A Healthy Balance

ATLANTIC CENTRE of EXCELLENCE for WOMEN'S HEALTH

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Advisory council
on the status
of Women

A community alliance for health research on women's unpaid caregiving

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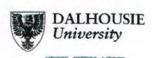Health Research on Women's
Unpaid Caregiving

Research Gaps
and
Recommendations

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1. The Healthy Balance Research Program View of Caregiving

The purpose of this paper is to identify, from the broader literature on unpaid caregiving, those areas where further research can advance knowledge and understanding in the field. It is hoped that this can assist the Healthy Balance Research Program (HBRP) in its own prioritization of research tasks. The definition of "caregiving" here includes not only caring for the ill and disabled, but also encompasses all normative caring across the life cycle.

Research gaps are "what we don't know" but need to or want to know. Research gaps are questions, and questions, as we know, are limitless. The answer to each question, if there is one, leads deeper into further questions and areas of inquiry. In many cases, the question *is* the answer. There is no pretence, therefore, that this paper provides a definitive answer as to the best and most productive areas of further research for the HBRP, since even the most well-researched aspects of caregiving raise questions on new and important dimensions of the subject that are worthy of further investigation.

There are, however, three broad conclusions that derive from the literature review of the last five months:
1) Any profound exploration of caregiving must be multidisciplinary.
2) There is as much need to offer a fresh perspective on "old" areas of caregiving research as to identify new "niche" areas for further research. That fresh perspective or view is the subjective, human, compassionate aspect of "care" that a women's health perspective is uniquely placed to provide.
3) The women's health and life balance perspectives of the Healthy Balance Research Project can help prioritize and define further research efforts.

A few words on each of these broad conclusions are in order.

The literature review of the last five months makes clear that any deep exploration of caregiving requires a multidisciplinary approach. Such an approach can be daunting, because the quantity of research to consider is enormous. In order to make this approach workable, a view has to be defined in order to connect the various studies and to identify research priorities for the future. When the view is clear, the research questions can then be defined with greater clarity, whether or not they have previously been asked.

The issue, therefore, is not simply to identify "new" research questions for the Healthy Balance Research Project. Even where important research questions have previously been identified, actual results are often inconclusive. Many studies have been criticized for lack of consistent definitions, flawed methods, small samples, biassed samples, and incapacity to be generalized.

Many of those earlier studies also had a narrower view and approach than that of the Healthy Balance Research Program. Contradictory results in previous studies, therefore, also suggest differing perspectives on the part of researchers. As a result, a "duplication" in efforts, if the view is clear, is unlikely. Indeed, the Healthy Balance Research Program may well make its greatest contributions through a fresh perspective on "old" research issues rather than simply by identifying new and specialized "niches" of previously under-researched issues.

At the same time, there has been a tremendous amount of very valuable research in the literature, and the Healthy Balance Research Program does not want to "reinvent the wheel." Researchers across all disciplines have been looking at caregiving and related issues for a long time, with interest intensifying in the last 10 years. Researchers in government, medicine, psychology, sociology, economics, public health, women's studies, ethnic and minority studies, and a wide range of other disciplines have been looking at a wide range of issues related to caregiving. Those issues include policy, physical and mental health, work, families, children, costs, health promotion, minorities, poverty and wealth, and more.

Yet very little of this voluminous amount of research has been synthesized across these different areas of interest, and much of it misses the human dimensions of caregiving. In fact, very little of the research on caregiving has been conducted from the broad perspective of women's health. Much of the relevant research to date from the women's health perspective has come from the Centres of Excellence for Women's Health.

Exploring the "full spectrum of caregiving" is clearly a vast undertaking. Caregiving involves every aspect of the life of human beings as they care for and relate to each other, as well as to the communities, societies, and world in which they live. Human beings cannot be conceived, born, raised, or live their lives without care. That care starts with care of an infant and proceeds to caring for children, family, and society. In its broadest sense caring can be extended to caring for the entire world. Caring for the entire world includes the animals, plants, air, water, and earth, without which there is no survival for anyone. From birth to death we need care. Care is the bottom line--the starting and ending point. Taking the study of care as the focus of research literally changes how everything is viewed.

The profound and crucial contribution of women at this point in history is to remind people about that fundamental perspective of care, which can literally help to pacify aggression in the world today. Their contribution is to introduce the element of heart, compassion, caring, and subjectivity back into the underlying fabric of our collective lives and to truly value it. All men and women of all ages in all cultures share the need to give and receive love, care, and respect. If the Healthy Balance Research Program can approach the subject of caregiving from the perspective of honouring, recognizing, and valuing the importance of empathy, affection, and caring, then it can make a unique and powerful contribution to the literature on the subject.

More specifically, the particular aim of the Healthy Balance Research Program is to relate caregiving issues to women's health and life balance. While the literature review of the last five months will hopefully provide a useful overall background perspective for the project's further research, it is recommended that the issues of women's health and life balance be used both to evaluate potential contributions to already existing research, and to prioritize further research.

In sum, the overarching conclusions of the background literature review are to adopt a multidisciplinary approach, to apply a women's perspective of care (in the human sense) to conventional and well-researched questions, and to use the HBRP's focus on women's health and life balance to identify and prioritize further research issues. These conclusions are really

one: care nurtures compassion, which in turn contributes to health, which leads to (or is) balance. Health and balance focus the goal and practical realities that need to be addressed.

2. Focus: Subjective Aspects Of Health And Balance

Identification of research gaps and research priorities must begin with an acknowledgment of definitional challenges, particularly in relation to "health" and "balance," which are the focus of the Healthy Balance Research Program approach to caregiving. Careful definition can help identify a research approach for the HBRP that is unique and that provides significant "value added" to the literature that currently exists.

Research that focuses on the health of caregivers, or of women in general, relies mainly on the biomedical view of health. Researchers often look at the immune system, stress, diseases, and number of physician visits or hospitalizations. Some studies, especially those researching dementia caregiving, look at mental health, usually depression or mental stress. Even when studies look at both physical and mental health, they look at them separately and do not see their interconnectedness. The view that health is not just absence of disease but includes physical, psychological, sociological, economic, and spiritual well-being is rarely applied.

Physicians, caregivers, and researchers mean different things when they think or speak of health. For some, health is simply a lack of dysfunction in the body; for others it implies a healthy lifestyle; for some it includes mental and spiritual well-being as well as physical health. Other researchers take a social perspective that sees disease as an imbalance in relation with society at large and is, thus, connected with poverty, racism, discrimination, and other social ills.

Subjective and objective definitions of health further complicate the picture. Many disabled, for example, report feeling healthy and having a good quality of life. This implies that definitions of health must also acknowledge subjective and multidimensional aspects. It is, therefore, important to know how caregivers think and feel, as well as what the "objective" and measurable health data tell us. These subjective indicators of health are not easy to identify with standard survey tools. When people are asked about their health in interviews, they often respond by referencing their physical health with deeper values often remaining hidden. This is even truer when there are language and cultural barriers.

Balance is similarly challenging to define. One can look at balance from outer and inner perspectives. The former includes having time and space for work, relationships, and leisure pursuits, where these different activities enhance and complement each other and provide satisfaction. For caregivers, it could mean the balance between caregiving and personal life (including family, children, and partners), and between unpaid caregiving on the one hand and money and material needs on the other. This type of balance has been measured quantitatively, in part.

Inner balance is subjective. In the holistic view, it combines body, mind, and spirit. With balance, physical health is less problematic and is seen in the perspective of an underlying sense of self-worth and basic well-being. The spiritual aspect may be a formal, religious belief or

practice, a feeling of connectedness and being part of a larger world, or perhaps having a general sense of meaning or purpose in life. That subjective, inner sense of balance has been much less well researched and could provide a useful focus for the contribution of the Healthy Balance Research Program to the literature on caregiving.

The subjective aspects of "healthy balance" are clearly challenging and have been largely neglected in the literature on caregiving. For example, the attitudes of caregivers toward their work contribute significantly to the apparently conflicting results in much of the literature, but are rarely acknowledged by researchers. For example, how can some caregivers feel positive about experiences that seem so demanding? That vital question has not been sufficiently probed in the literature on caregiving. The attitude could be due to the reciprocity between giver and receiver or to any number of other variables.

There is a fertile field for further research in assessing the differential impacts of different attitudes and subjective perceptions on the part of caregivers. The literature indicates that an adult daughter giving care to an elderly parent is often more stressed than a spousal caregiver, even if she spends less time and effort caregiving. More work is clearly necessary to understand the important impact of attitudes on the dynamics of a healthy balance in caregiving.

No research was found in the caregiving literature that looked at health and balance as deeply holistic and interconnected. The concepts of care, women's health, and balance and their interconnectedness could focus every aspect of the further research conducted by the Healthy Balance Research Project. In short, rather than simply identify "new" and specialized areas for HBRP research, the HBRP approach to healthy balance could potentially reframe and refocus research on caregiving altogether.

3. Specific Research Themes

In the literature scan for suggested gaps in the research or suggestions for further study, several related themes emerged that also could also help focus future HBRP research. These themes are presented here as pairs of opposites that can place the HBRP research in the context of the approach recommended above. These themes include the attitudes of compassion/conflict, positive/negative approaches, interconnection/separation, and looking at details/context. There is a need to look at both sides of the coin if a fuller picture is to be developed, with both sides equally relevant to the issue of balance. The themes are briefly outlined here.

(1) Compassion or conflict as research context.

Caregiving without compassion seems almost meaningless if "care" is understood according to the standard dictionary definition of "concern about or interest in others" or a "feeling of love or liking" for another. And yet, despite this common vernacular use of the word, much of the literature treats caregiving as a mechanical performance of tasks required to provide physical necessities to those who are ill or disabled.

Indeed, the literature subtly reflects a cultural bias that embraces the language of conflict rather than compassion and care. For example, we "fight" for peace, we fight for our rights, we fight the war on cancer or HIV/AIDS, we fight poverty, and we fight terrorists. This bias pervades much of the research on caregiving, which focusses on what is wrong, on conflict, burden, and the negative consequences of caregiving and illness in general. Reading literature reviews of caregiving research can be a depressing experience. So much research is focussed on problems that are so vast and overwhelming that what is actually possible can seem very limited.

(2) Focus on positive qualities of caregiving experience is rare.

Starting from the view of care or compassion rather than conflict and burden can empower caregivers by focussing on the positive aspects of the experience. Researchers do frame and influence the subject of their research with their own approach and attitudes. By approaching caregiving with a focus on strengths and basic good health, defined in the fullest sense of the term (above), researchers can identify obstacles to the full realization of health and recommend concrete strategies for the removal of these obstacles. By contrast, a focus on the burden of caregiving frequently makes the obstacles appear overwhelming and insurmountable – the very framework and definition of the caregiving experience itself.

Recognition of the positive qualities of caregiving does not confine caregivers to making the best of a difficult situation. Nor is this approach a way of providing tools for caregivers to cope in the face of undesirable circumstances. A positive attitude does not imply a "Pollyanna" naivete. Rather, it is fully capable of embracing the "good" and the "bad" aspects of caregiving and implies a more holistic, realistic, and skilful approach to health than much of the conventional research. That conventional research often implicitly assumes a unidirectional giving from caregiver to patient, and therefore highlights only the burden on the caregiver.

Appreciation of the positive aspects of caregiving also helps to empower the person receiving care with greater dignity and values the reciprocity of care. Almost no research in the literature examined takes this view or approach. One study that purported to look at the positive aspects of caregiving asked 10 questions using the Experience of Caregiving Inventory (ECI)--eight questions about negatives (problems with services, difficult behaviours, stigma, loss, etc.) and two about positives (rewarding personal experiences, good aspects of the relationship). The results showed few positive aspects. The study did concede that: "it is possible that the positive scale may not be powerful enough to indicate the effect of the positive experience on the family members" (Martens and Addington, "The psychological well-being of family members of individuals with schizophrenia," 2001).

(3) Focus on interconnections between issues and people

Most of the research on caregiving comes from the perspective of reductionism rather than a holistic view. The tendency has been to look at narrowly defined issues without reference to the interconnections that affect them. This is certainly true in the medical view. Doctors generally look at separate systems and organs and see their mechanistic function and how each works as a separate unit. The body is separate from the mind. Psychologists generally look at the mind without regard for the body.

This approach is beginning to change through the application of feminist and sociological perspectives on research. Holistic ideas that mind and body affect each other and actually cannot be separated, or that individuals cannot be separated from the societies in which they live, are becoming more accepted. Feminist approaches to research point to the reality that rugged, hearty individuals cannot "do it alone" and that individuals must work together in an atmosphere of caring and responsibility to make progress and achieve social goals. From that perspective, poverty, inequality, and lack of care and concern affect us all.

Similarly, the interconnectedness and reciprocity between the caregiver and recipient of care require greater focus in the research on the subject. Most of the literature has not taken this approach but focusses instead on the "needs" of the recipient and the capacity of the caregiver to provide for those needs.

(4) Balancing context and details

Having this view of the bigger picture, outlined above, provides a focus for looking at specific details of caregiving. Too often, research that does try to be holistic becomes too general and conceptual. Specific interconnections are seen as so overwhelming that particular patterns of interaction are neglected or overlooked. However a "healthy balance" requires that research itself properly balance the "big view" with important details about caregiving patterns. It is as possible to see the bigger picture in individual, specific situations as it is to see the details within the larger picture. Research on caregiving must, therefore, balance context and detail.

Keeping in mind the overall view and definition of care; relating caregiving research to women's health and balance; and exploring caregiving from the perspective of compassion, positive qualities, interconnectedness, and identification of patterns through details can add significant new and valuable knowledge to the literature on caregiving. Such an approach is markedly absent from most of the current research on the subject and could enable the Healthy Balance Research Project to provide a unique perspective on caregiving. This approach to research can also impact policy outcomes. If we have the basic attitude that "care is good," the road to helpful policy is half paved.

4. Specific Research Themes

Researchers in each area of unpaid caregiving have their areas of expertise, and extensive work has and is being done in a wide range of fields. The literature review of the past five months revealed that each research area has a whole world built around it, with its own language and major concerns. Many fields of research have particular organizations associated with them, both conducting important research and using that research to advocate policy initiatives.

This section will highlight some of these researchers' own recommendations for further work on unpaid caregiving, focussing especially on the issues relevant to care, women's health, and balance as described in the contextual introduction above. The section is organized by loose categories. Each category should inform others and cross-pollinate with issues in the other

categories. This is a representative list rather than an exhaustive one, and some categories have more detail than others. Categories with less information easily could be expanded, and their brevity does not imply lack of importance.

Specific research themes for the Healthy Balance Research Program could potentially build on some of the following recommendations:

Women's health

(4) A gender-based perspective is not part of most existing studies of caregiving. The Women's Health Movement has illuminated the need for research to reflect actual experiences of women within their social, economic, and political contexts. These contexts are complex and need multidisciplinary study across different areas. Penelope Ironstone-Catteral ("Feminist Research Methodology and Women's Health: a review of the literature,"1998) suggests we need:

> *"...research at the macro level which examines broad structural forces such as economic organization and political arrangements and processes; research at the meso level which looks at the institutional constraints on women's lives such as access to educational opportunities and medical care, or bias in the workplace; and the micro level which examines women's everyday lived experiences at work, in the doctor's office or in the domestic sphere, and the meaning that women attach to these experiences."*

She also recommends a critical look at policy as a determinant of health and "an in-depth analysis of a number of policy documents or initiatives as case studies."

(5) Cohen and Sindling ("Changing Concepts of Women's Health,"1996) also point out the importance of looking at the bigger picture:

> *"We need further experimental data and qualitative studies which might allow for and explore possible different meanings of health and ill health based on gender, class, culture, ethnicity, age, ability, and sexual orientation."*

Cohen and Sindling point out that addiction research is an example where the importance of context is clear. Apparently almost 80% of women treated for alcohol and drug abuse have a history of domestic violence or sexual abuse. As well, researchers should "draw attention to the effects on women's health of poverty, the physical environment of the home and workplace and the toxins accumulating in the air, the water, and the soil."

(6) Eakin, Brooker et al., ("The Restructuring of Work and Women's Health: An Annotated Bibliography," NNEWH,1999) do consider the issue of interconnectedness noted above. The following statement could be broadened to include most topics.

> *"There are voluminous literatures on the various components of this topic (i.e. on the nature of economic and labour force changes, women's health, women and work, women*

and unpaid work) but literature linking these components is scarce, as is literature that explicitly investigates the health implications of these issues."

- In speaking about multidisciplinary approaches, Hawe and Shiell ("Social Capital and Health Promotion," 2000) state:

  " multidisciplines may help to reverse the tendency of interventions aimed at redressing health inequality to focus too much on individual level, remedial activities. The entry of place theorists, urban designers, sociologists, geographers, and ecologists into public health interventions may serve to counterbalance the dominant influence of behavioural sciences. Established theories and models of intervention in these fields have been untapped."

- Davidson et al., ("Three top Canadian and personal health concerns of a random sample of Nova Scotian women," 2001) report that we need to assess women's subjective health concerns. They note that the perceptions women have of their own health needs have not received much attention. "The possibility that women have health concerns other than those emphasized by the health professional community has been suggested but not studied extensively."

We do not know, for example, whether the priorities and concerns women have about their own health are the same as those of health providers. It is interesting to note that in a randomly-dialled telephone survey of 458 Nova Scotian women aged 18-81, including 81 Native/Aboriginal and 75 Black women, most Caucasian/European women said psychosocial issues (stress, depression, anxiety, mental health, and socio-cultural stress) were most important. Black and Native women listed other specific diseases (diabetes, arthritis, flu, osteoporosis, migraine headaches, STD, and asthma) as the main health concern.

Davidson et al., suggest that, in addition to research on the health of minorities, we need a better understanding of how stress affects the quality of women's lives. "Research that focusses on women's health concerns about their psychosocial well-being, and how those factors in turn affect their physical health, appear particularly warranted by these findings." Looking into the escalating non-specific illnesses such as chronic fatigue syndrome and fibro myalgia might shed some light.

(1) In a Canadian Research Institute for the Advancement of Women report ("Women, Health, and Action," 2001) Morris discusses aspects of Health Canada's 12 determinants of health: income and social status, employment, education, social environments, physical environments, healthy childhood development, personal health practices and coping skills, health services, social support networks, biology and genetic endowment, gender, and culture.

Morris recommends we look more deeply at the following determinants of health. The health of caregivers, in turn, can be assessed from the perspective of these determinants:

- income, paid and unpaid work, and health--including impacts on health of inequality, anti-poverty programs, affordable housing, better access to education, pay equity, pensions
- self-esteem--how we treat children, crime and violence, poor school achievement, teen pregnancy
- nutrition, body image--the food industry, unhealthy food, fast and convenience foods
- physical activity--time for taking care of one's own health and that of children, presence of bicycle paths, walking trails, exercise in the work place, accessible buildings
- environment–the World Health Organization estimates that poor environmental quality is directly responsible for around 25% of all preventable ill-health in the world today-- environmental toxins, air pollution, unclean water, and toxic messes, which are often located in low income areas
- health protection, including inadequate testing of pharmaceutical drugs, contaminated blood, etc. (We could add medical errors)
- social support, sense of community, spiritual beliefs--social isolation and loneliness, connectedness, values of care and compassion. Since Morris notes that "spiritual beliefs and practices have a positive impact on health," further research could determine why this is so
- health care systems--privatization, more demands on women, emphasis on drugs, need for social change, emphasis on acute stages of illness
- violence as hidden abuse
- racism, discrimination, and the health of marginalized women

• Attempts to assess the physical health of caregivers have been conflicting and need further research. Some researchers say it has no effect and others disagree. Many studies ask only one question: rank your overall health rate from poor to excellent. According to Ory, et al. ("The Extent and Impact of Dementia Care," 2000) measurement of physical health outcomes can be classified into four major types:

> "self-rated global health; the presence of chronic conditions, illnesses, physical symptoms, and disabilities; health-rated behaviors, medication use, and health service utilization; and physiological indices. In contrast to the consistent findings among ADRD caregivers, findings based on physical health outcomes are less conclusive."

The issue of how the physical health of caregivers should be assessed is worthy of further investigation.

Normative caregiving, families, men, children, elders, social supports, and reciprocity

• Neysmith (*Carers as a Labour Force*, 2000) looks at care from different perspectives and also emphasizes the importance of context. It is very important that we understand what the word "caregiving" means to the caregiver, since people routinely interpret this concept differently. Women, especially, often do not see the normal caring work they do as "caregiving."

Neysmith's analysis raises important questions: how are respite and coping seen? Do they imply a weakness on the part of users, a questioning of their ability to cope? She suggests coping might be an indicator of a problem rather than an answer. How much coping is realistic? She says:

"it is all too easy to blame the victim if the analytic gaze focusses too strongly on individuals struggling to survive under conditions over which they have very limited control. Thus, context, social conditions and an appreciation of the social location of the parties are not so much denied as they become part of the backdrop, rather than the primary focus, for research and policy making."

- Moen ("Caregiving and Women's Well-being: A life course approach," 1995) suggests that key themes in the life course paradigm are social interdependence, the importance of early experiences in shaping later experiences, the significance of time and roles, and personal resources. She says that:

"...most research assumes caregiving is stressful and has a negative impact, although acknowledging some potential benefits. By contrast, a life course, role context approach draws on role theory and temporal considerations to suggest no such simple or straightforward relationship between caregiving and emotional health."

Moen talks of "linked lives" and how we need to see how women's life paths are "embedded in, and structured by the experiences and expectations of husbands, children, aging parents, societal gender-role norms." Looking at early experience, she says:

"The transition to caregiving and its implications for quality of life cannot be understood without knowledge of the prior life course. What women bring to this experience, in terms of previous roles and resources, may well shape the impacts of caregiving on their well-being."

It is equally important to look at when in the life course caregiving is taking place. When did it start, what is its duration?

"Roles may have different impacts at different stages of the life course. Little is known about the import of unexpected role changes in mid life. Caregiving in later life may be seen as more normative and commonplace and accepted as such."

We might add other pertinent research questions: how is caregiving for children similar to or different from caregiving for elders in later life? What is the gender role orientation of the caregiver? Do women with a more traditional gender role orientation experience higher or lower levels of well-being?

Missing in much of the research is attention to social participation in the broader community, including unpaid work such as volunteering or participation in religious practices, which might help define the caregiving role as a "calling" rather than an unwanted obligation. Other research questions might focus on questions such as: what reduces the negative effect of

caregiving? What is the impact of networks of relationships, marriage, employment, education, and previous high levels of well-being on the experience of caregiving?

Moen says that her own research findings:

> "...suggest that simple assumptions about positive and negative ties between caregiving or other roles and well-being portray a very limited, snapshot picture of a much more complicated relationship. The answer to the role strain, role enhancement argument is 'it depends.' What is needed is a greater understanding of how the taking on (or exiting) of particular roles in the context of other roles and resources encourages or hinders psychological [and physical] health at various life stages."

- Hawranik & Strain ("Health of Informal Caregivers: effects of gender, employment, and use of home care services," 2000), among others, report that elders often deny problems in their desire to remain independent and function without support. How prevalent is this and how does it affect reciprocity with the giver? Are receivers respected for their positive roles, knowledge and wisdom, and encouraged to be productive, engaged, and as independent as possible? Can they influence the type and quality of the care they receive? Can they influence rules and policy? Are the values and preferences of giver and receiver the same or different, and are both respected?

Most seniors under 80 are healthy and have no need for caregiving support. The care that the elderly give their spouses, adult children, grandchildren, friends, and community is often overlooked. This care is related to reciprocity. Care could take many forms: child care, financial support, home maintenance, emotional support, volunteer work, etc.

- Child development and well-being have been researched extensively. However, there are conflicting results on whether the amount of parental child care has risen or declined recently. Zuzanek ("Parenting time: too little or not enough?" 2001) suggests these inconsistencies may result from "differences in the way researchers measure parents' time spent with children and variations in the amount of child care accorded by parents to children of different ages."

Zuzanek suggests there is a "need for distinction between trends in direct child care (physical or social) and contact time (time spent in the presence of children but not necessarily interacting with them.)" Few researchers have assessed the relationship between quality time and amounts of time parents spend with children who need both focussed time and "hang-around" time. Research should include single parents, dual-earner couples, and unpaid caregivers.

- The study of men in relation to caregiving is very sparse. Most of the work looks at spousal caregiving, especially among the elderly. As more mothers take paying jobs or pursue careers, fathers are experiencing increased pressures to assume more caregiving responsibilities. What are their child rearing beliefs? And what do they do? Do they drop out when needs intensify? Do they become caregivers willingly or by default? How involved are

men with the difficult medical demands (giving shots, managing medications, changing dressing, etc.) that are increasingly being required of caregivers to the ill?

According to the National Institute of Child Health and Human Development ("Factors Associated with Fathers' Caregiving," 2000), fathers are more involved in caregiving when they work fewer hours, when mothers work longer hours, when both parents are young, when the father has positive qualities, when mothers report greater marital intimacy, and when the children are boys.

- Campbell ("Caring Sons," 2000), in discussing male caregivers, recommends research is needed "that explores the more affective dimensions of the caregiving relationship and the 'relationship history' that develops across the life course and how that influences care."

- Stoller ("Males as Helper" 1990) warns of "limitations that result from viewing men caregivers through the lens of women's experiences," and calls for "an unbiased and fresh perspective in future research."

- Many studies have been done on men and work, but mostly from the point of view of how family responsibilities impinge on their work pressures rather than vice versa. (Women are looked at from the view of how work impinges on family caregiving.) What is the gender bias in such studies? This bias is very important when looking at different cultural groups, which may have different views of appropriate gender roles.

- Most of what we know about how informal care is organized comes from looking at dyads, usually one primary caregiver and the recipient. We need to know more about the networks that are usually involved, such as multiple family members and friends. What do these larger networks contribute to caregiving? What are the patterns in family networks? Are they influenced by the length of the caregiving term, by gender, and across generations?

- The Vanier Institute of the Family ("The Ties That Bind Aging Families," 2001) recognizes there is "little evidence of the nature and implications of caregiving roles outside the context of family life, or the implications of the emergence of other kinds of caring relationships such as 'friendship' families."

Well-being, empowerment, positive aspects, quality of life, spirituality

(1) Albrecht and Devlieger ("The Disability Paradox: High quality of life against all odds," 1999) talk eloquently about the "disability paradox" and say that "patients' perception of personal health, well-being, and life-satisfaction are often discordant with their objective health status and disability." They speak of a "balance theory," which emphasizes relationships between body, mind, and spirit in the context of a larger environment:

- body ("organic and physical function dimensions");
- mind ("rational and intellectual capacities of the self"; and

- spirit ("recognition that the self is part of a higher order of the universe, a belief in a higher being and/or having a purpose in life larger than and extending beyond the self.")

According to Albrecht and Devlieger: "the able-bodied public and even health care and social service workers concentrate on the organic, functional and rational aspects of the conditions and problems while grossly under-estimating the importance of the mental, spiritual, emotional and social components that contribute to the person's ...quality of life."

They suggest that research include "different types of imbalance [and balance] between body, mind, and spirit, identifying, exploring their consequences," and note that this would "contribute to quality of life theory, help explain what constitutes well-being and suggest intervention strategies."

(2) Positive aspects of caregiving that have been studied include reciprocity (caring going both ways, enjoyment from the relationship, satisfaction gained, and gratification from seeing a desirable outcome), and empowerment (sense of mastery is one definition.) Positive aspects of caregiving can also be correlated with demographics, income, education, adequate social support, time spent, and the nature of the relationships.

Cohen, Gold, Shulman, and Zucchero ("Positive aspects in caregiving: an overlooked variable," 1994) suggest future studies include questions such as: "how can we define and measure positive aspects of the caregiving process more consistently across studies; how do different positive aspects correlate with one another; how do positive outcomes relate to different personality traits of the caregiver." They suggest that a better understanding of these issues is important in understanding outcomes such as psychological well-being, service use, and rate of institutionalization.

(3) Lee, Brennan, & Daly ("Relationship of Empathy to Appraisal, Depression, Life Satisfaction, and Physical Health in Informal Caregivers to Older Adults," 2001) report that the positive influences of empathy increase the effectiveness of caregivers, who then are less influenced by stress.

> *"Burden depends on the caregiver's appraisal or perceptions of the situation and their resources....The caregiver's subjective appraisals of the caregiving situation were better predictors of depression and life satisfaction [and physical health] than were other measures of the caregiving situation."*

Further research is necessary to determine whether this conclusion is generally true. How do cognitive understanding, "distancing" and emotional empathy relate to the caregiver's well-being and ability to cope?

- Folkman ("Positive Psychological States and Coping with Severe Stress," 1997) points out that the coping theory has traditionally focussed on the management of distress:

> *"We need to learn more about coping processes that help sustain positive psychological states in the context of enduring stress, the conditions that trigger the search for positive*

psychological states, and the intensity and duration of positive psychological states necessary to help sustain individuals."

There is growing literature on the characteristics of individuals that could help explain this ability including "hope, hardiness,...optimism," etc. Four types of coping processes are noted by Folkman: reframing situations to see them in a positive light, having personally meaningful goals, spiritual beliefs and practices, and infusing ordinary beliefs with positive meaning. In conclusion she recommends, "that this is an area of investigation that needs systematic theoretical and empirical development."

- Empowerment is spoken of in many ways in the literature. The Armstrongs ("Thinking it Through: Women, Work and Caring in the New Millennium," 2002) say that:

  "empowerment must be defined in ways that understand that power is about access to resources. The resources are material, political, social and symbolic and profoundly influence whether women can participate in making decisions about their own lives."

  What does empowerment mean to women, and how is this expressed cross-culturally?

- Ozaal ("Gender and Empowerment," 1997) says that research has "highlighted the relationship between powerlessness and susceptibility to ill-health, and the health-enhancing capability of empowerment" on all levels--institutional, domestic, and individual. According to Ozaal, empowerment "emphasizes women's individual sense of self-worth as it connects to the value they attach to their own health (linked to 'power within')." Women have collective empowerment through organizing (for example, to make health services more accountable and to increase women's choice, decision-making, and control over their bodies).

- Feelings of power and powerlessness have been looked at in terms of empowering caregivers, receivers, and families. Rutman (1996) is concerned about the communication gaps between the professional health care teams and caregivers. How much does the team respect the knowledge, experience, and capacity of caregivers? How much do caregivers participate in the ongoing process or personal and health care planning?

- Control has been linked to empowerment and has been seen as one factor in the ability to manage stress and burden. This experience is not static. It changes back and forth over time. Szabo and Strang ("Experiencing Control in Caregiving," 1999) suggest further research is required to explore how caregivers experience control throughout all stages of the caregiving experience, i.e., how they lack or gain control, maintain and lose control, and regain it over time.

- Empowerment recognizes that women have vision, leadership skills, knowledge and wisdom, ideas, and aspirations that need to be acknowledged in both the micro and macro spheres. In speaking about intervention practices, Kabeer ("Resources, agency, achievement: reflections on the measurement of women's empowerment," 2000) warns that:

"...to attempt to predict at the outset of an intervention precisely how it will change women's lives, without some knowledge of ways of 'being and doing' which are realizable and valued by women in that context, runs into the danger of prescribing the process of empowerment and thereby violating its essence, which is to enhance women's capacity for self-determination."

- The Canadian International Development Agency has developed a range of both quantitative and qualitative indicators of women's empowerment. Some questions for quantitative analysis are: how have changes in national/local legislation empowered or disempowered women or men. Is the part women, as compared to men, are playing in major decisions in their locality increasing or decreasing? Qualitative questions include: to what degree are women aware of local politics and their legal rights? Are changes taking place in the way in which decisions are made in the household, and what is the perceived impact of this?

(4) Daaleman ("Spirituality and well-being: an exploratory study of the patient perspective," 2001) in a study of spirituality and well-being, says:

> *"spirituality has become a construct of interest in health care, however, there remains a limited understand of how patients themselves describe spirituality and view its impact on their health and well-being.... Patient spiritual beliefs wield a significant influence over health beliefs and some spiritual beliefs may have a direct effect on clinical outcomes."*

Core beliefs ground and maintain "an interpretative structure through which participants view their life events and positively frame their experiences." Daaleman continues:

> *"This perspective is particularly salient in the field of health-related quality of life, where the assessment of patient experiences, beliefs, expectations, and perceptions are critical in gauging subjective well-being. A conceptual clarification of patient-reported spirituality might serve to promote further understanding, since measures of both religiosity and spirituality have been positively tied to subjective well-being."*

Socio-economic issues, time

- According to Coburn ("Income Inequality," 2000):

> *"In most developed countries health inequalities have not gotten better despite rising national wealth (as measured by the GDP).... Attention has turned to the more indirect influence of psycho-social factors on health status rather than simply the direct and immediate effects of material life circumstances.... Not enough attention has been paid to the social context of income inequality."*

Further research is needed to understand causes and not just effects in this very large and important area. The Armstrongs have also addressed this issue in "Thinking it Through."

- Chernomas ("Social and Economic Causes of Disease," 1999) suggests:

  > *"the current struggle for adequate funding for health care, crucial though it is, must be combined with the environmental movement's concerns for the quality of our air and water, the nutrition movement's concerns for the quality of our food, the labour movement's concern about the quality of our work, and the anti-poverty movement's concerns for income and wealth equity. Only by broadening in this way our understanding of the determinants of health and disease will we be able to effectively deal with the health concerns of Canadians."*

- Caregivers' experiences vary over time, and we need to understand the patterns of need over time. Fast and Keating ("Family Caregiving and Consequences for Carers: Toward a Policy Research Agenda," 2000) report that little is known about the "nature of those changes, about how the course of an illness or disability affects the patterns of caregiving demands over time." How do transactions change, i.e., do the roles of giver and receiver reverse? How does the capacity to care change over time? Are caregivers' experiences at different ages, from young to old, qualitatively different?

- The nature of caregiving changes over time. Szabo and Strang ("Experiencing Control in Caregiving," 1999) point out that informal caregiving often begins almost imperceptibly as an extension of normative care with:

  > *"...a period of 'semi-care' where the task entails more of a sense of responsibility than demanding instrumental tasks. The second stage of part time is characterized by increasingly heavy demands, greater conflict between caring and other responsibilities, a diminishment of the elder's social network and increased isolation of the caregiver."*

  The final stage, full care, is when the carer works full time to provide care. This is one pattern, but there are others such as when the need for caregiving is sudden, after stroke or injury, or when disease is chronic and goes into remission. What effect do these transitions have on giver and receiver experience? How does this impact on need for formal support services?

- The U.S. Bureau of Labor Statistics ("Time Use, Non Market Work, and Family Well-Being," 1997) suggests that:

  > *"some of the issues that we can address with time use data deal with how families make decisions about how to allocate their full income across goods, services, and activities, by income, meaning time and monetary income. There are clearly substitutions and complements between some goods purchased in the market and some activities 'purchased' with time. (e.g. convenience foods)."*

  The impact of these time use and market trade-offs on caregiving patterns and the health of caregivers clearly requires further investigation.

- Zuzanek ("Time Use, Time Pressure, Personal Stress, Mental Health, and Life Satisfaction for a Life Cycle Perspective," 1998) suggests that "an analysis of complex issues would benefit from combining measurements of time use, perceived time pressure, life stress, mental and physical health, life satisfaction, and life cycle in one comprehensive survey."

- Duxbury and Higgins ("Work-Life Balance in the New Millennium," 2001) question whether we "thrive on being busy? When does the pace of life reach a point where it affects the quality of life and the quality of performance at work and at home?"

Immigrants, minorities, ethnic groups, rural dwellers, marginalized peoples

- Immigrants include many sub-groups that are markedly different from each other and need separate study: recent immigrants, refugees, professionals (whose credentials often are not recognized), immigrants in a high economic bracket; different ages, children, and women. Kinnon ("Canadian Research on Immigration and Health", 1999) notes that there is little research on immigrants and health that recognizes the strengths of immigrants or their positive effect on society in general and the health care system in particular.

  Most existing studies focus on public health concerns and the transmission of disease, and there is a need for an immigrant perspective on management of risks, including the value of alternative therapies they may have brought with them. The Metropolis Centres of Excellence and the Centres of Excellence for Women's Health have proved to be the richest sources of federally-sponsored research on immigration health. Together they have produced over 80 studies looking at immigrants and immigrant health from many different angles.

- Hyman ("Immigration and Health," 2001) suggests that the "health immigration effect" be explored in more detail. This "refers to the observation that immigrants are often in superior health to the native-born population when they first arrive in a new country, but lose this health advantage over time ... The effect of acculturation on health -- acculturative changes in health behaviours and changes in social support and stress are among the determinants of health which have been least explored in relation to changes in immigrant health status."

- Meadows, et al., ("Immigrant Women's Health," 2001) note that discussions of personal health experiences with immigrants usually focus on the physical aspects. "It was only through discussions of the everyday aspects of their life rather than a specific focus on their health that the mental, spiritual and social factors related to ...health became apparent."

- All of the research questions in each category can apply to minorities. Most of the research in this area is in its early stages, although quite a lot of research has been done in some areas (e.g., aboriginal women). Some of these studies have been criticized for not looking at differences within each group and some for not looking cross-culturally. Henderson ("Caregiving issues in culturally diverse populations," 1994) says:

  "the keys to understanding the influence of culture on caregiving include the fact that beliefs and behaviors evidence variable degrees of intensity and frequency of expression;

many cultural factors are present but are not obvious; many subtle cultural factors are highly significant."

- Murray-Garcia ("Multicultural Health: Setting the Stage for Innovative and Creative Approaches," 1999), in the introduction to an annotated bibliography that has numerous innovative suggestions, stresses the importance of respecting and valuing diversity, especially as a source of innovation and creativity. Critical areas identified include:

    "...[the] relationship between socio-political forces and health status and behavior; the influence of cultural patterns, beliefs, and values on health; issues related to health care access and diversity in the workforce; mandates and models of achieving cultural competency; best-practices in community based interventions; and applied research and evaluation approaches for health care interventions."

- Questions for research suggested in other studies include the following: how are provincial and federal health reforms affecting the economic, social, psychological, and physical well-being of women? What are the cultural views regarding obligation to care? How does the nature of caregiving vary across ethnic groups? How do economic status, general health, accessibility of health services, and needs vary across groups?

Policy

- In talking about privatization, the Armstrongs ("Thinking it Through", 2002) point out major problems for researchers. Their remarks are relevant to policy research in general:

    "Privatization is a major problem for researchers. It is both difficult to monitor and difficult to assess, particularly in terms of the impact on different groups of women. Change is so rapid that it is virtually impossible to keep track of what is happening, let alone assess the results. Combined with government secrecy, reversals in policy, programs announced but never delivered, the failure to produce or publish much data on women and limited research funding, much of which is tied to partnerships with the private sector, the issue is a researcher's nightmare. It is also a researcher's dream, because it leaves plenty of scope for new and innovative work on women from different groups."

- Informal caregiving is an issue relevant to all sectors of society and as such requires long-term public attention and policy consultation. As of 2000, according to Fast & Keating ("Family caregiving and Consequences for Carers," 2000): "no Canadian research has examined the collective effect of the complex web of policies that affect family caregivers."

They believe (Bridging Policy and Research in Eldercare, 1997) "that the key policy issues that need to be addressed fall into three categories: research to clarify concepts such as what are the costs of eldercare; research to clarify the nature of caring partnerships; and research that is client-centred and focusses on issues such as consumer satisfaction."

In terms of research-policy links they suggest an evidence based policy, "...making policy assumptions explicit through the use of a theoretical framework; decreasing the time between identification of a gap in knowledge and the dissemination of research results; working at the interface between policy and research to translate knowledge and anticipating as well as responding to policy agendas."

- Policies should accommodate variability. Montgomery and Kosloski ("Family Caregiving: Change, Continuity and Diversity," 2000) point out that, "when patterns of diversity are identified it becomes possible to mould and target interventions to different types of caregiver relationships and the different stages in the caregiver career." There is a need for flexibility and continuity in support services.

- In terms of work, The Vanier Institute of the Family ("The Ties That Bind Aging Families," 2001) notes that the women doing non-traditional work, including contract work, do not have benefits nor retirement savings contributions, and they see implications for economic security in later life undermined.

- An interesting footnote to the policy issue comes from the Federal/Provincial/Territorial Ministers responsible for the status of women ("Women's Economic Independence and Security," 2001). While recognizing women's health as a priority issue, they decided to focus on "the economic aspects of women's living."

The ministers reported that for the "foreseeable future" they will focus on several priority areas:
1. identifying key opportunities and challenges to women's participation in the non-traditional sector of the labour market, including the knowledge-based economy
1. studying key gender issues related to the tax system
2. examining women's access to current employment insurance measures
3. exploring possibilities for improved access by part-time, contractual, and self-employed women to maternity and other related benefits.

Work (paid and unpaid), work/life balance, roles

(1) Messias et al., ("Defining and Redefining Work," 1997) look at how resources affect women's health.

> *"The multiple properties, contexts, and dimensions of women's work (e.g. time, energy, activity, place, space, value, product, reward, cost, relatedness, meaning) all contribute toward influencing women's health, well-being, and the extent to which women have access to resources. Such resources include inner, personal resources as well as informal and formal health care resources within the community.*

> *"Rather than limiting the focus to how the number of activities, jobs, or roles may affect women's health, research also needs to examine the extent to which women are able to choose their roles and organize the available resources to meet their demands.*

Uncovering how different women manage their time, resources, environment, activities, and energy, and how they space, time, coordinate, share and delegate their various work activities and responsibilities may lead to better understanding of the interactions of women's work and health on individual as well as collective levels."

- Early role research looked at role combinations and questioned their effects on health. Pavalko and Woodbury ("Social Roles as Process," 2000) say that most recent investigations look at how the context of roles affects the situation. This includes looking at the experiences in those roles, rather than solely at the occupancy of roles. How does a heavy workload, low control and decision-making, and monotonous work effect the caregiving experience? They say we need to focus greater attention on the attitudes and preferences people bring to their roles as well as on the contexts.

- Eakin, Brooker, et al., ("The Restructuring of Work and Women's Health," 1999) note: "There are voluminous literatures on the various components of this topic (i.e. on the nature of economic and labour force changes, women's health, women and work, women and unpaid work) but literature linking these components is scarce, as is literature that explicitly investigates the health implications of these issues."

- Some studies point to a needed shift in perspective in current research on caregiving. Work studies often look at health promotions from the point of view of how they can help employers reduce absenteeism, increase productivity, and so on. Scharlach ("Caregiving and Employment: competing or complementary roles," 1994) points out that it would be helpful if employers were equally concerned that care recipients "receive optimum care" and notes that employers need to understand how this perspective would be beneficial for all.

- Research has found that work-life conflict has become worse over the past decade. Duxbury and Higgins ("Work-Life Balance in the New Millennium," 2001) suggest that this conflict occurs when the time and energy demands of various roles become incompatible with one another. They point out three types of conflict: role overloads, work interfering with family, and family interfering with work. They ask what factors have the biggest impact on achieving balance and what can be done to help employees balance their roles.

Duxbury and Higgins make numerous recommendations for different policies, practices, and strategies that could reduce all three aspects. In further research, these suggestions could be looked at in more detail in terms of workers' and caregivers' own experiences.

- Duxbury and Higgins also feel that we need to determine if the differences we see between women and men in terms of stress, depression, role overload and family-to-work and work-to-family interference are due to social, workplace or family factors, or some combination. They point out that:

    "[a] large number of researchers in an increasing range of disciplines and publications (such as business, psychology, sociology, economics, gerontology, nursing, social work, law and human resources) are examining the issue of work-life balance. Organizations are now competing to be an employer of choice with respect to supporting working

mothers and providing balance. Yet despite all this attention, we still see little concrete progress in this area."

- The Canadian Council on Social Development ("Work, Family and Community: Key Issues and Directions for Future Research," 1999) has done extensive work on work-life balance. The council's report provides a synthesis of what is known and examines the relevance of community to work-family conflict. The report also identifies gaps in knowledge and directions for future research, especially research that can inform policy and program development. They say that we:

  "...have more understanding about what contributes to work/family/community conflict than we do about how to alleviate it. Part of the problem lies in emphasis on 'conflict.' By focusing on conflict, research preserves the barriers between our private and public lives. These discussions fail to acknowledge how the private and public dimensions of our lives sustain each other."

  Further research is needed in order to understand these connections better.

In sum, there are clearly many possible directions for further research on unpaid caregiving in which the Healthy Balance Research Project can make a significant contribution. Here we have simply listed a few directions suggested by researchers themselves, culled from the literature review of the past five months. It has been suggested in the introductory section of this paper that a multidisciplinary approach to caregiving that acknowledges the subjective components of health and balance, and the positive, reciprocal, and interconnected aspects of the caring relationship can provide an important context for this further research.

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