NORTH AMERICAN ELDER AND DISABLED DOMICILIARY CARE IN REGARD TO THE FRENCH SYSTEM

Interactionist Perspective

Dr. Georges GOMA-GAKISSA,
Scholar and Lecturer
Department of Sociology and Social Services

Dr. Dianne Rush Woods

Associate Professor

Department of Social Work

Dr. Benjamin P. Bowser
Professor

Department of Sociology and social Services

California State University East Bay Hayward, California 94542

Consultant

Andrew Scharlach

Eugene and Rose Kleiner Professor of Aging

University of California Berkeley

Berkeley, California

SUMMARY IN FRENCH AND ENGLISH

L'ambition globale de ce projet de recherche est de comprendre l'économie politique du handicap et du vieillissement de la population dans ses applications au maintien à domicile des sujets âgés et handicapés en Amérique du Nord entendue Californie (Baie de San Francisco) et Colombie Britannique (Vancouver). Plus concrètement, les six principaux objectifs suivants constitueront la matrice et la trame de l'étude. (1) Sur le plan personnel et interpersonnel du sujet vieillissant et/ou handicapé, il s'agira d'explorer et de comprendre comment il construit son monde social à travers l'entrelacs des processus de sa prise en charge sociale dans son milieu de vie naturel. (2) Au niveau interactionnel, l'étude se propose d'observer, d'évaluer et de comprendre les interactions complexes, nombreuses et variées entre les sujets handicapes (sens large) et ceux qui pourvoient à leur prise en charge aux trois niveaux micro, mezzo et macro de l'action sociale. (3) Au niveau socio-économique, il s'agira d'examiner, d'évaluer et de comprendre l'impact financier, fiscal et même professionnel de l'intervention sociale sur la vie quotidienne des sujets âgés et handicapés à domicile. (4) Sur le plan politique, mieux au niveau des politiques sociales, l'étude questionnera et évaluera les processus de prise de décision concernant la reforme et/ou la mise en place des programmes sociaux adaptés à la situation des personnes handicapées par l'âge et le corps. (5) A la triple dimension scientifique, académique et médiatique en Amérique, l'étude se propose de déterminer, d'évaluer et de mieux comprendre l'idée de la construction médicale du sujet âgé et/ou handicapé par le truchement des processus de biomedicalization et par l'usage des technologies nouvelles à l'actif du maintien à domicile. Il s'agira aussi, dans cette rubrique, de voir comment la recherche scientifique, l'industrie technologique, l'entreprise, la firme pharmaceutique et l'entreprise médiatique s'activent pour un bon vieillissement et une meilleure prise en charge du handicap en Amérique du Nord. (6) Enfin, cette recherche se voudra critique en elle-même en terme de réflexivité et tout aussi critique sur tous les acteurs significatifs du processus de prise en charge à tous les niveaux que l'étude sollicitera.

L'accent mis sur le sens que donnent les acteurs de leurs pratiques (évaluer et comprendre) explique le choix méthodologique d'une induction amplifiante – à la Bacon – articulée à une théorisation fondée sur les faits réels (Grounded theory). Dans la même logique d'idée, nous choisirons le principe de *the hypothesis-generative* à la traditionnelle *hypothesis-testing* pour être non seulement en cohérence avec nos choix conceptuels mais aussi affirmer notre ambition théorisant. Non pas aussi que l'inférence causale soit impertinente de notre point de vue sur le sujet abordé mais plutôt qu'elle s'érige en seconde phase de cette entreprise.

Overall, research planning consists in two main phases over two years: (1) First 12 months will be devoted to data collection (refining the research design, completing the measurement tools, field interviews and consultation in Paris, all completed by Fall 2010); (2) Second 12 months will be devoted to data analysis and dissemination for findings (data analysis, findings reporting, second consultation in Paris and data dissemination by Fall 2011).

LITERATURE REVIEW

DÉMOGRAPHIE.

α Tout comme le déclin de la croissance naturelle, le vieillissement de la population canadienne est inéluctable puisqu'en bonne partie déjà inscrit dans la structure par âge de la population actuelle. Le vieillissement démographique, déjà amorcé, s'accélérera dès 2011 avec l'arrivée des premières générations nombreuses de baby-boomers à l'âge de 65 ans. Ce vieillissement rapide devrait perdurer jusqu'en 2031, moment où la proportion de personnes âgées devrait varier entre 23% et 25% de la population totale. Cette proportion continuerait d'augmenter par la suite, mais à un rythme plus modéré, et varierait entre 25 % et 30 % en 2056. Bien que plus jeune en 2005 que celles de la plupart des autres pays du G8, la population canadienne est appelée à vieillir plus rapidement dans les années à venir, une conséquence directe du baby-boom marqué que le pays a connu aux lendemains de la Seconde Guerre mondiale » (Bélanger, Martel, & Caron Malenfant, 2005).

Almost all western societies are becoming gerontic and the above quote portraying the situation in Canada applies in France and the United States (U.S.). This means that all these countries are about to face the same event, but they will address them differently because of their cultural and political differences and differing approaches to aging. In Europe, including France, countries have adopted very different policy options for training, employment and the social protection of their populations. Anne-Marie Guillemard has highlighted the fact that policy options from one country to another have created specific and antagonistic "age cultures" (Guillemard, 2003). In the U.S., the concept of wellness is predicated on the belief that there are identifiable lifestyle factors that can prevent, or at least delay, the onset of serious illness or disability in the coming wave of baby boomers. Occupational therapy (Lewis, 2003) is beginning to add wellness programming as another modality to the practitioner's bag of interventions to reduce the negative outcomes of growing older.

From the perspective of change in the U.S., the "University of Southern California Well Elderly" program is a prime example of occupational therapy engaging in the community with a wellness emphasis. In 1997, Dr. Florence Clark discussed some of the outcomes of the USC Well Elderly study. She asserted that preventive occupational therapy could have a major impact on the outlook and well-being of the elderly by improving their mental and physical health, slowing declines in bodily pain, decreasing emotion-based limitations and increasing vitality (Mandel, D.R. et al., 1999). Findings of the USC Well Elderly study demonstrated that occupational therapy is an effective way to promote health and to increase the quality of life of America's rapidly growing older adults. In Shephard's work one can find the latest theories on how aging and exercise strongly affect medical conditions (1997). Wellness has become an important priority for United States' government policy on health care for elderly and disabled people.

HEALTH CARE ISSUE

If occupational therapy mostly emphasizes adopting an optimal lifestyle at advanced ages, biomedicalization of elder care is another dramatic feature that has rapidly evolved in the last two decades. This powerful and controversial concept is defined in several ways depending on one's level of analysis and the discipline or field from which one comes. Certain scholars have addressed the issue with a more general focus, placing attention on the larger social trends affecting health care and health care service delivery (Clarke, et al., 2003). Clarke and associates' definition of biomedicalization is very broad in scope and describes this process from the standpoint of recent shifts in American medicine.

Other scientists have focused more specifically on biomedicalization within the aging field (Estes & Binney, 1989) which has brought to light ethical concerns and options unheard of just twenty years ago. Medical innovation and geriatric clinical intervention have impacted the understanding of the nature of late life and provided multiple options for health in advanced age, options in medical decision-making and alternative decisions for family responsible for elder members' care. Research into these various options has mapped a new form of biomedicalization in the U.S. (Kaufman, Shim, & Russ, 2004). An example is the biomedicalization of research in alcoholism. Where there use to be one form of treatment, there are now multiple forms of treatment, each reflecting a different medical emphasis and ideological approach to recovery (Madanik, 2006).

SOCIAL ISSUES AND ECONOMIC CONSIDERATIONS

A consistent research finding is that health care for the elderly varies by social economic status (SES), specifically education and income (House, J, et al., 1994). There is consistent evidence that among higher SES persons, the onset of health problems is usually postponed until late in the life, while health declines are prevalent in lower SES groups much earlier in middle age. The lack of past interest in geriatrics inspired a team of researchers to study the shortage of geriatric professionals (Kovner, Mezey, & Harrington, 2002). They found that medical students in Europe and the U.S. are more interested in general medicine or pediatrics than they are in geriatrics. They asked the following question, "twenty years from now, will health professions students look back on the early twenty-first century with wonder about how things have changed? As they study in departments of geriatrics, take

required courses in geriatrics, and learn to care for older adults, they may look back on 2002 with (wonder at their) arrogance—as well they should."

GERONTOLOGY COURSEWORK IN UNDERGRADUATE NURSING CURRICULA Concerns about the shortage of physicians in geriatrics go together with the necessity of gerontology coursework in undergraduate nursing curricula (Grocki & Fox, 2004). According to Juliet Grocki, gerontological nursing has received inadequate attention in undergraduate nursing programs in the United States. With the increase of the older adults, there is a need for nurses to be well educated in caring for elderly and disabled. In social work education there is the same concern about the lack of interest in gerontology and aging. A Council on Social Work Education Report found that only 3 percent of graduate social work students chose aging or gerontological social work, while 62 percent of members of the National Association of Social Work said that gerontology is essential in their work (Scharlach et al., 1997).

The bottom line is that in almost all western countries (gerontic societies) there is a growing need to train more students in medical and nursing schools and to educate social workers for an aging society (Scharlach, Damron-Rodriguez, Robinson, & Feldman, 2000). This is an important challenge and an unavoidable necessity. There is yet another angle and that is the less-studied issue of criminology and gerontology (Wahidin & Cain, 2006). Findings show that older people are more often victims of crime and, ironically, an increasing portion of prisoners, especially in the U.S. Criminology and gerontology, as well as sociology and social policy, help us to understand the complex relationship that old men and women have

with crime. There are authors who seeking to re-theorize both crime and aging to show how violence against the aged may be more common within family and care homes than we realize. This work is also using research on the aged as both victims and offenders to inform policy makers.

Missing is a comprehensive and comparable overview of aging, of U.S. public policy, and the impact of public policy on aging members of American Society. An essential question is: what old age policy do we need for the elderly and disabled at the onset of the 21st century?

RESEARCH PROJECT: AGING IN THE 21^{ST} CENTURY

The Maussian concept of "total social phenomenon" (Mauss, 2000) can apply to the visions we may have of home care, also known as domiciliary care, for the aged and disabled. The real effects of an aging baby boom generation are still unknown and need an in-depth exploration. The U.S. Social Security Act of 1935 and its Medicare variant, the Programme fédéral de sécurité de la vieillesse in Canada, and the Assurance vieillesse branch of the French welfare system all address elder care in their respective country and will severely test each provision. Although this project is rooted sociology (theoretical) and social work (practice), we will not ignore anthropology, philosophy, political science and medical science. This research project aims to study the meanings and complexities of home care for aging populations (Doyle & Timonen, 2007).

The focus will be on British Columbia (Vancouver, Canada) and the U.S. using California and the SF Bay Area as case studies. James Birren is quoted as saying that the study of

aging is "data rich and theory poor" (Birren & Bengston, 1998). So, this project will pay particular attention to developing a new theory of extreme old age and disability beyond the existing gerontological theories such as disengagement theory (Cumming & Henry, 1961); activity theory and successful theory (Abeles, Gift, & Ory, 1994); theory of life course (Bengtson & Allen, 1993); social constructionist theories (Estes, 1979; Gubrium & Holstein, 1999); age stratification (Riley, Johnson, & Foner, 1972), and the aging and society paradigm (Riley, Foner, and Riley, 1999). Our ambition to think of a new theory takes into account the challenge of extreme old age not yet faced in society.

OBJECTIVES

This research project aims to gain in-depth understanding of the public policies driving care of the elderly and disabled, how those policies are translated into action and what impact they actually have on their clients. The project aims are the following.

- 1. At the <u>personal and interpersonal dimension</u>, the project aims to explore and to understand how elder and disabled individuals construct their social world through the institutional process of care in their <u>natural social environment</u>. It is our view that the client is an important element within the overall process.
- 2. At the <u>interactional dimension</u>, the project aims to observe, to evaluate, and to better understand the numerous and various <u>interactions</u> between those who either age or are disabled and those who socially and/or professionally care for them at the <u>micro</u>, <u>mezzo</u>, and <u>macro levels</u>. It is our view that the nature and the scope of these multidimensional interactions command and influence the outcomes of the social intervention for the aged and disabled.

- 3. At the <u>socioeconomic dimension</u>, the project aims to examine, to evaluate and to understand the <u>financial</u>, <u>fiscal and professional impact</u> of the social intervention upon the lived experience of the aged and disabled in home care. It appears that aging comes at a high economic cost when the social response to it might stimulate the economy rather than be a burden.
- 4. At the <u>political dimension</u>, the project aims to learn and to evaluate the processes of <u>decision making</u>. There is an interaction between those who ask for and consume aid; those who organize and provide aid; and those who make decisions about the aid.
- 5. At the <u>scientific, academia and media dimensions</u>, the project aims to understanding the medical construction of the aged and disabled patients through <u>biomedicalization</u> and the use of technology in domiciliary care. It is our view that with the dramatic increase in life expectancy, mortality has shifted largely to the chronic conditions of disability and illness requiring a "negotiated order of chronic pathologies" (Bazanger, 1998). Carroll Estes tells us the "concentration of disease at advanced ages has coincided with the substantial increase in the social and technical power of the medical profession, setting the stage for the dominance of biomedicine and its way of viewing life over old age" (Estes, 2001). Thus, this project proposes to examine <u>how scientists</u>; entrepreneurs; pharmacists and the media interact to address the greatest challenge to elderly yet.
- 6. Finally, at the <u>critical level</u>, this project aims to draw attention to the: (1) ability of the researcher, the practitioner, and the policy-maker to <u>reflect upon her/his own</u> <u>practices</u>; and (2) to examine <u>structural inequalities</u> that shape the everyday

experience of growing older (Estes, 2003). It is our view that although the day-to-day thought or "common sense" of the process of growing older is what appears real, it must be established as a starting point of scientific inquiry, not an answer in itself.

HYPOTHESIS-GENERATING PERSPECTIVE

The emphasis of this project upon understanding the growing older phenomenon and disability through lived experience of those who are cared for and those who do the caring explains why we cannot rely on traditional hypothesis-testing research. Rather, this epistemological posture leads us to conduct hypothesis-generative research (Auerbach & Silverstein, 2003) using grounded theory (Strauss, 1990) rooted in two basic principles: (1) Questioning rather than measuring and (2) generating new hypotheses rather than confirming existing ones. Thus, our approach will be to develop hypotheses after the observations and interviews are completed in phase one and then seek the meanings of findings and infer causation in phase two. However, at this point, it will be important to be careful of the assumptions we make about domiciliary care and to clearly outline our methods.

PHASE ONE: QUALITATIVE METHODOLOGIES

This research proposal puts emphasis on the meanings of human life at very advanced ages. Emphasis will be upon social interactions and social processes that make sense of social interventions for the elderly and the disabled in their natural (social) environment. The methods to complete each aim will be conducted in the U.S. and Canada in exactly the same way and as followed:

- ✓ Aim one Personal and Interpersonal Dimension: the organizations that provide home care in the San Francisco East Bay and Vancouver will be listed. Ten will be randomly selected and the first two will be asked to participate in the study. If any refuse, we will go to the next on the list. For those agencies that agree to participate, we will randomly select ten home care clients by client number. Research team members will interview these clients about their care.
- ✓ Aim two Interactional Dimension: A licensed social worker team member will review their case records to construct an official picture of the services each client uses and the programs they participate in. Agency staff or family care givers will be interviewed as well about the issues they are challenged by and the effectiveness of the services they provide. Whenever possible these interviews will be conducted as focus groups.
- ✓ Aim three Socioeconomic Dimension: Given the diversity of home care services and facilities in the East Bay and Vancouver, the random selection should result in programs that service clients with different socioeconomic backgrounds. *Comparing observational and interview notes* between services should provide care evidence of their differences. In addition, *interviews of program directors* should provide additional perspectives.

- ✓ Aim four Political dimension: We will be able to outline the political dimension of home care practices and services by *interviewing U.S. county, state and federal and Canadian City, Provincial and National service program directors* as well as newspaper and television reporters responsible for health and welfare reporting.
- ✓ Aims five and six Scientific and Academic: We will seek to *interview* two additional groups of people. The first will be university-based academic experts who have studied government home care policy and effectiveness. The second will be experts in policy institutes who also study public policy regarding home care, but who also have responsibilities to influence government policies.

PHASE TWO: ANALYSIS

CASE-STUDY LOGIC & CONTENT ANALYSIS OF GOVERNMENT DOCUMENTS

Analytic level of the proposed framework will include four dimensions. (1) The first is to assess the societal impact of the current economic slowdown on policies for the elderly. We need to find out in what ways have services been impacted and how has the financial crisis affected the organizations and agencies responsible for elder care. (2) The second dimension is to see what changes, if any, are anticipated in future services. Both dimensions reflect upon anticipated revenue and political change as well as efforts improve services and cover additional clients in coming decades. Analysis at this level will also investigate questions regarding the state's role in social provisions for the aged and the disabled.

(3) Sex-gender based analysis is the third analytical dimension that this project intends to address. The project will try to clarify and better understand differences between males and females, their relationships, their different realities, life expectancies and economic circumstances. The framework that will provide this analysis will identify how these circumstances affect women's and men's health status and their access to and interaction with the health care and social services systems regarding home care. This analysis will also assess the traditional dominance of males in managing health care systems and closely analyze the growing power of females within both medical and social systems (Clark, 1999).

(4) The fourth analytic dimension is the race-ethnicity, class, and sexual orientation implications to understanding differences in aging and disability. The changing ethnic composition of the United States, Canada and France makes this analytical dimension unavoidable. This analytic dimension is strongly correlated to all the others. A number of studies have identified differences in the use of home care services by racial and ethnic groups in the U.S and Canada. Learning more about these differences is critical.

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TENTATIVE PLANNING OF RESULTS TO BE REPORTED

CALENDAR 2010	FIRST 12 MONTHS TERM - CONCEPTUALIZATION & DATA COLLECTION -	
January February	WINTER 2010	Refining: (1) Conceptualization & (2) Measurement Instruments
March	VVII. (1131C #010	♣ First Trip to Paris (Spring Break)
April May	SPRING 2010	♣ Preparing Field Work Research♣ First Trip to Vancouver
June		Testing Preliminary Inquiries
July August September	SUMMER 2010	♣ Testing Preliminary Outcomes♣ Review of Overall Methodology
October November December	FALL 2010	♣ Field Work Research Totally Completed
CALENDAR 2011		ND 12 MONTHS TERM ANALYSIS & RESEARCH FINDINGS -
January February March	WINTER 2011	♣ Data Analysis I
April May June	SPRING 2011	↓ Data Analysis II
July August September	SUMMER 2011	 Confronting Results Reporting Findings Second Trip to Paris (Fall Break)
October November December	FALL 2011	♣ Findings Dissemination♣ Publication