What Do Canadian Seniors Say Supports Their Quality of Life?

Findings from a National Participatory Research Study

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ABSTRACT

Background: A national project investigated seniors' perceptions of the influences upon their quality of life. The seven participating cities were Montreal, Quebec City, Ottawa, Toronto, Regina, Vancouver and Whitehorse. The project focussed on policy decisions affecting the quality of life of seniors. It was a participatory study in which seniors controlled the direction and shape of the project in each city.

Methods: Focus groups and individual interviews with seniors and stakeholders. Data analysis used qualitative methods to see the world through the eyes of participants. Each project was committed to hearing the voices of seniors and their views on which issues were affecting the quality of their lives.

Results: Across the seven cities, seniors highlighted access to information, health care, housing, income security, safety and security, social contacts and networks, and transportation as key issues that affect the quality of life of seniors in Canada.

Conclusions: The findings affirm the value of participatory activities that involve seniors working with other sectors as a productive policy-informing approach. The Seniors' Quality of Life projects demonstrate the conceptual power of the determinants of health perspective to understand seniors' quality of life issues. While seniors considered health care to be a continuing concern, they also recognized socio-economic issues as significantly affecting the quality of their lives.

La traduction du résumé se trouve à la fin de l'article.

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The health and well-being of Canadian seniors is an important public health focus in Canada.¹⁻⁶ During the International Year of Older Persons (IYOP), a national consortium of seven research groups implemented participatory research projects by which seniors would identify and address the factors seen as influencing their quality of life.

This article has two purposes. The first is to show how the key elements of the project – participatory nature, concern with quality of life, determinants of health perspective, and a policy focus – contributed to the establishment of successful research groups across Canada. The second is to present issues seniors see as influencing their quality of life. Such participatory research projects that address seniors' issues from a policy perspective are rare.

Raphael had been working with a Toronto Seniors Health Promotion Interest Group at the University of Toronto's Center for Health Promotion to identify avenues for funding to address seniors' issues. The group provided a venue for seniors and university staff to address health promotion issues relevant to seniors. In response to Health Canada's IYOP funding announcement, the committee made inquiries to the Federation of Canadian Municipalities and the Canadian Consortium for Health Promotion Research to identify interested seniors groups and university researchers. Local projects would be participatory, directed by the seniors themselves, and would address issues related to "quality of life." In the participating cities of Quebec City, Montreal, Ottawa, Toronto, Regina, Vancouver, and Whitehorse, seniors councils associated with municipal governments initiated research processes.

These concepts – participatory nature, quality of life, and policy emphasis – made the project attractive to seniors. The determinants of health framework was new to most seniors, but was known to the local university staff whose role was to assist the seniors in doing the research. The objectives of the project were to:

- engage Canadian seniors in a process to identify and address the determinants of health and their effects upon health, thereby improving their health;
- provide local, provincial, and federal municipalities with information to form the basis for policy decisions related to the health and well-being of seniors;

- provide resource materials to allow seniors groups across Canada to carry out a similar process of identifying and acting upon health determinants;
- demonstrate participatory activities involving seniors working together with other sectors as a valuable policy-informing activity;
- evaluate the project, its process and products.

The full reports from each of the seven participating cities are available on-line as is the original project proposal.⁷ An extensive synthesis report on the national study is also available.⁸

Brief overview of concepts informing the project

The project drew upon recent advances in understanding how the health of Canada's seniors is affected by individual, community, and societal factors, or what are termed the determinants of health.⁹⁻¹¹ The project provided a mechanism by which seniors could both learn about these determinants and identify their effects upon their health.

Participatory research approach. Participatory research is about subjects of the research having control over the carrying out of the research.¹² In each locality, a Seniors Coordinating Committee of volunteer seniors was established and had final control over the process and product of the research. Project Coordinators were paid through project funds and hired by the local Seniors Coordinating Committee. University support staff provided support and guidance to the project activities and assisted in technical matters of data analysis and report writing.

Quality of life approach. Quality of life is a holistic construct that views human health and well-being within the contexts of proximal and distal environments.¹³ It combines elements of broad societal indicators with the actual lived experience of people.¹⁴ Quality of life also offers the advantage of being understandable to both community members and policymakers and can be seen as a proxy for health and well-being.¹⁵ Quality of life is also being considered in national and local policy environments.¹⁶⁻¹⁸

Determinants of health approach. One purpose of the project was to assess whether seniors' perceptions of quality of life influences would be consistent with

Health Canada's determinants of health (e.g., income and social status, social support networks, education, employment and working conditions, physical and social environments, etc.).¹⁹ Such congruence would indicate these concepts were of value to health promotion work with individuals and communities.⁹

METHOD

In each participating city, a lead seniors group – usually a municipal seniors council – supported by a paid project coordinator, university staff, and municipal partners such as the local health unit or city services staff, organized the project. Most projects had strong local university involvement while others had less or none. Each city formed a Seniors Coordinating Committee that controlled the project and an Advisory Committee consisting of representatives from seniors groups, service sectors, and municipal staff. These working groups adapted the general project design to their specific locality.

A participatory and qualitative methodology enabled seniors themselves to identify how the determinants of health influence their own quality of life.²⁰ Methods consisted of focus groups and interviews with seniors, service providers, and others involved in seniors' issues within each community such as municipal staff. The Toronto questions were provided as a potential template, but each project developed somewhat similar open-ended questions that helped identify the key issues affecting seniors. In each site, data were collected from seniors, service providers, and governmental staff. This paper reports data obtained from seniors.

This variation could be seen as problematic. But the nature of participatory research is to allow local adaptation of the research process. In any event, the consistency of findings across locations (see below) suggests that the divergence in question wording and study process was not a major problem. See the Appendix for examples of questions applied.

Group discussions and interviews and the data analysis were usually carried out by professionally trained personnel supporting the projects using commonly accepted qualitative research methods.²⁰ The approach taken by the Toronto group

was typical. Focus group discussions and interviews were tape-recorded and transcriptions of sessions were prepared.

The transcripts were carefully read by two team members – sometimes seniors, sometimes research staff – and key themes and ideas were identified using coloured pens and markers. The process of categorizing and forming themes was repeated until the best fit between the data and the interpretive themes was achieved. The themes for each group or individual were then written up in the form of a six- to seven-page narrative that identified the themes from the session.

These themes were then reviewed and verified by members of the Seniors Coordinating Committee. In essence then, the process of theme identification involved a team approach of the project participants. Seniors themselves determined the formats of the reports and the interpretations of findings.

Each project carried out its own data analysis using similar methods. Each reported its findings, drew their own conclusions, offered their own recommendations, and concluded with an eight-month action component. To illustrate, the Toronto study used the concept of distributive justice as an organizing concept²¹ and the Montreal group employed an ecological approach.^{22,23} Seniors in each location were responsible for implementing project findings by disseminating results through their networks, lobbying and advocating.

RESULTS

There was agreement across all locations as to the importance to seniors' quality of life of the following: access to information, health care, housing, income security, safety and security, social contacts and networks, and transportation. Participants in most localities also identified issues of ageism of society, having voices heard, promoting healthy lifestyles, and lack of political will as barriers to address key issues. The following section highlights some of the issues on which there was consensus across local projects.

Access to information

Participants expressed concern about seniors' access to information about available programs and services. Seniors need to

TABLE I**Issues Related to Access to Information**

"But I think the other thing is a lot of the information, even when it gets down to ordinary people, the language of that information is language that they don't understand. And you can see it anywhere. They tell us that we need to have all the information on a can or a jar of what's in that product, yet ordinary people, they can read the 12 different things that are on there, and they don't understand any of those things."

"Healthy aging and what is available for seniors. You can put all this information in the community centre. You can put it in the churches, but there are people who cannot get out of the building they are in."

TABLE II**Issues Related to Health Care**

"So then you get cuts in services...lying on gurneys in hospital hallways and having to wait for surgery and not getting adequate care because there are not enough backup staff, nurses, and technicians...staff are overworked and can't give tender loving care."

"But let's remember that until the Long Term Care Act was passed, if you were discharged from the hospital to home care, you did not pay home care. You were entitled to that service because your physician had discharged you to home care. We've lost that insurance now. Now you go home and you have to apply to the committee at the Community Care Access Centre and they will give you the best they can."

TABLE III**Issues Related to Housing**

"Canada should have a policy that everybody should know about, that this is what we stand for. We need to have a clear policy on what being a Canadian citizen means in terms of housing and any other issues...Money from the surplus should reactivate a federal commitment to housing."

"...no new housing is being built, except for very expensive housing."

TABLE IV**Issues Related to Income**

"So once they are in [a retirement home] it gets to be expensive, and the funds run out. A lot of families say they don't have the heart to tell their mom and so somehow the burden falls onto the kids, and they are putting up extra money or paying for the rent."

"They have not taken any long-term thinking and planning, or vision, because we know, barring some mysterious disease that kills people over 65, we are going to have a whole whack of people over 65 in 30 years. That is just the way it is."

be able to access information about the availability of services and resources in formats that are easy to read and comprehend. Community organizations and governments must work with seniors to develop and make these kinds of information available. Table I provides examples that illustrate seniors' concerns over these issues.

Health care

Participants expressed concern about recent federal and provincial decisions that are leading to a demise of the principles of Medicare. They are also concerned about reductions in federal transfers to provincial health plans. Participants related health issues to concerns about the state of long-term care and home care services. Coupled with these were concerns regarding the continued ability of seniors to access the health services they need and to make decisions about their own care and where they

receive it. Access to required drugs is also a common concern.

In some localities, participants identified ageism among health care professionals and their perception of seniors as unable to understand their health care issues. In most localities, participants thought that there should be special training on seniors' issues for health care professionals. With the increasing demographic of older Canadians, the need for such training and education is apparent. Table II provides some illustrative statements by seniors.

Housing

Seniors were especially concerned about the lack of housing options for seniors. They tied housing to financial independence and autonomy, and the ability to access social and health services. Seniors need to be able to choose where and how they live, and not to have decisions forced

upon them by others. Participants made numerous suggestions for increasing the housing stock. Underlying all of these actions was the political will to create more affordable housing for seniors and other Canadians. Table III provides illustrative findings.

Income security

Participants identified income security, particularly for senior women, as a serious issue. It represented the difference between independence and dependence on others, and most importantly the ability to remain in one's own home in the community. Women and immigrants may not have worked, or worked at jobs that did not provide pensions. Economic issues are seen largely in terms of pension plans and having enough money to remain active. They frequently considered existing pensions such as Canada Pension Plan, Old Age Security, and the Guaranteed Annual Income as insufficient. Participants across localities recommended indexing these plans to inflation. Table IV provides illustrative findings.

Transportation

Transportation and the attendant issue of mobility are important issues for seniors. Participants linked these issues to avoiding loneliness and isolation, particularly among those suffering chronic health problems, recently widowed, or living alone. They identified good public transit as key to link seniors to recreation activities and support networks. Participants considered public transit and volunteer drivers as means to help seniors with mobility difficulties to get around their cities to access services they need and participate in the life of their cities.

Barriers to change

All locations identified ageism as a significant barrier. Many attributed this difficulty to prevailing attitudes towards seniors, particularly through the perpetuation of myths about seniors. Participants linked ageism to older adults' lack of political voice. Many argued that society does not value seniors for their wisdom from life experience. Participants called for recognition of seniors and appropriate representation of seniors in public consultations. Governments need to consult seniors and

include them in decision-making processes, particularly on decisions that affect the well-being of seniors.

DISCUSSION

The seven cities involved in this research differ with respect to services offered, local political trends, and institutions. Each study used somewhat different questions and procedures. It is therefore striking how similar the findings are across locations. These findings suggest that the research approach applied is, first of all, robust in its power to detect important seniors' issues. The findings suggest common needs exist among seniors that are not being met by local authorities. The consistency of findings is reassuring as the actual participatory research process applied within each location was unique.

The Health Canada health determinants relevant to seniors in this study are income and social status, social support networks, physical and social environments, and health services.¹⁹ Government policy-making influences the quality of these determinants.^{24,25} The findings are also consistent with the WHO social determinants of social status and income differences, stress, social exclusion, social support, food, and transport.¹⁰

Seniors complained that governments do not listen to their voices. This finding is consistent with evidence of a diminishing role of civil society in public decision-making processes in western nations.^{4,26} Increasingly, Canadian governments limit opportunities for civil society actors to influence legislation and public policy.

This is most apparent in the changing role of government in the areas of housing and health care that seniors identified as problematic. In both areas, provincial governments increasingly invite private sector involvement.^{27,28} For example, the Ontario government opened long-term care community services to market competition. Service providers with a long history of non-profit service provision must now compete for contracts with private for-profit corporations.

CONCLUSIONS

The Seniors Quality of Life Project enabled seniors to identify and explore the determinants of their quality of life. The

Appendix

Questions Asked in Three Seniors Quality of Life Studies

Montreal

1. What contributes to your well-being, so that you and those in your community have a good quality of life?
2. What are the events or situations that have diminished quality of life for you or for people living in your community?
3. What are the events or situations that have improved quality of life for you or for people living in your community?
4. Are there any measures that could be taken by you, your friends, or the organizations in which you participate that could make your life more pleasant?
5. Do governments have a role to play in your life? Could you provide examples?

Toronto

1. What policy decisions being made by governments are affecting seniors' quality of life?
2. How do these decisions affect the quality of life of seniors?
3. What factors are influencing governments to make these decisions?
4. What responses to these decisions could be made?

Vancouver

1. What things affect your life for better or worse?
2. Which ones of these could be influenced by governments (federal, provincial, municipal, or regional)?
3. What suggestions do you have for resolving these issues?

findings across localities and seniors' ability to report these findings demonstrate the usefulness of the determinants of health perspective and the participatory research methodological approach.²⁹

Seniors can examine broad policy issues and identify how governments, service agencies, and communities can promote seniors' quality of life. These approaches provide rich areas for public health inquiry and action to improve the health and well-being of our growing older population.³⁰

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RÉSUMÉ

Contexte : Un projet national s'est penché sur la perception par les aînés des facteurs qui influencent leur qualité de vie. Les sept villes participantes étaient Montréal, Québec, Ottawa, Toronto, Regina, Vancouver et Whitehorse. Le projet a porté sur les politiques qui ont un effet sur la qualité de vie des aînés. Il s'agissait d'une étude participative où des aînés ont contrôlé l'orientation et la forme du projet dans chaque ville.

Méthode : Nous avons organisé des discussions de groupe et des entretiens individuels avec des aînés et des professionnels. Pour l'analyse des données, nous avons adopté une méthode qualitative afin de voir le monde avec les yeux des participants. Chaque projet s'était engagé à écouter les aînés et leurs points de vue sur les enjeux qui ont un effet sur leur qualité de vie.

Résultats : Dans les sept villes, les aînés ont souligné l'accès à l'information, les soins de santé, le logement, la sécurité du revenu, la sécurité et la protection, les contacts et réseaux sociaux, ainsi que les transports comme étant les principaux enjeux touchant leur qualité de vie au Canada.

Conclusions : Ces constatations soulignent la valeur, en tant que démarche productive sous-tendant les politiques, des activités participatives où des aînés collaborent avec d'autres secteurs. Les projets « Qualité de vie des aînés » font la preuve de la puissance conceptuelle d'une perspective axée sur les déterminants de la santé pour comprendre les enjeux liés à la qualité de vie des aînés. Les soins de santé sont bien sûr une préoccupation constante pour les aînés, mais ces derniers reconnaissent aussi que les facteurs socio-économiques exercent une influence considérable sur leur qualité de vie.

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