Fonofale model, the roof of the fale (traditional Maori house) represents cultural values and beliefs which are integrated into both traditional and contemporary healing methods. The foundation of the fale represents the family and each of the *pou* (house posts) represents the biological, spiritual, mental, and other dimensions such as gender, class, age, and sexual orientation. The fale is surrounded by a context that represents the environment (Aanae *et al.*, 2001).

Furthermore, Finau *et al.* (2004) add to this conceptualization of health and well-being by explaining that the absence of disease and pain is the ultimate goal. Furthermore, the inability to meet family and community obligations and the inability to achieve personal goals are considered possible outcomes of poor health and well-being. This inclusive and collective conceptualization of health and well-being can assist service providers in clearly framing their understanding of the experiences of immigrant Samoan and Tongan American elders.

### **Methodology**

#### ***Research Questions***

The research question explored in this article relates to the cultural context of health and well-being of Samoan and Tongan American elders: What are the consequences of strong connections and

commitment to cultural values and beliefs on health and well-being? Specifically, what is the influence of culturally related risk and protective factors on the health and well-being of Samoan and Tongan American elders? These questions are informed by the integration of the Ho'okele model (Vakalahi *et al.*, 2007) and concepts of risk and protective factors. The Ho'okele model speaks of the centrality of Pacific elders in navigating the future of their families and communities. It focuses on connections and transactions across multiple systems, beginning with the elders as keepers of cultural knowledge, practices, traditions, and customs. Elders are entrusted with the responsibility of connecting and nurturing all of the generations and systems (Ibid.).

### *Design*

The inductive nature of grounded theory as an exploratory qualitative research method was utilized for this study. Grounded theory provides a systematic set of procedures for constructing a theory about a phenomenon that is grounded in data and the interpretive understanding of the meanings of an individual's lived experiences. Grounded theory research focuses specifically on describing a phenomenon and its meaning from a participant's perspective, and as a result, constructed theories are grounded in the participant's lived experiences. In grounded theory research, an individual's meaning-making process is understood only in the context in which it occurs and is embedded. Data collection, analysis, and theory construction are regarded as reciprocally related. This interweaving is a way to increase insights and clarify the parameters of the emerging theory (Charmaz, 2006).

The phenomenon that was explored in this study was the influence of cultural related risk and protective factors on the health and well-being of Samoan and Tongan elders. Because Pacific cultures view health and well-being holistically (Agnew *et al.*, 2004; Finau *et al.*, 2004), this study embraced the idea of the interconnectedness and interaction of the bio-psycho-social-spiritual dimensions.

### *Sampling Procedures*

The setting for this study was Honolulu, Hawaii, the most common port of entry and the U.S. location with the largest populations of Samoans and Tongans. Due to limited knowledge regarding parameter

estimates of Samoan and Tongan communities in Hawaii, a networking non-probability sampling method was used to recruit study participants (Denzin & Lincoln, 1994). The research team solicited participation through contact with Samoan and Tongan churches, activity groups, and community organizations. Recruitment employed the use of flyer distribution and word of mouth communication, both proven effective in these communities. Research team members were from the community and utilized their community networks to assist in recruiting participants for the study. To assist with retention, every effort was made to schedule interviews during times convenient to the participants. All participants received a gift for their participation.

### *Participants*

Ten Samoan and ten Tongan elders, proportional between males and females, participated in the study. Most participants were in their 60s or 70s, and three were in their 80s. All were born in Samoa or Tonga and migrated to the U.S. as early as 1958 and late as 1997; only 2 elders were 2<sup>nd</sup> generation Americans. The elders lived on the island of Oahu, from Honolulu to La'ie. The number of people living in the home ranged from one to 10 people (median of three), and included children, spouses, nieces, nephews, mothers in law, parents, and siblings. Only 4 elders were currently employed, with the remainder living on social security and spouse's pension. Annual income ranged from less than \$20,000 to \$80,000 with more elders renting rather than owning a home. Samoan and Tongan languages were predominantly spoken in the homes. Four elders reported attending college and the lowest educational achievement level was elementary school.

### *Data Collection*

In grounded theory, data collection, analysis, and theory construction are regarded as reciprocally related (Charmaz, 2006). Data were collected through individual interviews with participating Samoan and Tongan elders who were regarded as experts in their lived experiences. The questionnaire for the individual interviews was developed specifically for Pacific American elders in collaboration with several Pacific American community leaders and scholars in Hawaii. In addition, the works of Malcarne *et al.* (2005) on the Scale of Ethnic Experience; Wallston *et al.* (1978) on the Multidimensional Health Locus

of Control; Renzentes (1993) on the Hawaiian Culture Scale; and the Marin and Marin Acculturation Scale by Marin *et al.* (1987) were utilized to inform the interview guide. The instrument included questions about the influence of cultural duality (being Pacific in America); strong connections and commitment to cultural values and beliefs; commitment to carrying out cultural expectations and practices such as reinforcing spirituality/religiosity, leading the family and community, teaching the young about cultural pride and preservation, codes of social interaction; hierarchies on health and well-being; and self care.

In emphasizing the significance of the naturalistic environment, interviews were conducted at each participant's home, a location of preference by the participants. To ensure confidentiality and privacy, locations for the interviews were safe and convenient to participants. Interviewing these elders individually was important for understanding their lived experiences and the meanings and themes regarding Samoan and Tongan cultures. The individual interviews were a one-time, two hours in length activity that used a semi-structured interview guide approach. All efforts were made to adhere to cultural rules regarding the positions of elders as leaders and final arbiter of the interview. Interviews were tape recorded and interviewers also took detailed notes.

Interviews were conducted by two members of the research team. The interviewers were trained associates with English, Samoan and Tongan languages capabilities. Participants chose the language in which the interview was completed. In translating data to English, back translation was conducted to ensure that the contextual meanings were kept. The interview process began with participants verbally completing a brief demographic questionnaire, with information pertaining to age, gender, family income, place of birth, number of and relationship between people living in the home, language use at home, educational level, employment status, and type of employment. Upon completion of the demographic questionnaire, participants were interviewed regarding their cultural experiences as elders and the impacts on their health and well-being.

#### *Data Analysis*

Following data collection, information was transcribed. Atlas.ti<sup>®</sup> software was used to organize the data. In keeping with the tenants of

grounded theory, the initial step was immersion in the data, reading the data transcriptions verbatim, line by line and reading for natural emergence of themes, patterns and categories. Coding of the data followed and thereafter, memo writing and annotating of interrelationships among the codes occurred. The line-by-line analysis of each transcript was conducted verbatim in order to discover and describe significant themes related to the phenomenon. Memos were used to define interrelationships among themes and identify recurring patterns which were sorted into categories. Constant comparative analysis was conducted in order to identify and compare themes and interrelationships among themes. Line-by-line analysis, memo writing, and constant comparison were conducted until redundancy, a point in which no new themes were discovered (Charmaz, 2006).

According to Drisko (2005), grounded theory is the core qualitative research metaphor evident in Atlas.ti. This qualitative data analysis software was used as a means of organizing the textual data into an analytical framework that is conceptually clear. The coding capability of Atlas.ti was an especially useful data analysis tool for helping the researchers determine themes and patterns related to the cultural context of health and well-being of Samoan and Tongan elders.

#### **Findings**

##### *Cultural Practices in the Family*

Samoan and Tongan American elders spoke with much pride about customs, traditions, values and beliefs practiced by their families in the U.S. Themes pertaining to codes of conduct and cultural protocols which have been preserved are presented below:

*Respect.* Participants discussed respect practiced by both young and old as a code of conduct expected and evident in their families. Respect for the elders in terms of caring for and honoring them, respect for community and church leaders, and respect for teachers were identified. Reflecting the centrality of the elders to the survival of their families, one elder said, "I believe that if I wasn't an encourager and guide for them, I don't believe any of them will still be around." Another elder said, "I try to keep them close." Still another stated, "One of the things that I like about our children, they honor our traditions

such as bending when walking in front of people, you have to say *tulou* (excuse me), help each other, giving to others.”

*Reciprocity.* Interdependent living and relationships, sharing, giving, and exchanging of resources and support were indicated by the participants as cultural protocols practiced in their families. Participants identified the family as a forum for reciprocating love and togetherness. The practice of *Fa’aSamoa* (Samoan way) and *fa’alavelave* (duties and responsibilities) ceremonies and celebrations were discussed as mechanisms for sustaining reciprocity. One elder said, “To me, the Fa’aSamoa is our way of life, exchange of fine mats and money.” Another elder said, “Cultures in the home that is part of me is giving to others. That is very important...we must always give and love people. People will always return the favors.” Still another indicated, “My oldest child says that she will never leave me because it’s her duty to take care of her mother. I agreed that because she is my oldest, she will care for me until I die then she will leave. This is why I believe there are positive things in the Fa’aSamoa and in my spirituality that helps me.”

*Spirituality.* The church, spirituality and prayer as part of the traditional Samoan and Tongan cultures were important to these participants. One elder said, “I tell my children that even though the church is far away in Kunia, I make sure that I go because they are the reason. I want them to be safe.” Another stated, “Love others and go to church are the Samoan cultures that are very good. Prayer is the main thing. Respect for older people, like Reverends at church.”

*Language, Food and Music.* The Samoan and Tongan languages were identified as significant in the family for purposes of carrying out cultural responsibilities and transmitting cultural practices to the next generation. One elder said, “My husband taught me how to speak the chief language. I used to be a spokes person when we take stuffs to a funeral.” Another elder said, “I am a speaker during *fa’alavelave* on behalf of my *aiga* (family) because of my *matai* (chief) title.” Traditional Samoan and Tongan foods and music were also discussed as integral parts of the ways of life of these Samoan and Tongan American families.

### Cultural Sources of Protection/Benefit

Participants talked about certain cultural practices as possible sources of protection and benefits for their biological health and psycho-social-spiritual well-being. In relation to positive impact on biological health, participants talked about eating traditional Samoan and Tongan food (coconut, taro, yam, fish) and using herbal medicine (aloe, ti leaves) indigenous to their cultures. As one elder said, “I use the ti leaves to massage my mother as well when I see that my mother is not feeling well.” Preparing these foods freshly, which was how food were prepared traditionally, as well as avoiding fried foods and not overeating were also discussed as positively impacting their biological health. Another elder said, “We grow our own food, vegetables and fruits. It is very good for our health.” In addition, farming and traditional *dancing* (*siva*) provided exercise for many of the participants.

In terms of impact on psychological well-being, participants described cultural practices as a source of encouragement and strength for their psyche. Several elders said, “Our self-esteem and self-worth increase when we give or help others. The more we give the happier we are so when we accumulate wealth (foods, animals, land and crafts), it is to give and donate to others when needed for one day I may need help myself.”

Regarding social well-being, for participants, cultural gatherings, celebrations, and ceremonies provided a support system of extended family, opportunities for reciprocity, a social life, and connection with nature (i.e., water). One elder stated, “Lucky to have that much support” while several other elders said, “I love the Samoan social life. If one person is in need, everyone helps out. Keeps my mind occupy when I socialize.”

In terms of spiritual well-being, participants talked about cultural practices as ways to strengthen connection with the church, relationship with and belief in God and the strength and wisdom He provides, and relationship with others. One elder said, “Yes, worshiping together, and the fellowship, the women group talk about health issues facing the Samoan women.” Ultimately, cultural practices were identified as a major contributor to happiness and spiritual well-being. One elder



stated, "That's where I get my strength. The wisdom comes from God and all thoughts." Another said, "God that teaches us, gives us knowledge, and to strengthen us in this life. Pray fervently to God it helps our spiritual wellbeing. We are in a good place and I'm happy." Still another indicated, "I believe that's why my family is blessed."

Finally, participants discussed the overall impact of cultural expectations on their health and well-being. In Samoan and Tongan cultures, families are expected to care for the elders. It is considered a blessing to care, support, respect, and acknowledge the elders. At the same time, participating elders talked about being expected to preserve and teach cultural traditions such as *fa'alavelave* and ceremonial speech to the next generation. The impact of these cultural expectations was positive for these elders. Essentially, cultural expectations gave these elders a purpose, happiness and joy, emotional and monetary supports, and social opportunities.

### **Cultural Sources of Risk/Downside**

As much as cultural practices were embraced as positively impacting health and well-being, participants also identified the over-doing and over-giving aspects of the culture as sources of risk for their health and well-being. For instance, in terms of the biological dimension, participants described the downside of Samoan and Tongan cultural practices relating to overeating which is often reinforced by the practice of White Sunday gatherings where food is over abundant and very little physical movement occurs.

In relation to the psychological dimension, participants talked about over-giving, especially in current difficult financial times, and of miscommunication due to lack of English proficiency as contributing factors to feelings of depression. Regarding the social dimension, cultural practices such as *fa'alavelave* (duties and responsibilities) often leads to lack of resources, little privacy, conflicting family relations, jealousy, and unnecessary stress for the elders. One elder said, "It is too much. When there's too many *fa'alavelave* at the same time and not enough resources to contribute." Likewise, in terms of spiritual well-being, lack of financial resources was a source of stress for elders which impacted their sense of spirituality. As indicated by one elder, "You believe in God, and sometimes you don't believe in God" speaking of bad economic

times. Another said, "It impacts the congregation it causes friction in the church and that's not a good thing."

### **Cultural Duality as a Source of Risk and Protection**

The immigration experience presents the issue of cultural duality. The duality of Samoan/Tongan American cultures was discussed as a source of both risk and protection for the health and well-being of participants. Negotiating the duality of traditional Samoan/Tongan and American cultures was described by participants as challenging, and conflicts between the two cultures sometimes negatively impacted their health and well-being. The reality of language barriers and subsequent miscommunication often led to disconnects between people, especially among the elders and the young. One elder stated, "It can be challenging and conflicting at times. Trying to keep our core values where the western culture emphasis is on individual rights and choices regardless of how others feel and think." Another said, "Communication, especially speaking to my children and grandchildren, is a challenge and sometimes most of our family problems are miscommunication." Another stated, "Here in America, you pay for everything where as in Tongan culture, I can ask anything of anybody so I can enjoy both. American culture is driven by money and it's very expensive so I'm too busy trying to make money to care for my family." Still another said, "It is different here, cost of living is too high, I have to care for my family's needs before mine. The focus here is money and people expect it when they do things for others. People are too busy making money they don't have time to enjoy."

On the other hand, participants also saw the positives in the duality of their Samoan and Tongan American culture. They perceived cultural duality as opportunities to create options for themselves and their grandchildren. Participants talked about doing their best to keep only the positives from each culture. For example, they learned to negotiate between independence and interdependence in their Samoan and Tongan American context. One elder said, "I have choices....when there is conflict between the two cultures, I choose my Tongan culture. I keep only the 'good things' from both cultures." Several others said, "I love my cultural medicine but I go to the doctor when I'm sick. I am involved in my culture through involvement in my church and our

Fa'aSamoa practices. I don't understand the American way very much but I do understand the depth of the Samoan culture. This is one of the big reasons why I am active with my Samoan community."

### Discussion

Similar to other immigrants in the U.S., Samoan and Tongan Americans continue to face challenges linked to the immigration experience regardless of how many generations of their family have lived in the U.S. In this study, the immigration experience of Samoan and Tongan American elders framed the context in which their lived experiences with culture and the impacts on health and well-being was examined. Traditional Samoan and Tongan cultures conceptualize health and well-being as holistic. These study findings continue to affirm these concepts as critical to the lives of the elders and those for whom they are responsible. Understanding these holistic conceptualizations is significant to social work practice with these immigrant elders.

The elders in this study further shared the preservation and perpetuation of Samoan and Tongan cultural practices such as respect, honour, and care for the elders, reciprocity and interdependency (Fa'aSamoa, fa'alavelave), spirituality and the church, Samoan and Tongan language, traditional medicine, food, and music and the protective impacts of these practices on their health and well-being. Traditional Samoan and Tongan food prepared fresh, herbal medicine, and music positively impacted the elders' biological health whereas cultural ceremonies and celebrations provided psychological encouragement and strength. Engagement in Samoan and Tongan cultural practices provided strong social support systems, opportunities to practice reciprocity and interdependency, and opportunities to strengthen relationships with God, others, and the church. These elders believed that their cultural expectations provided them with purpose, joy, and support. Continuity of these cultural practices in the U.S. context is significant for the health and well-being of these immigrant elders and generations to come. This also may be the story of other ethnic and immigrant communities around the world.

Furthermore, study findings indicate that maintaining balance is important in sustaining health and well-being. For instance, over-giving as a cultural standard often leads to lack of resources for an individual's

basic needs, which leads to feelings of depression, stress, and conflicting family relations. Moreover, global migration naturally leads to exposure to other cultures and subsequently, cultural duality. Such duality generates urgency in preservation and perpetuation of cultural practices among the larger Pacific American group. These elders discussed cultural duality as a source of both risk and protection for their health and well-being. For instance, language barriers often lead to miscommunication between the elders and family members. However, they also perceived cultural duality as offering options and opportunities for themselves and their families. In essence, balance in integration of the two cultures with the goal of enhancing health and well-being must be negotiated carefully, and the elders are central to this process.

### Implications for Research and Policy Practice

Specific implications for research and policy practice are offered in this discussion with possible relevance to other ethnic communities in the U.S. and globally. Future studies need to explore the cultural conceptions of health and well-being among elders in immigrant and dual cultures. Decision makers need to support the testing of indigenous cultural theories on health and well-being in such communities. Exploration is needed on the protective or risk-related aspects of cultural duality on elders' health and well-being. The specific issue of language barriers needs further exploration, particularly in terms of the impacts on the elders' roles as navigators, teachers, and transmitters of traditional cultures to the younger generation. Language barriers have been documented as being responsible for misunderstandings and conflicting family relationships.

In addition, future research should explore the practice of reciprocity and collectivity across cultures and particularly among indigenous people around the globe. Research on the role of the elders in maintaining reciprocity and a collective perspective could inform 21<sup>st</sup> century community practice. Increased global travel and migration offers opportunities for cutting edge cross-cultural research on protective aspects of reciprocity and collectivity.

With increasing diversity in demographics, policies in countries around the world need to reflect the cross-cultural backgrounds and ways of life of their citizens. It is beneficial for professionals providing

services to immigrant populations to understand and respect the decision making role of the elders in their families and communities, as working with these elders can be beneficial for the outcomes of the work.

### Footnotes

<sup>1</sup> Pacific Americans include immigrants born outside of the U.S. and those born in the U.S. to immigrant parents/grandparents.

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## **The Right Not to Know: Exploring the Attitudes of Older Iranian Immigrants about Medical Disclosure of Terminal Illness**

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### **ABSTRACT**

*The analysis presented in this study is part of a larger exploration of health and mental health related beliefs and behaviors of older Iranian immigrants in the United States. The focus is older Iranian immigrants' attitudes about medical disclosure of terminal illness. Using a phenomenological methodology, in-depth, semi-structured interviews were conducted with 15 older Iranian immigrants. Participants were asked about medical disclosure of terminal illness in the United States as well as in their home country of Iran. They were also asked to describe the ideal method for health care providers to disclose terminal illness to them. The major themes that emerged were: 1) the delivery of bad news in United States, 2) the delivery of bad news in Iran, 3) the right not to know, 4) treat me without scaring me to death, 5) tell my family and 6) strength of the heart (quvvat-I qalb). Although, this study focuses on older Iranian immigrants, it has implications for other older culturally/ethnically diverse populations for whom health and social service professionals provide essential care.*

**Key Words:** Delivery of Bad News, Culturally appropriate care, Qualitative research, Middle Eastern immigrants, Patients' rights, Terminal illness/diagnosis.

Nobody wants to be the bearer of bad news, but for many medical professionals this is inevitable. Bad news has been defined as "any information which adversely and seriously affects an individual's view of his or her future" (Buckman, 1992). Bad news, however, is in the "eye of the beholder," such that one cannot estimate the impact of the

bad news until one has first determined the recipient's expectations or understanding (Ibid.). Health care providers in America have legal and ethical responsibilities to disclose a diagnosis of terminal illness to their patient, no matter how painful the news may be to the patient. They also have a legal obligation to provide patients with as much information as they desire about their illness and its treatment (Annas, 1994).

News about terminal illness is disclosed, so that the patient can make informed decisions about treatment options and/or end-of-life planning. How the diagnosis of terminal illness is disclosed can affect the patient's comprehension of information (Maynard, 1996), satisfaction with medical care (Ford *et al.*, 1996), level of hopefulness (Sardell, & Trierweiler, 1993), and subsequent psychological adjustment (Last, & van Veldhuizen, 1996). Few studies have explored the patients' preferences for disclosure of unfavourable medical information (Walsh *et al.*, 1998). In this paper, the attitude of older Iranian immigrants about medical disclosure of terminal illness will be explored.

## LITERATURE REVIEW

Although the patient's right to know is a fundamental part of today's American health care system, as recently as two decades ago doctors in the United States did not disclose diagnoses of terminal illness to their patients (Oken, 1961). Surveys conducted from 1950 to 1970, when treatment prospects for cancer were bleak, revealed that most physicians considered it inhumane and damaging to the patient to disclose the bad news about the diagnosis (Ibid, Friedman, 1970). Beyene (1992) explained, "This shift of American physicians toward disclosure is attributed to underlying changes in the social structure of the U.S. health-care system". The majority of literature previously focused on whether to tell the patient the diagnosis, but more recently the focus has shifted to what information to give and how to convey it (Oken, 1961; Friedman, 1970; Miyaji, 1993; Ptacek, & Eberhardt 1996). The diagnosis of terminal illness is an issue that most doctors and patients describe as difficult to discuss, and uncertainty exists about the best way to present prognostic information that optimizes patient understanding, psychological adjustment, and decision-making (Hagerty *et al.*, 2005).

The literature reveals that the desire to know about terminal illness is not shared by all people. As described by Brotzman and Butler (1991), "All cultures do not share Western views on the positive value of disclosure". Many patients desire accurate information to assist them in making important quality-of-life decisions. Others who find this too threatening may employ forms of denial, shunning or minimize the significance of the information, while still participating in treatment (Baile *et al.*, 2000). Some populations such as Japanese (Swinbanks, 1989), Italians (Gordon, 1991) and Ethiopians (Beyene, 1992) believe that a diagnosis of terminal illness should not be revealed to the patient.

Theories of holistic medicine (Williams, 1998), culture care diversity and universality (Leininger, 1991), cultural competency (Goode, 2002), and ethno relativism (Paige, 1993) guided the research questions and established the framework for this study. These theories suggest that culture must be considered when providing care for patients. They also make connections between culture and a person's definitions and experiences of health, illness, and care. As explained by Williams (1998), culture is like a lens through which an individual perceives and interprets the world. This lens helps define the meanings and behaviours associated with health, illness, care, and healing.

### *Iranian Immigrants*

During the past two decades, more than 3 million Iranians have immigrated to other countries, making them one of the largest new immigrant groups from the Middle East (Bozorgmehr, 2001). The number of Iranians (also known as Persians) in the United States has grown rapidly, from approximately 15,000 in 1965, to 121,000 in 1980, and is now estimated at about 1,000,000 (Ibid). Many Iranians migrated to the United States as the result of the 1979 Islamic revolution and the 1980-1988 Iran-Iraq war (Pliskin, 1992). The largest concentrations of Iranians in the U.S. are found in Los Angeles, New York, Washington, and Atlanta (McConatha *et al.*, 2001). Despite the large number of Iranian immigrants in the United States, little research has been conducted concerning the health status and health care needs of this population (Jalali 1982, Lipson, & Meleis, 1983, Lipson, 1992, Pliskin, 1992, Ghaffarian, 1998). Research on the health of older Iranian immigrants in the U.S. is even more scarce. Salari (2002) described

older Middle Eastern immigrants as “invisible” in the ageing literature. The main body of research on older Iranian immigrants comes from studies done in Sweden (Lipson, 1992; Emami *et al.*, 2000; Emami *et al.*, 2000; Moghari, 2000; Emami *et al.*, 2001; Emami & Torres, 2005). These studies provide some perspectives on the health status of older Iranian immigrants. Moghari (2000) reported that “aged [Iranians] immigrants have more health problems than the other groups in the host country”. Emami *et al.* (2000) and Lipson (1992) found that older Iranian immigrants are more vulnerable than younger immigrants. Poor acculturation has been identified as a contributing factor to poor self-reported health among Iranian immigrants in Sweden (Wiking *et al.*, 2004). Despite many years abroad, older Iranian immigrants have been found to be resistant to acculturation, struggle with the language of the host country, feel isolated, and remain highly dependent on their children (Ghaffarian, 1998; Lipson & Meleis, 1983). In addition, older Iranian immigrants have been found to be more culturally resistant (Ghaffarian, 1998) and to rely more on their past experiences, which may not be compatible with the norms of the host society.

### **Purpose of Study**

Given the growing numbers of older Iranian immigrants who utilize health care services in the United States, the need to understand their culturally specific attitudes about medical disclosure is important. Understanding cultural beliefs and attitudes can help health care providers deliver culturally sensitive care to their patients.

The purpose of this study was to:

- 1) Explore the attitudes of older Iranian immigrants about disclosure of terminal illness by health care providers.
- 2) Explore how attitudes about medical disclosure of terminal illness may influence the care seeking behaviours of older Iranian immigrants in the U.S.?

### **Design and Methods**

This was an exploratory qualitative study using Phenomenological methodology. As described by Creswell, (1998), “A phenomenological study describes the meaning of the lived experiences for several

individuals about a concept or the phenomenon”. In-depth interviews were conducted in order to obtain rich, descriptive, and meaningful data on complex cultural issues (Miles & Huberman, 1994).

### **Recruitment**

Sampling was purposive, which is compatible with phenomenological methodology because it facilitates access to information-rich cases (Patton, 1990). Participants were eligible for inclusion in the study if they were Iranian immigrants who migrated to the United States after the age of 50. Having been diagnosed with a terminal illness was not an inclusion criterion. The study setting was Salt Lake City, home to approximately 2000 Iranians (Bakhshandehpoor, 2004). Although close-knit, the Iranian community in Salt Lake City is geographically dispersed throughout the city, with a few Iranian stores and restaurants serving as points of concentration for this community. Recruitment flyers, translated into Persian, were distributed to locations in Salt Lake City frequently visited by members of the local Iranian community, including the Persian restaurants and grocery stores. Potential participants were told that the purpose of the study was to gain a better understanding of the health-related attitudes and experiences of older Iranian immigrants in the United States. The study had received approval through the University of Utah Institutional Review Board.

### **Data Collection Procedures**

The participants were asked a series of open ended questions and probes (using an interview guide) during the in-depth in-person interviews. Some of these questions were: How do you think news about terminal illness should be delivered by health care providers? What do you think about the way news about terminal illness is delivered in America? What do you think about the way news about terminal illness is delivered in Iran? Interview questions were tested in a pilot study. The interview guide included demographic questions, open-ended questions and probes. All interview material was prepared in both English and Persian. An Iranian American peer reviewer provided input on the cultural and linguistic appropriateness of the translated material. Interviews were conducted at the homes of the participants. The interviews were conducted in Persian and each interview lasted

approximately 2½ to 3 hours. All interviews were audio-recorded with the participants' consent.

### *Researcher Role*

As a first-generation Iranian immigrant, the researcher is familiar with many aspects of life for Iranian immigrants in the United States. However, having migrated to the United States at a young age (15 years old) and speaking English fluently, she did not share many of the participants' struggles and experiences. This led to the dual role of the researcher as both an insider and an outsider. When looking at the Persian transcripts, the researcher felt like an insider, while the English transcripts distanced her from the participants and made her feel like an outside observer. Although many of the cultural practices the participants discussed were familiar to the researcher, some of the participants' health related beliefs and behaviours came as a surprise. As noted by Ely (1991), when qualitative research is conducted properly, the familiar begins to feel unfamiliar to the researcher.

### *Trustworthiness and Rigour*

As Padgett (1998) explained, it is not necessary to eliminate personal feelings and biases, but to become cognizant of them and their influence on the study. The researcher used the techniques of bracketing, peer review, and participant feedback in order to mitigate researcher bias and enhance the trustworthiness of this study. Bracketing is a process whereby all previous knowledge, beliefs, and common understandings about a given phenomenon are set aside. This was done through an analytical and reflexive review of the researcher's emotions, perceptions, and reactions to the data (Sandelowski, 1986). The researcher kept detailed notes as part of an audit trail, documenting and separating her own feelings and experiences from those of the participants. Peer review refers to working with a peer to discuss the interpretations and conclusions drawn from the data. Using peer review helps keep the investigator's interpretations in check and allows for verification of the findings by another person. In this study, the researcher worked with an Iranian American colleague and an American social work professor who challenged the investigator to provide solid evidence for the data interpretations and conclusions. To confirm the accuracy of the emerging themes, the participants were

contacted to verify the themes and to ask for their feedback. This is referred to as member checking or participant feedback.

### *Data Analysis*

Data were transcribed in Persian and then translated into English. This approach to translation is referred to as sequential transcription (Padgett, 2004). Data segments were compared across the two languages to minimize loss of meaning that may have occurred in the translation. Using initial and focus coding (Lofland & Lofland, 1995), the data were coded and divided into categories that covered various responses regarding health definitions and health behaviors. Using the data analysis methodology developed by Colaizzi (1978), significant statements that pertained to each category were extracted, while duplicated statements were eliminated. Meaning units were formulated from these statements by constant comparison between the English and Persian transcripts, as well as frequent review of the audio-tapes. Meanings were considered in both linguistic and cultural contexts. These meaning units were then organized into themes that were compared, contrasted (between and within cases), and sorted until thematic saturation was reached (Creswell, 1998). ATLAS-ti, commonly used qualitative data management software (Pugh Computers Ltd., 2002), was used to navigate the large data text files, create codes and categories and do word searches.

## **Findings**

### *Demographics*

Seven men and eight women participated in this study. Their ages ranged from 53 to 87. Seven of the participants were married, three were divorced, two were never married, and three were widowed. Three of the participants reported living alone, while the rest of the participants lived with family members such as spouses or children. Seven participants had retired before immigrating to the United States; three worked full time; one worked from home, one worked part time; and three had never worked. All participants reported having left Iran after the age of 50, and at the time of the interviews, they had been in the United States for an average of 13.5 years. All had graduated from high school, and three men and two women had graduated from college. Many participants described their English as minimal and self-

taught. Three participants reported speaking enough English “to get by,” and five described their English as nonexistent and reported a need to rely on their children for translation. All participants reported having health insurance.

### Major Themes

Six major themes regarding the attitudes of older Iranian immigrants about medical disclosure of terminal illness emerged from data analysis; 1) the delivery of bad news in United States, 2) the delivery of bad news in Iran, 3) the right not to know, 4) treat me without scaring me to death, 5) tell my family and 6) strength of the heart (*quvvat-i qalb*). Direct quotes from participants are presented to provide evidence for the themes and to allow the reader to hear the participants’ voices. Names used for the participants are all pseudonyms. For the purposes of this study, the term “bad news” refers specifically to “a diagnosis of terminal illness”.

#### Delivery of Bad News in United States

In this study the participants were asked about their opinions on how news about diagnosis of terminal illness is delivered in the United States. In nearly every case, there was an immediate objection to the term “terminal illness”. The participants emphatically stated that no one (e.g., doctor, surgeon, specialist, nurse, and family members) can make that kind of judgment about another person’s health and, most importantly, this is because it takes away a person’s sense of hope and appetite for life.

Ahmad : The doctor should never tell you that you have a terminal disease.

Interviewer : What if it is not treatable?

Ahmad : First of all, no one knows that except for God; secondly, there is always some kind of a treatment and that’s the doctor’s job to find that. It is also the doctor’s job not to disappoint his patient, not to deprive the patient of his strength of heart, his hope. Doctors should never take away a patient’s hope. That hope is what gives you strength to fight. If they take that away, they are not treating you; they are making you worse. That’s

not what a doctor is supposed to do; he is supposed to make you better. They have sworn to do that.

The participants expressed dissatisfaction with the way American doctors deliver the diagnosis of terminal illness. They felt that diagnosis of terminal illness is often handled in a cold, blunt, and matter-of-fact way with no prior preparation and no *quvvat-i qalb*, which literally means strength of heart and is referred to giving patient a sense of hope and optimism.

Ahmad : Here the doctors walk in with a file folder under their arm . . . while the husband or wife is sitting in the corner waiting scared, . . . and then he tells them bluntly you have cancer or you have this and that. Well this to me is very painful. I don’t like this approach. To tell someone coldly that they are going to die . . . that’s not right . . . I don’t approve of that.

Fatemeh : This is something here that I am really opposed to. I don’t agree with it at all. In here, the doctors tell you everything very bluntly . . . whether you are a child, adult, or elderly. . . . They don’t show any consideration for the person’s spirit.

Some participants argued that American physicians’ approach to the delivery of news about terminal illness can be more damaging than the illness itself. Following are two examples that illustrate this point:

Sara : It is not easy to sit there and have your doctor tell you that you have cancer. Your spirit is suddenly shattered. You lose your appetite for life, and this can kill anybody.

Roya : If a doctor comes and tells me I have cancer and I am dying, I will probably collapse and die from the shock. They need to take time and give you strength of heart (*quvvat-i qalb*). They should not just suddenly tell you, that shatters a person.

The above quotes illustrate the immigrants’ desire for their doctors’ consideration for their emotional/mental/spiritual (*ruhi*) health beyond consideration for their physical health. Iranian immigrants believe that once a person is given certain information, they can no longer return



their mind, body, and spirit to the state that it was prior to receiving the information. This can lead to what they call the “loss of appetite for life” which can ultimately lead to the deterioration of their health.

### ***Delivery of Bad News in Iran***

I asked the participants to tell me about how news about diagnosis of terminal illness is given by doctors in Iran. A majority of the participants reported that the doctors in Iran do not tell patients about terminal illness, although they do tell the family. This also seemed to be these participants’ preference.

Ahmad : First of all, an American doctor will tell you right away, like he says you have cancer, but an Iranian doctor won’t tell you. But here they tell you . . . right there . . . they will tell you straight . . . like it is no big deal. Like you know how to deal with something like that.

Interviewer : How is it done in Iran?

Ahmad : If I am married, they will tell my wife; otherwise they tell your daughter, your son . . . and, of course, a daughter, a son knows their father better than any doctor could ever. They know if their father can handle it or not . . . so I think those closest to the patient should be the ones to tell the news to the patient.

Sara : In Iran, they prepare you and then gradually they tell you it is like this and that, but don’t worry . . . you will be fine. . . . They would have never told me like they did here.

### ***The Right Not to Know***

This study illustrates an overwhelming desire by the participants for *not* wanting to know about a diagnosis of terminal illness. Following are some examples that illustrate the participants’ desire not to have diagnosis of terminal illness disclosed to them.

Reza : They shouldn’t tell you at all. What’s the point? It only makes the person lose their spirit. It doesn’t do any good.

Fatemeh : I would rather the doctor did not tell me. . . . Why tell, the patient will get scared. . . . In my case, I don’t want to know. . . . Please don’t tell me. . . . I get scared . . . that’s my nature. I am telling you right now . . . I don’t want to know . . . I don’t want to be told.

Bitia : You should not be told at all. Life is short, why live with worry and panic. Every day worry. . . . Oh am I going to die today or tomorrow? . . . So yes, you should not be told at all. What good is it to tell? What is going to happen if they tell you? No miracle will happen.

Fear of bad news was an important factor influencing the participants’ decisions to seek or not seek necessary health care services.

Interviewer : Why do you like your current doctor so much?

Fatemeh : Because every time I go to her, she tells me I am doing well, and not to worry, that everything looks good.

Interviewer : And you think that makes her good?

Fatemeh : It does, because she doesn’t scare me and that’s why I am not afraid of going back to her. If you go to a doctor and every time he tells you, you are in a bad shape and you need to have a surgery or so on and so forth, the next time you are so afraid of what he is going to say that you rather not go at all. Sometimes it is just better not to know.

Many participants considered knowing about the illness as more harmful to their overall health (mind, body & spirit) than the actual illness.

Fatemeh : What am I going to do if, god forbid, I have cancer and I am going to die . . . God forbid. . . . I might as well keep my spirit so that I can enjoy whatever is left of this life. . . . I don’t think you can enjoy your life once you are faced with such information. . . . So you may as well be dead . . . ‘cause that’s no life.

Shahin : Once you have received certain information, you can never return your spirit, your body to the state that it

was before obtaining that information. There is an innocence that is gone . . . taken away and cannot be restored. Shouldn't people's right not to know be respected as much as their right to know?

The participants' desire to not know was demonstrated by their reluctance to seek preventive care and an equal reluctance to seek care when a serious illness was suspected. The desire not to know became evident in the participants' wariness towards preventive care such as breast, colon, or prostate cancer screening.

Shahin : In our culture, not knowing is the best. This is why we don't go see a doctor. For example, I know I have to go for a prostate check, but I don't want to go. I am afraid. I rather not know if there is something seriously wrong.

The reluctance towards preventive care was also documented by Lipson and Meleis (1983). They reported that Middle Easterners generally do not practice preventive care.

They believed that they were too old to worry about prevention.

Interviewer : Do you think that it is important to have your affairs in order if God forbid you were faced with a terminal illness?

Abbas : My dear, if you have already swept your floor, then you have swept your floor.

This suggests that older people have already come to know that their death is near and, therefore, have been working to put their affairs in order with or without the diagnosis of terminal illness.

### ***Treat Me Without Scaring Me to Death***

The participants' resistance to know about terminal illness led to the issue of treatment options; how could they receive proper treatment if they do not want to know the diagnosis? Would they rather not be treated? So the participants were asked about the importance of following certain treatment procedures when faced with terminal illnesses. It was further explored how the participants thought doctors could monitor whether patients were following the necessary treatment regimen if

the patients were not told the true diagnosis. Following are a few of the responses:

Interviewer : What if the illness would require a certain treatment?

Fatemeh : They should tell you what you need to do . . . and tell you in a normal way . . . not in a bad way. I mean not to scare you. If they scare you . . . being scared is the worst thing for your health. . . . Like they say, "Fear is the brother of death." When you are scared . . . you lose sleep day and night, you worry and can't sleep. . . . This fear itself will make you even sicker.

Zohreh : It is not at all right to tell . . . tell what? Tell that your time is up. The percentages of those who have been told and died are higher than those who were not told.

Interviewer : So why even go to a doctor?

Zohreh : No, it is better if he tells you what you need to do or have done but not to say that you are not going to make it and there is no cure for you . . . that breaks your spirit. . . . Poor patient . . . you should never say there is no cure. . . . They must instead try to condition the person's spirit and give them strength of heart.

I asked the participants how they would prefer to have the diagnosis of terminal illness disclosed to them, should it have to be done?

Shahin : If they have to tell you, then tell you, but tell you nicely, spend time with you, give you lots of *quvvat-i qalb*. Warm your heart.

Ahmad : They shouldn't tell you. Not to tell you at all.

Interviewer : Would you rather not know at all?

Ahmad : The doctor should know his patient's state of mind. . . . He should know what he or she is capable of taking or not taking.

The above quotes illustrate that the participants do want to be treated, but they do not want their doctor to "scare" them. Instead they want their doctor to be gentle and considerate when recommending treatment and to do so without giving them a bleak diagnosis.

### Tell my Family

Nearly all participants preferred to have the news about terminal illness disclosed to their family members. One participant explained, "My family knows what is best for me, they know what to tell me or not to tell me. They know how much I can handle." Following are a few examples that illustrate the study participants' desire to have family members be the recipients of important information on their health, thus leaving it up to family members to make the judgment about what or how information should be conveyed to the patient.

Interviewer : How do you think bad news should be delivered?

Mahin : It is best to tell your family first. The doctor must know his patient. He should know if this person has the ability to take the news or not.

Interviewer : How do you think he should have told you about your cancer?

Sara : He should have given it some time ... for example, after a couple of visits, after he had prepared me; for example, he should tell your daughter, your husband.. .. I mean he should prepare you, ... not right there after the examination, ... because from there on you have no hope, ... from there on they are just talking about surgery, opening you up and doing this and that to you. . . . All these things affect [*sic*] you. . . . He should have told my daughter. . . . In Iran, they would have never told you right there.

### Strength of the Heart (*Quvvat-i qalb*)

The term *quvvat-i qalb* covers a combination of concepts such as hope, assurance, and optimism. The participants placed great importance on the ability to instill hope and optimism in others and regarded this as a vital role to be played by their family and health-care providers. The Iranian immigrants perceived giving hope and optimism or what they call *quvvat-i qalb* (strength of heart) as one of the primary roles of a doctor. This is illustrated in the following example:

Interviewer : How do you think terminal illness should be disclosed to patients?

Reza : If they absolutely have to tell the patient, then they should also give him *quvvat-i qalb*, reassure him. . . . Don't worry, it is not too bad, you will be treated. . . . You will be fine. . . . I will take care of you.

Bitra : If it has to be told, then it should be done with much time, care, and *quvvat-i qalb*.

The participants feared that diagnosis of terminal illness can devastate and shatter their spirit; in fact, they look to their doctor to care for their *ruh* during difficult times. The participants explained that doctors should take their time and prepare the patient, telling the news gradually while providing lots of *quvvat-i qalb*.

Roya : They need to take time and give you *quvvat-i qalb*. They should not just suddenly tell you, that shatters a person.

### Discussion and Implications

This study showed that the older Iranian immigrants viewed the delivery of "bad news" in the U.S. as cold and matter of fact. They felt that American doctors ignored their *ruhi* (emotional/mental/spiritual) health and neglected to offer them hope (*quvvat-i qalb*) when communicating "bad news". The participants view optimism and pessimism as socially driven. To them, optimism and pessimism are not only internal but are also derived from those around them. In the face of illness or trauma, they look to those around them, particularly those they hold at high esteem such as doctors or family elders to give them hope, reassurance, and optimism (*quvvat-i qalb*). Giving hope to a patient is a form of caring that is embedded in a cultural context (Good *et al.*, 1990). The Iranian immigrants who participated in this study seemed to actively seek assurances and optimism from those around them and by the same token avoid those who took their hope and optimism away.

The Iranian immigrants are not alone in their preference to have "bad news" delivered to their family. This desire for disclosure to family members was also found among Ethiopian refugees. Beyene

(1992) reported that in Ethiopia medical information is disclosed to the patients' family. "The family then uses the information at its discretion for the benefit of the patient". This preference points to a possible difference in cultural values between traditional societies versus modern Western societies. Beyene (1992) explained, "In traditional societies like Ethiopia, where the family's importance dominates over individual members', any information, including diagnostic facts, belongs to the family".

### Implications

The findings of this study have implications for health and mental health professionals who care for older Iranian immigrants and other culturally/ethnically diverse populations. Many participants believed that being informed about a terminal illness can severely damage their spirit and take away their appetite for life. Therefore, they expressed a preference not to know about terminal illness. The participants' choice to protect their spirit may come at the cost of what biomedicine may consider the standard of care. However, in these participants' minds, protecting their *ruhi* health translated into protecting their overall health.

In accordance to Health Insurance Portability and Accountability Act (HIPAA) privacy rule, in the United States medical information is disclosed directly to the patient and no other unauthorized individual. In the American health-care system emphasis is placed on knowing exactly what is wrong with the patient and transmitting this knowledge to the patient so that he or she can make informed decisions. The older Iranian immigrants who participated in this study reported a desire not to have information about terminal illness disclosed to them directly but instead to their family. The participants believed that being informed about a terminal illness can severely damage a person's spirit, which can consequently interfere with the body's healing.

The participants' desire to not know was demonstrated by their reluctance to seek preventive care as well as an equal reluctance to seek care when a serious illness may be suspected. For example, this study revealed that the participants' fear of bad news may cause them to avoid seeking preventive care and screening for such things as breast, prostate, or colon cancer; an important consideration in caring for older Iranian immigrants.

Many participants reported that if they have to receive bad news, the doctor should prepare them by giving them *quvvat-i qalb* so that they can fight better against the illness. This means that they would like the providers to give them hope, even in the face of terminal illness, and keep them optimistic about the treatments and the future. By providing *quvvat-i qalb*, health-care providers can minimize the patients' anxiety and increase their level of compliance -and overall sense of wellbeing. Stewart-Patterson (2004) noted:

Patients often note that they experience compassion inconsistently in the corporate-like environment of medical offices and hospitals. This is not surprising, given the current economic pressures on medical care and the minimal emphasis on compassion skills in medical school. (n.p.)

The need for receiving hope and assurance from doctors was also identified by Beyene (1992) in the study of Ethiopian refugees. "Ethiopian patients rely on their physicians to cure their illnesses and help them manage their pain. Most of all, they want to be reassured that they will get well". Care providers need to remember diagnosis of terminal illness should be handled with much care and consideration and in a culturally sensitive manner.

North America is increasingly becoming a mosaic of many cultures, reflecting a mixture of ideologies, beliefs, and health care practices (Purnell & Paulanka, 1998). It is important to provide health care that reflects the unique understanding of the values of diverse populations. It is hoped that the findings of this research will serve to alert health and social service professionals to the cultural differences that influence health behaviors of ethnically/culturally diverse populations. Applying the research questions of this study to other culturally/ethnically diverse populations may help in establishing broader concepts, commonalities, and intervention models that will help improve the overall health and well-being of diverse populations.

### Limitations of Study

A potential limitation of this study relates to the researcher's status as an Iranian American. While her perspective as an insider could be viewed as an asset for this study, her identity as an Iranian immigrant may have influenced her perceptions. The researcher used the techniques of bracketing, peer review, and member checking to address

these concerns. Another limitation of this study is the fact that the original data have been translated for this manuscript. In many ways the process of translation enriched and informed the analysis of this study. However, it is inevitable that some meaning has also been lost in translation. A bilingual peer reviewer was helpful in resolving some of the linguistic dilemmas.

Since, these findings were part of a larger exploration of health related attitudes of older Iranian immigrants in the United States, having been diagnosed with a terminal illness was not an inclusion criterion. Although, this may appear as a weakness, the focus of the study was to explore attitudes about terminal illness and their influence on care seeking and/or compliance with medical procedures. This is an important question regardless of having been diagnosed with terminal illness or not. Since the fear of receiving “bad news” can be great enough to keep some patients from going to doctors when they need it and hence suffer the consequences of treatable illnesses. For example a patient with high blood pressure, may avoid going to a doctor, due to fear of receiving “bad news”, and hence suffer from a heart attack caused by untreated blood pressure. It is equally important to ask these interview questions of those who have and those who have not been diagnosed with terminal illness. In a future study, the researcher plans to study these two groups separately and comparatively.

The findings of this study are based only on interviews with 15 Iranian immigrants and hence not representative of all older Iranian immigrants. The researcher acknowledges that there are many differences between and within cultural groups. The objective of this study was not to make generalizations from the findings, but only to add a new dimension to the study of culture and health/mental health from a population that is rarely studied.

### Conclusion

This paper addresses the question of how culture informs the disclosure of medical information, specifically about terminal illness to older adults. As the older population grows larger and more diverse, it is important to learn how to communicate with older adults from different cultures about serious and life-limiting conditions in culturally sensitive and appropriate fashion. The findings of this study showed that there

are cultural differences in the way older Iranian immigrant prefer news of terminal illness to be delivered to them. The study participants objected to the cold and blunt way of delivering bad news directly to the patient and prefer news of terminal illness to be delivered to the patient’s family. They also emphasized the importance of providing hope and optimism (*quvvat-i qalb*) when delivering bad news. Given the growing numbers of older Iranian immigrants who utilize health care services in the United States, the need to understand their culturally specific attitudes about medical disclosure is important. Particularly as fear of receiving bad news can discourage some older Iranian immigrants from seeking care even when the illness is treatable. Understanding cultural beliefs and attitudes can help better equip health and social service providers to intervene on behalf of older Iranian immigrants and provide them with culturally appropriate health care.

### Dedication

I would like to dedicate this article to my beloved mother Khadijeh Lashgari-Iravani Sahami. My mother, who was an older Iranian Immigrant and did not speak English, lost her short battle to pancreatic cancer on Dec. 6, 2009. As one of her primary care-givers, I was faced with the burden of having to translate the news of her cancer diagnosis to her. I had suddenly found myself smack in the middle of my research study. My family insisted on keeping the news from her, to shield her spirit. .... I on the other hand was torn between my Iranian cultural beliefs and my Western sensibility. Suddenly the question that I had wrestled with for years became about something much more important than academic curiosity, it became about honouring my mother’s wishes in her final days; is she like the many of my participants who simply did not want to know, or is she different? I didn’t know, but I knew I had to get it right! I decided to strike a delicate balance; if my mother asked me directly what her diagnosis is, I would tell her, otherwise I would not. My mother had guided me through all the tough decisions in my life. I was desperate for her to help me through this one, and she did..... She never asked!

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## **Ageing and Cancer : A Global Concern for Social Work**

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### **ABSTRACT**

*Age is a known risk factor for cancer, which is the second leading cause of death globally. As the world's population ages, countries will experience significant increases in cancer incidence and mortality. Advances in early detection and treatment result in better outcomes and contribute to increasing cancer survival. Older people are increasingly living with cancer as a chronic and often co-morbid condition. This paper reviews world cancer trends, established approaches to cancer control, and provides exemplars of low cost cancer screening approaches that offer cost saving opportunities. We demonstrate the role of social work in framing cancer control efforts in appropriate psychosocial contexts. Global efforts to reduce cancer morbidity and mortality must have cultural and linguistic relevance to the target populations. Social workers, as members of provider teams, are ideally suited to translate advances in cancer control into local and regional populations.*

**Keywords:** Ageing, Cancer, Psychosocial, Global, Social work

Annual cancer estimates by the World Health Organization (2009) indicate that in 2008, approximately 7.6 million people died with some form of cancer, which accounts for 13 per cent of the world's deaths during that year. Cancer is the second leading cause of death worldwide, following heart disease (World Health Organization [WHO], 2009), and cancer incidence and mortality rates are expected to increase worldwide. In 2030, for example, projections indicate that there will be 26



million new cancer cases and 17 million cancer-related deaths (Thun *et al.*, 2010).

Incidence rates of new cancers are of particular importance given that advances in medical technology have led to improved early detection and treatment. Increasing proportions of new cases diagnosed and treated at early stages of the disease course result in survival. As a result cancer—once seen as a fatal acute illness—has taken the dimensions of chronic disease to be monitored, managed, and resourced. In 2002, it was estimated that there were 24.6 million cancer survivors worldwide (Mackay *et al.*, 2006). Cancer survivorship presents unique challenges on micro and macro levels as it focuses on the health and life of an individual beyond the diagnosis and treatment phases and encompasses physical, psychosocial and economic concerns for patients, families, communities, countries, and global regions (National Cancer Institute [NCI], 2010; WHO, 2005).

### Ageing and Cancer

The United States (US) increasingly recognizes cancer to be a disease of older adults (American Society of Clinical Oncology, 2010; Overcash, 2004). As the global population ages, cancer morbidity and mortality rates are expected to increase proportionally (Jemal *et al.*, 2011). Older people will continue to bear a disproportionate global cancer burden with approximately 50 per cent of all cancers occurring in individuals over the age of 65 (Yancik & Ries, 2004). Organizations such as the World Health Organization and its affiliates, the International Agency on Research for Cancer (IARC) and Globocan, are providing leadership in efforts to decrease morbidity and mortality and improve the quality of life for older cancer patients and survivors. Because increasing age is a risk factor for almost every type of cancer, more needs to be known about the nexus between ageing and cancer on global dimensions.

### Cancer

Cancer encompasses a large group of diseases recognized as the rapid creation of abnormal cells that invade any body part and spread

to other tissue or organs. Cancer typically progresses from pre-cancerous lesions to malignant tumors. There are three categories of external agents that interact between an individual's genetic factors causing the progression of disease. They are physical carcinogens, such as ultraviolet and ionizing radiation, chemical carcinogens, such as asbestos and arsenic, and biological carcinogens such as infections from certain viruses, bacteria or parasites (WHO, 2009). In addition, there are multiple dimensions of cancer: distal, regional, metastasis. Metastasis (when cancer cells spread and form new tumors in different parts of the body) is the major cause of death from cancer (Ibid).

Paradoxically, while cancer is the second leading cause of death in the world, early detection and advanced treatment offer hope for decreased morbidity and mortality in some of the world's most prevalent cancer types. Cancers of the lung, stomach, colon and rectum, liver and breast have the highest world-wide incidence rates. Among men, lung, stomach, liver, colorectal, oesophagus, and prostate cancers are the leading causes of cancer deaths, while women die most often from breast, lung, stomach, colorectal and cervical cancers (Ibid).

### Global Surveillance of Cancer

The World Bank (2010) classifies countries as low, medium or high resource. A country's level of resource classification is determined by calculating its gross national income (GNI) per capita. Low resource countries typically have a GNI of \$995 or lower per capita, medium from \$996 to \$12,195 per capita, and high of \$12,196 and above per capita. These are important classifications because resources may be related to the presence of medical technology needed for public health initiatives, early detection, and effective treatment of cancer. To aid in the surveillance of wellness and disease, the World Health Organization partitions the globe into six regions; Africa, the Americas, Eastern Mediterranean, Europe, Southeast Asia, and Western Pacific. Table 1 reports resource classification by WHO regions with select countries within each region identified as an exemplars.

**Table 1. Low, Medium and High Resource Countries by region (WHO, 2010a; The World Bank, 2010)**

Region	Africa	The Americas	Eastern Mediterranean	Europe	Southeast Asia	Western Pacific
Low Resource	Ethiopia Ghana Kenya Liberia Uganda	Mexico	Afghanistan Somalia	Benin Tajikistan	Bangladesh Myanmar Nepal	Cambodia Solomon Islands Togo Lao PDR
Middle Resource (Upper* and Lower)	Nigeria South Africa*	Brazil* Colombia* Honduras Nicaragua Uruguay*	Egypt Iran* Iraq Libya Pakistan Sudan	Armenia Lithuania* Romania* Serbia* Ukraine	India Sri Lanka Thailand	China Fiji* Malaysia* Mongolia Philippines
High Resource	N/A	Canada United States	Saudi Arabia	Belgium Croatia Israel Italy	Korea	Australia Japan Singapore

Note: \*Asterisk indicates upper resource within middle resource classification. Middle resource countries are designated as either upper or lower resource.

Increasing cancer incidence is expected to occur primarily in low and medium resourced countries that face a larger cancer burden than higher resourced countries (International Agency for Research on Cancer [IARC], 2008; Jemal *et al.*, 2011). Currently, the World Health Organization (2007a) reports that 50 per cent of all cancer cases and 70 per cent of all cancer deaths occurred in low and medium resource countries. In countries with higher resources, opportunities for early detection and improved treatment may decrease morbidity and increase survival rates. Increased survival, however, results in the added burden of ongoing healthcare costs related to the maintenance of cancer as a chronic—and often comorbid—condition (Economic Intelligence Unit, 2009; Fernandez-Taylor & Bloom, 2010).

The WHO (2006) projections of number of deaths by type of cancer within regions are reported in Table 2. These projections evidence the need for regions and countries to prepare for increasing cancer incidence and survival. The Western Pacific region, which includes

the emerging economic superpower of China, has the highest number of projected new cancers in the next two decades. European, Southeast Asian (which includes India) and Western Pacific countries are projected to have the highest numbers of deaths due to certain cancers. Interestingly, the African region has some of the lowest projected rates of cancer death with the exception of cervical cancer.

**Table 2. Projected deaths (in thousands) by site (for all ages) in WHO Regions in 2030 (WHO, 2006)**

Cancer	World	Africa	The Americas	Eastern Mediterranean	Europe	South east Pacific	Western Pacific
Oesophagus cancer	766	43	50	34	49	*165	*425
Stomach cancer	1389	77	132	44	162	122	*853
Colorectal cancer	908	49	158	30	*242	126	*303
Liver cancer	975	101	60	30	70	111	*602
Lung cancers	2242	40	288	77	*363	*474	*1000
Breast cancer	714	81	120	61	*153	*184	116
Cervix uteri cancer	435	86	49	16	24	*197	63
Prostate cancer	465	90	*138	19	*120	60	38
Total projected deaths	7894	567	995	311	*1183	*1439	*3400

Note: Asterisk indicate the highest rates in each cancer type

### The Case of India

Building on WHO predictions, a recent report (IARC, 2008) predicted a threefold increase in the global cancer burden by 2030 with a disproportionate rise in cases from the developing world in countries such as India (Boyle & Levin, 2008). India has a total population of approximately 1.2 billion people, 17 per cent of the world's population. Projections indicated that there would be approximately 948,000 new cases of cancer in India for 2010. That means that India will bear the burden of approximately 7.5 per cent of the new cases of cancer in the entire world. In addition, approximately 633,000 deaths were projected for India in 2010, which would account for 8 per cent of the world's cancer mortality (IACR, 2008). Although India is currently experiencing large population growth due to 2.7 births per woman, India's fertility rate is expected to decline while cancer morbidity and mortality rates increase. India's older population is expected to quadruple by 2050, in

contrast to the tripling of the older population globally (US Census Bureau, 2009). India's population shift will very likely result in a proportional surge of cancer incidence.

### Cancer Control

World-wide cancer control efforts focus on a broad constellation of approaches; prevention, screening and early detection, and treatment. Prevention focuses on reducing the risks associated with cancer. Screening and early detection offers opportunities for diagnosis and treatment at an earlier cancer stage, which increases the likelihood of decreased morbidity and, in some cases, even cure. Treatment focuses on curing cancer, prolonging life and improving the quality of life after a cancer diagnosis. Increasingly, when aggressive treatment is not an option, palliation is the approach of choice. This is often the case with frail older adults with multiple chronic conditions. Managing cancer symptoms, keeping a patient as comfortable as possible in order to maintain an optimal quality of life, might be culturally more desirable than aggressive surgical intervention combined with debilitating radiation and chemotherapeutic interventions. Palliation focuses on relieving symptoms and providing psychosocial and supportive care for patients and their families (WHO, 2007c)

Given a hierarchy of societal needs, cancer control generally holds a lower priority than infectious disease programmes in developing countries (Boyle & Levin, 2008). Eighty percent of advanced stage cancers in developing countries may have been detected earlier (Ibid). Late stage diagnosis is partially due to low cancer awareness. Low and middle resource countries are likely to have the lowest health care budgets, poor treatment facilities, shortages of cancer health professionals, and lifestyles increasingly influenced by Western practices such as cigarette smoking and unhealthy diets that increase cancer risk (Aranda, 2009). In addition, only five percent of global cancer resources are currently spent in developing countries, which account for 80 per cent of disability-adjusted life years lost to cancer (The Lancet, 2010). The disproportionate cancer burden in under-resourced countries is related to the lower likelihood of advanced population-based cancer screening programmes needed for early diagnosis (Sankaranarayanan & Boffetta, 2010; WHO, 2010b).

### Opportunities for prevention

The World Health Organization (2009) estimates that 40 per cent of all cancers are preventable by controlling exposure to risk factors. In low and middle resource countries, such as Brazil, India and Mexico, tobacco use, alcohol abuse, low fruit and vegetable intake, hepatitis B (HBV), and hepatitis C (HCV)—the leading risk factors for lung, liver, colorectal and esophageal cancers respectively—are prevalent (ACS, 2010a; Danaei *et al.*, 2005; World Cancer Research Fund & American Institute for Cancer Research, 2007; WHO, 2009). Human papilloma virus (HPV) is a leading cause of cervical cancer death among women in low-resource countries. In high resource countries, such as the United States and those in the European Union, tobacco use, alcohol abuse and obesity are the major risk factors for cancers such as prostate and breast (WHO, 2009). By identifying risk, countries can develop health promotion initiatives that educate populations and decrease exposure to known cancer risks.

Tobacco use is the single most preventable cause of death and accounts for an estimated 4.2 million deaths, 60 per cent of all cancer mortality. More than 80 per cent of the world's one billion smokers live in low and middle resource countries (Hale *et al.*, 2008; WHO, 2010c). Estimates indicate that in India, more than 60 per cent of all patients with lung cancer are smokers. The need for smoking cessation initiatives is evident. Studies consistently demonstrate the relationship between alcohol use and cancers of the colon/rectum, liver and breast. It is estimated that 20 per cent of all alcohol-related deaths are due to cancer (Baan *et al.*, 2007). Alcohol related deaths occur primarily in low and middle resource countries (Danaei, 2005; WHO, 2007a), which presents an opportunity for improved outcomes since behavioural interventions need not be costly.

Improved dietary and exercise practices are also related to behaviour. According to the most recent WHO (2003) data available, dietary factors are estimated to account for 30 per cent of cancers in industrialized countries and 20 per cent in developing countries. Obesity, high body mass index, physical inactivity, and lack of fruit and vegetable intake contribute to 274,000 cancer deaths globally each year (WHO, 2007a). Obesity and physical inactivity are estimated to account for

159,000 deaths from colorectal cancer and 88,000 deaths from breast cancer (WHO, 2007a). As more low and middle resource countries adopt Western lifestyles, diet and exercise become increasingly relevant (Sarrafzadegan *et al.*, 2008; WHO, 2003).

Chronic hepatitis B infection causes approximately 340,000 liver cancer deaths world-wide each year (WHO, 2007b). Ninety-two per cent of all hepatitis virus cases occur in low and middle resource countries. While the incidence rate of liver cancer is decreasing worldwide, this decline has been slower in low and middle resource countries (Thun *et al.*, 2010). Similarly, approximately 80 per cent of global cervical cancer deaths occurred in low resource countries. Almost every death from cervical cancer (99%) is caused by genital human papillomavirus (HPV). Global deaths from cervical cancer are projected to rise from 320,000 in 2015 to 435,000 in 2030 (WHO, 2007b). While rates are expected to rise worldwide, cervical cancer rates have decreased in industrialized nations primarily due to the pap tests (also known as pap smears or cervical cytology). Developing countries that cannot afford population control pap tests continue to experience high incidence and mortality cervical cancer rates. The inability to offer the test contributes to the large burden of cervical cancer among developing countries (Thun *et al.*, 2010).

One example of a possible health promotion action that developing countries might take is minimizing exposure to asbestos and tobacco, which is empirically associated with lung cancer (WHO, 2010b). Tobacco smoking and asbestos exposure, well established causes of lung cancer, have a particularly potent effect in causing lung cancer when they occur together (Selikoff *et al.*, 1968; Vainio & Boffetta, 1994). Southeast Asia is the region where the highest lung cancer rates are projected to occur. Current estimates suggest that approximately 8,000 cancer deaths in India are related to asbestos exposure. Public education campaigns to create awareness about such risks are ongoing (WHO, 2007b). This is particularly important for the developing world where asbestos and tobacco products are heavily marketed, as industrialized countries are increasing restrictions on such products. Public education about risk factors and low-cost interventions are major goals of global cancer prevention efforts. Health care providers, which include social workers, play key roles with community

leaders to provide information as well as specific interventions (WHO, 2007a).

### Screening and Early Detection

The goal of early detection and screening is to locate cancer cells while they remain in the tissue or organ of origin before it spreads to the surrounding tissues and other organs. Approximately one-third of all cancers can be diagnosed through early detection, and early detection may lead to cure (WHO, 2007c). Exemplars include breast, cervix, colon, rectum, and prostate cancers. When detected early, these cancers have the most favourable treatment outcomes (ACS, 2010b).

The World Health Organization (2007c) identifies two strategies for early detection. The first includes patient contribution; learning to recognize symptoms, and then to communicate them to a provider. The health provider then refers the patient for screening, diagnosis, and treatment as necessary. The second approach is national or regional screening initiatives to test an identified (asymptomatic) population for pre-cancerous lesions. Those with positive screening findings for possible cancers are referred for diagnosis and treatment as needed. In each approach, both the public and health professionals must be educated about the signs and symptoms of cancers, especially those that can be detected early. Screening programmes that are cost effective should be considered by low and middle resource countries. Teaching women to perform clinical breast exams (CBEs) may be an effective way of reducing costs associated with breast cancer control. For example, early detection of breast cancer in India utilizing a CBE model resulted in a cost-effectiveness ratio (CER) of \$793 in international dollars per life year gained. The CER increased to \$1135 per life year gained for every five years during which a CBE was performed and to \$1341 for biennial CBEs (Okonkwo *et al.*, 2008). Another cost-effective intervention is brief screenings for alcohol abuse, since alcohol is a recognized risk factor for colorectal, liver and breast cancers (Baan *et al.*, 2007).

Population control programmes are needed to educate people about the etiology, risks, detection and treatment of cancer. If cancer is perceived to be an untreatable, debilitating or fatal disease, patients may choose not to follow-up with further testing. Ethical and social

justice issues underscore the importance of including entire populations in early detection, diagnosis and treatment initiatives—regardless of ethnicity, race, social class or region. It is especially important to include populations who tend to have worse cancer outcomes in education and screening initiatives, namely those who are vulnerable and marginalized.

### **Treatment**

Once a positive diagnosis has been confirmed, the goal of cancer treatment is to cure the disease or prolong life while maintaining and improve quality of life. Medical treatment of cancer may include combinations of surgery, radiotherapy, chemotherapy and hormone therapy. Effective diagnosis and treatment requires a multidisciplinary approach, including physicians, nurses, psychosocial (such as social work) and rehabilitation staff working together (WHO, 2008). Low and middle income countries can adopt approaches that are cost-effective and clinically sound. The Clinical Breast Exam promotes screening and early detection of breast cancer and is an exemplar among low cost health promotion efforts. Social work's contributions to multidisciplinary efforts are particularly important when treatment results in meeting the psychosocial and rehabilitative needs of patients and their families. According to WHO (2002, 2008) psychosocial care consists of providing patients and their families with emotional support and information, communicating with patients and families in a person-centered manner, and referring patients and families to support groups and other supportive psychosocial experts. Psychosocial support is especially important because of the fear and stigmatization that cancer represents in many countries. Patients who receive appropriate psychosocial care during the period of diagnosis and treatment tend to experience less anxiety and depression, and are more likely to adhere to cancer therapy (Jacobsen & Jim, 2008; US Institute of Medicine [IOM], 2008).

**Palliative Care** as a series of approaches that improves the quality of life of patients and their psychosocial support is especially important when palliative care is initiated. The WHO (2007d) estimates that millions of cancer patients are in need of palliative care. This is due to the large number of patients who present with advanced stages of cancer, particularly in low and middle resource countries. Estimates

indicate that over 80 per cent of advanced cancer patients benefit from relatively simple and low-cost palliative interventions that can be integrated into primary care and in-home health services. By contrast, less than 20 per cent of advanced cancer patients will require costly specialized palliative care services (WHO, 2007d). Ethical issues important to consider during palliation include recognizing perspectives and attitudes about health, illness, and cancer screening, diagnosis and treatment in differing cultural contexts. Cultural variation can be seen in attitudes and beliefs about quality of life versus length of life, pain relief and end of life, and informed consent decision-making about treatment.

### **Special Needs of Older Cancer Patients**

Individualized assessments of an older individual's physical and cognitive functioning includes evaluation of functional status known as activities of daily living (ADLs) and instrumental activities of daily living (IADLs), comorbid conditions and cognitive functioning (Extermann & Hurria, 2007; Rodin & Mohide, 2007). Older adults with cancer often require assistance with ADLs and IADLs (Extermann & Hurria, 2007; Patel *et al.*, 2006), as they are more likely to have some form of physical disability, which may contribute to their ability to function (Griffith *et al.*, 2010). When ADLs and IADL's are considered in combination with comorbid conditions, such as diabetes, arthritis and respiratory problems, and cognitive losses (including hearing and vision), clinicians are better able to effectively plan with patients and minimize treatment complications (Blank & Bellizzi, 2008; Cohen, 2007; Given & Given, 2007; Pal *et al.*, 2010).

Pain must be adequately assessed with older cancer patients. Pain assessment is a critical component of cancer care and addressing quality of life for patients. Older individuals may not report pain for fear it will deter the physician from treating the cancer or for fear that the cancer is getting worse (Hart-Johnson & Green, 2010). Older patients with cognitive impairments may be unable to convey their needs and physical condition to health care providers. The inability to assess and/or convey one's own physical condition may have a direct outcome on diagnosis, treatment and maintenance (Badura & Grohmann, 2002; Hart-Johnson & Green, 2010; Montague & Green, 2009). In addition to behavioural

observations, clinicians should use pain assessment tools for people with cognitive impairments (Balducci, 2003).

### **The Role of Social Work**

According to WHO (2007d), social workers provide instrumental service in cancer control efforts, and are a necessary part of multidisciplinary teams to ensure optimal cancer control outcomes. The International Social Work in Development (ISWD) (2006) posits the centrality of social work in successful international public health efforts such as cancer control. Core social work skills of assessment, planning, community organizing, resource mobilization, care management and monitoring, and outcome evaluation are essential elements needed to maximize world-wide cancer control initiatives. In addition, these core social work skills are essential elements of efforts to help patients and families across the cancer control continuum.

Clinical social workers are uniquely positioned to provide older cancer patients, survivors and their families with comprehensive clinical case management services based on assessments that incorporate their medical and psychosocial conditions during initial diagnosis, treatment, and discharge into the community—all within the cultural context. Social workers are ideally suited to facilitate communication between patients, families and interdisciplinary teams. As members of interdisciplinary teams, social workers can help older cancer patients navigate the medical terrain and understand the enormous quantity of biomedical and psychosocial information about cancer. Communication between patient, family and various oncology professionals is essential for efficacious cancer care. The Institute of Medicine (IOM) report on cancer care (2008) states that the entire medical team should work to enhance communication with the patient and family. Patient-provider communication—meaning team members' listening and speaking with patients—is a critical element of diagnosis, treatment and discharge. Social workers are trained to listen closely and broker each individual patient's communication with medical oncologists, to help families understand the disease and treatment options, and to explore emotional and social issues related to the specific cancer in the patients' psychosocial circumstances. In sum, a skilled social worker will help patients adhere to the treatment plan by negotiating the medical and

psychosocial aspects of each case in the context of its disease specific dimensions (Berkman, 1996).

### **Social Work's Cultural Considerations**

International social work approaches to cancer must include individuals' cultural values regarding health and illness. Anthropologists suggest that culture is an integrated pattern of human behaviour that includes thoughts, communications, actions, customs, beliefs and values, and is referred to as the totality of ways (Geertz, 1973; Wilson & Dorne, 2005). Attitudes and beliefs about health and illness vary, within and among cultures, as they are passed from generation to generation. Members of specific cultural groups may respond differently to specific situations (Schweder, 1991). More specifically, beliefs about health and illness are grounded in values. These beliefs are a particular way of conduct that is personally or socially preferable and are the criteria that individuals use to guide their behaviour (Rokeach, 1973). Most people are not able to articulate their cultural values, and are even unaware of them (Hall, 1976; Hofstede, 2001). It would, therefore be difficult to ask a patient if their cultural values prevent them from participating in cancer screening. It would, however, be possible for a skilled social work clinician to assess beliefs about cancer screening, diagnosis and treatment. The importance of cultural and linguistic relevance in health communications between clinicians and patients is supported by the US-based IOM (2002). A culturally grounded psychosocial assessment can help both treatment teams and families anticipate and prepare for all aspects of cancer screening, diagnosis, treatment, and when needed, palliation. Clinicians such as social workers who are prepared to incorporate the psychosocial and cultural considerations into treatment approaches will enhance treatment compliance and decrease cancer mortality (Wedding *et al.*, 2007).

### **Summary**

Projections indicate that increasing numbers of older adults will be diagnosed with cancer. While technological advances in high resource countries, like the United States, will result in increased cancer survivorship as well as quality of life among survivors, older adults in low and medium resource countries may have higher degrees of morbidity and mortality due to late stage diagnosis, less access to

treatment, and fewer treatment options. Regardless of diagnostic and treatment resources, social work clinicians are well versed in the medical aspects of the disease and its treatment options. Older adults typically need assistance in communicating with providers and families during the cancer disease trajectory. Social work clinicians are ideally suited to incorporate issues of older adults' cultural and social environments into the provision of healthcare so that providers do not minimize older adult's emotions, behaviours and social relationships—as underscored by the IOM (2008) report on cancer care. Clinicians can increase positive outcomes and decrease morbidity and mortality by addressing both the biomedical and psychosocial aspects of cancer diagnosis and treatment. Medical and oncology social workers are trained to fill the disciplinary divides along the biopsychosocial cancer continuum. Social workers' communication among patients, families and providers is especially important for older cancer patients. Older patients require special consideration to help them understand the disease and its treatment, to minimize barriers that block treatment and maintenance, and to monitor not only the disease but also patients' physical and cognitive functioning during survivorship. Social work's interdisciplinary training, commitment to social justice, and its ability to work in linguistically and culturally relevant contexts, make it an integral discipline in cancer control efforts aimed at translating advances into local and regional populations.

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**(Footnotes)**

- <sup>1</sup> Pacific Americans include immigrants born outside of the U.S. and those born in the U.S. to immigrant parents/grandparents.
- <sup>2</sup> Pacific and Oceania are used interchangeably to include Polynesians, Micronesians and Melanesians.

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