



Winnipeg Regional Health Authority
Research and Evaluation

Office régional de la santé de Winnipeg
Recherche et évaluation

Final Report

MOVING FORWARD IN INTEGRATING CHRONIC DISEASE MANAGEMENT WITH PRIMARY CARE

A Summary of Qualitative Findings from the Chronic Disease Management of Congestive Heart Failure via Health Lines Demonstration Project

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Committee
Winnipeg Regional Health Authority, Research and Evaluation Unit

March 2009



Acknowledgements

The authors would like to acknowledge the contribution of the Provincial Health Contact Centre chronic disease management nurses, Muriel Tweed and Jeanne Saj, led by Nurse Project Manager, Linda Coote and Paul Nyhof, Executive Director of Manitoba's Provincial Health Contact Centre (PHCC), who worked so hard to support the delivery of this Program and evaluation activities. Special thanks are also extended to the Steering Committee members (chair: MaryAnne Robinson (2004-2005) and Jeanette Edwards (2005-) and Dr. Sheldon Permack (2004-)), and all patient participants in the study. Special recognition should be paid to Dr. Malcolm Doupe for their analysis of survey results and for leading the research component of the evaluation. Appreciation is also extended to Miriam Gonzalez for assistance and coordination of patient focus groups. A number of WRHA Research and Evaluation staff advised on the analysis of the qualitative findings, including Dr. Michael Moffatt, Dr. Sarah Bowen, and Dr. Sara Kreindler (for editorial advice).

The research component of the evaluation was funded generously by the Canadian Institutes for Health Research, Partnerships in Health System Improvement grant. Dr. Alan Katz was the Principle Investigator and led the research component. There was also an active and strong team of decision makers, health care providers, and researchers who supported the collaborative components of the evaluation design and dissemination of findings between 2004 and 2008.

Citation: Ingrid Botting, Alan Katz and Provincial Health Contact Centre Congestive Heart Failure Steering Committee. *Moving Forward: Building on Project and Evaluation Activities: Chronic Disease Management of Congestive Heart Failure via Health Lines Demonstration Project*. Winnipeg, Manitoba: Winnipeg Regional Health Authority Research and Evaluation Unit, March 2009.

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KEY POINTS

- The innovative Program design was integrated and built on the evidence of effective chronic disease management including delivery system re-design, self-management support, and decision support that is integrated with Primary Care.
- The Research component of the evaluation, led by Dr. Alan Katz, focused on effectiveness in terms of patient use of health services (with the exception of Emergency Department). The research also considered the impact of the intervention on patient health outcomes.¹
- From the perspectives of patients and health care professionals, the self-management support component as integrated with primary care² was central to its overall success. Lack of formal links to specialty care and community-based services, such as peer led CDM support programs was identified as an issue for further development.
- Evidence indicated the monitoring technology was not just an add-on, but changed the **nature** of the intervention. There was stronger evidence of preference for one model of self-management support (the core Health Lines service) over the other model with enhancement (Health Lines service + in-home monitoring).
- The need for regular support, follow-up, and contact with a health care professional (health lines nurse and/or family physician) was important for many of patients, especially those with serious co-morbidities – cancer, COPD, arthritis.
- Patients supported using the telephone, with tailored call-schedules, for core self-management support and considered this as improving access and continuity of care.
- Evidence is lacking on the population of greatest need for targeting this kind of intervention in terms of disease severity, age, gender, SES, culture, First Nations status, and rural and urban.
- Family physician engagement in the implementation of the project presented many challenges related to lack of history of participating in WRHA led programs.
- A core group of family physicians felt the intervention addressed many of the challenges of delivering quality care to patients with chronic diseases in their practices, and indicated interest in being involved in Program improvement.
- Nurse participants and family physicians highlighted areas for improvement in communication between the Program and primary care physicians.

¹ The research results are found in Alan Katz and Malcolm Doupe, Preliminary Report of Research Findings from the Chronic Disease Management of Congestive Heart Failure via Health Lines, (unpublished) March 2009. To obtain a copy of the report, contact Dr. Alan Katz directly.

² In the case of the demonstration phase and in this report primary care primarily refers to care by family physician.

EXECUTIVE SUMMARY

a) Purpose of Report

This final report presents a synthesis of evidence from the demonstration phase of the CHF project, with a focus on qualitative findings. The purpose is to assist health system planners, decision makers and providers in learning from the evaluation activities as they begin developing activities for ongoing Provincial Health Contact Centre (PHCC) involvement in chronic disease management in Primary Care. The demonstration phase of the project was also a research study, conducted by Dr. Alan Katz and a team of researchers and decision makers. The findings from the quantitative research component have been put together in a separate report and will be available through publication at a later date (see Footnote #1 for reference)

b) Background on Program Design

This demonstration project provided specialized health lines chronic disease management support to patients with Congestive Heart Failure between 2005 and 2007. It was designed and administered by the WRHA Primary Care Program, in partnership with Manitoba Health and Healthy Living and Central RHA, and funded by the Primary Health Care Transition Fund. The Program operated out of Manitoba's Provincial Health Contact Centre (PHCC) located at Misericordia Health Centre in Winnipeg, and involved collaboration with several fee-for-service physicians in Winnipeg and Central RHA. The evaluation was funded by a Canadian Institute for Health Research Partnership in Health System Improvement grant.

The intervention expanded the core services of the PHCC (24/7 nurse-led symptom assessment and health information system) into the more integrated area of chronic disease management. In 2004, when the initiative was launched, chronic disease management via health lines and as integrated with primary care was a new area of service delivery for provincial health contact centres across Canada. The program was also developed in response to several service needs within Manitoba, including family physician need for support in caring for patients with CHF and other chronic diseases, while addressing the gap in self-management support for these patients. Delivery-system redesign and role redesign for health lines nurses and family physicians were key aspects of the demonstration phase.

Integration with primary care in the operational context of this Program meant health lines nurses communicated regularly with family physicians around patient care. The objective was to increase patients' management of their condition (e.g., medications, diet, symptoms recognition, and timely and appropriate use of health services). It was anticipated that the regular interaction between health lines nurses, family physicians and patients would improve overall communication, resulting in better health outcomes for patients. The regular communication between health lines nurses and patients' family physicians was central to the program's innovation in self-management support.

c) *The Participants*

Over the course of the demonstration phase 106 urban patients served by 61 urban physicians and 70 rural patients served by 22 rural physicians were enrolled. As the project was also designed to support research and evaluation activities, patients were randomly assigned to different groups: 1) Health Lines (HL group) received the intervention 2) Health Lines + Monitoring (HL+M) group received the intervention plus an enhancement of in-home monitoring devices (weight scales and blood pressure monitors) and a computerized call schedule that prompted patients to enter in weights and blood pressures regularly throughout the year. 3) Usual care (active control group) received no intervention. Each patient enrolling in the study had to have a family physician consenting to participate as well. A number of physicians had more than one patient enrolled in the study at a time.

d) *Description of the Intervention*

The regular health lines intervention. Upon enrollment, the health lines nurse would do an individual assessment over the phone with participants. Based on current medications, heart failure severity, psychosocial status, co-morbidities etc., nurses were able to stratify patients and develop a customized management plan for each one. The content of the program covered a large scope of issues relating to self-management of CHF, and included education relating to heart failure basics, diet, preventative strategies, as well as support in home monitoring of symptoms, medication adherence, and other self-care strategies. Nurses also referred participants to local support services, when necessary. After the initial assessment at baseline, each participant received a call schedule tailored to the severity of his/her disease, and was able to call the nurse any time (during business hours) with questions or concerns about symptoms or self-management support. Nurses made regular contact with patients' family physicians on issues related to patient assessments, health action plans, and symptoms necessitating medical intervention. The software module prompted nurses with physician alerts, based on clinical monitoring and ongoing evaluation to re-assess patient risk. Those patients receiving the regular health lines intervention with enhancement were provided with in-home monitoring devices (weight scales and blood pressure cuffs) and a computerized call schedule that prompted them to receive three automated calls per week asked them to enter in weights and blood pressure.

e) *Summary of evaluation findings and issues for consideration*

Key successes from patients' perspectives

The need for regular support from a team of health care professionals (in this case, health lines nurses, family physicians, and home care nurses to a lesser extent) communicating regularly with each other was important for many patients, especially those who were older and had serious co-morbidities – cancer, COPD, arthritis. The elements of self-management support that seemed to work the most was the human dimension: the follow-up, continuity (relationships developed with nurses), and “someone who cares”. Further development and expansion should build on these successful elements.

Health services utilization

The Research component of the evaluation, led by Dr. Alan Katz, focused on effectiveness in terms of patient use of health services (with the exception of Emergency Department).¹ More monitoring of the Program's impact Program on ER visits and hospitalizations as the program expands is needed, as is more thought on different health services utilization patterns for different chronic diseases (e.g., is CHF a condition with higher/different acute care use patterns than diabetes?).

Integration with Primary Care

The demonstration phase focused on integrating the Provincial Health Contact Centre health lines service with primary care by requiring patients and their family physicians to participate and by developing regular communication mechanisms between health lines nurses and family physicians around patients' health. There is strong evidence that this integration with primary care was central to the success of the Program, and improved coordination of care. More thought and evaluation of the further integration of the Program into specialty care, other points of care (e.g., ER), and community-based services (e.g., home care, and chronic disease support services) needs to be done.

Technologies

The extent to which the introduction of the in-home monitoring devices and automated calling technologies changed the nature of the intervention and influenced patient experiences of the Program, strongly indicates that much further thought needs to be given to the relative benefit of the introduction of technologies in chronic disease management.

Patient perspectives on access and continuity of care

Patients perceptions of the importance of continuity of care (seeing their own family physician rather than a walk-in or locum) was strong, and many indicated that participating in the program gave many of them quicker access to their doctors and more desired continuity of care. This was important for rural patients and elderly patients who did not have to travel at all to access healthcare advice. These findings are supported in the international research literature that advanced access in primary care is key in meeting patients needs for more timely and appropriate care (e.g., continuity of care) (Kreindler, 2008).

Population of greatest need

More program thinking is required on identifying the population of greatest need for this intervention. Further development of the patient profile of those who participated in the demonstration phase (with regard to age, gender, SES, ethnicity and culture, rural and urban) is warranted, as well as an understanding of who did not access the Program but could have benefitted (e.g., some First Nations communities in the rural RHA). The perspectives of health professionals are also central to identifying these populations. Further evaluation or analysis of the findings based on patient characteristics is suggested to gain further understanding of differential impact.

¹ The research results are found in Alan Katz and Malcolm Doupe, Preliminary Report of Research Findings from the Chronic Disease Management of Congestive Heart Failure via Health Lines, (unpublished) March 2009. To obtain a copy of the report, contact Dr. Alan Katz directly.

When to introduce the service to patients

Many patients indicated that they would benefit most from the Program if enrolled at the time of diagnosis, but there was little consensus about what “diagnosis” actually meant (e.g., discharge from heart surgery, family physicians diagnosis, specialist diagnosis, self-diagnosis (coming to terms with illness after a few months)). Several access points is the recommendation here. There is a need to better coordinate community services and ensure populations at risk and most likely to benefit from chronic disease management support are referred to appropriate programs, such as cardiac rehabilitation and Provincial Health Contact Centre services.

Interprofessional communication

Nurses and family physicians expressed similar concerns and frustration over communication processes around patient monitoring and care. Family physicians attributed the frustration to the amount of paper that they received by fax from the health lines nurses. Some physicians also felt that the action plans were time consuming to fill out. Nurses’ expressed frustration at the difficulty in reaching many physicians offices and in getting a response back. Both groups appreciated the importance of communicating with each other regularly about patient care, but neither felt like they were really part of a team in this intervention. More thought needs to be given to address the sources of frustration and concern of providers around communication.

Family physician engagement

Recruitment of family physician for this project was difficult, for a number of reasons such as lack of a history of family physician involvement with the WRHA at the time of the demonstration phase in 2004, and lack of engagement and education around the development of the initiative. The research component may have been a barrier to some physician participation. A number of family physicians did participate in evaluation activities, and it is recommended that communication of evaluation findings to physician participants would be important. Issues of engagement and involvement of family physicians in further expansion and development of the intervention is needed.

Rural/Urban

While a rural-urban comparison was not identified as a focused evaluation question there were several findings that highlight the need for further thinking about rural and urban differences in the delivery and impact of this service. There appeared to be stronger uptake of the intervention among rural participants than urban. For example, rural participants indicated that the use of health lines facilitated their access to health care, cutting down on travel time, and facilitated access to their family physicians. A possible reason for the relative success may be associated with the fact that the rural physician participants were affiliated with one clinic and the communication between health lines nurses and the physicians of that clinic was generally more successful. Further thought and evaluation needs to be given to rural-urban comparison.

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SECTION I: BACKGROUND

Purpose of this report

This report presents a synthesis of the evidence from the demonstration phase of the CHF project (referred to hereafter as “demonstration phase”). It presents a brief context of the demonstration phase, and then presents an overview of key findings from a variety of sources of data (including the evidence from international literature and local contextual evidence that was gathered and analyzed as part of the evaluation, including quantitative and qualitative data and Program data). The report’s purpose is to assist health system planners, decision makers and providers, including RHAs and sites (e.g., Misericordia Health Centre) and Provincial government stakeholders, in learning from the evaluation of the demonstration phase as they begin developing activities for ongoing Provincial Health Contact Centre (PHCC) involvement in chronic disease management in Primary Care. For this reason, the paper is organized around key questions of relevance to these stakeholders.

Sources of evidence in this report

The analysis is based on three main sources of evidence, including 1)the international research literature on chronic disease management and health lines as a follow-up for CHF patients 2)The WRHA Directional Document on Chronic Disease, *Lifting the burden of chronic disease: What works, what hasn't, what next?* (Kreindler, 2009) 2)Program evaluation and research findings – including randomized controlled trial findings and qualitative results 3)Program Management Data

i) International Research Literature

Two vast bodies of literature are relevant to this intervention, particularly in light of the innovation of the project (e.g., new use of health lines in Canadian context) and its implications for broader system change (delivery system redesign), and include literature on

- chronic disease management
- health lines as a follow-up for CHF patients

Findings from both of these bodies of literature have been considered in this analysis.

ii) WRHA Directional Document on Chronic Disease

This document was a review of the evidence on chronic disease, prepared for decision makers and service planners at the Winnipeg Regional Health Authority. The directional document was produced in the WRHA Research and Evaluation Unit, with input from a number of decision makers and Program representatives within Community Health Services.

iii) Program Evaluation and Research Findings

An evaluation of the demonstration phase was completed with (see description of evaluation below) participation of a team of researchers and decision makers.

- **Qualitative Findings** These data included patient and provider experiences – collected through focus groups with patients in rural and urban sites, interviews with health system and government decision makers, Program management, and others. Qualitative evidence also included data collected through observational methods and document review.

How Report is organized

This report is organized into six main sections:

- ✓ Background. Evaluation Design and Methods
- ✓ Program Design and Description of Intervention
- ✓ Emerging Issues re: Self-Management Support
- ✓ Emerging Issues re: Health Services Utilization
- ✓ Emerging Systems Issues, including
 - Coordination of Care
 - Physician Engagement
 - Rural/Urban
- ✓ Areas for Further Consideration

Evaluation design

During the early phases of the project planning, the Winnipeg Regional Health Authority Primary Care Program management (under the direction of the Chief Operating Officer and Vice President Community Health Services) and Manitoba Health and Healthy Living, Division of Primary Care (by way of participation in the Multi-Jurisdictional Western Health Lines Collaborative) requested that an evaluation of the demonstration phase be conducted. There was considerable emphasis placed on the innovation and the possibility of designing the evaluation as a research study. The evaluation was developed as a partnership between external university researchers, WRHA and Central RHA Program representatives, and Manitoba Health and Healthy Living stakeholders. In the early planning phases (2004), the WRHA Primary Care Program approached Dr. Alan Katz from the University of Manitoba's Primary Care Research Unit/Manitoba Centre for Health Policy to collaborate with them in carrying out the evaluation activities. Funding was secured in 2005 from the CIHR Partnerships in Health System Improvement competition (Dr. Alan Katz, PI).

Development of Evaluation Questions

The central evaluation questions were negotiated in the developmental phase (Summer and Fall of 2004). At this time Program representatives emphasized the importance of measuring the impact of the project on patient outcomes and on the utilization of health services. The two central evaluation questions proposed were

- What was the impact of the intervention on patient health outcomes, including self-care behaviours, patient health status, satisfaction with health care services, and quality of life?

- What was the impact of the intervention on health services utilization and drug compliance?

Other evaluation questions emerged over the course of the developmental period of the demonstration phase in response to stakeholder interests. These included two supplementary evaluation questions.

- What was the impact of the intervention on coordination of care?
- What was the impact of the intervention on acceptance of health lines as a means of access to health services?

To address these questions, the evaluation was based on two different conceptual models: experimental research (RCT to determine outcomes) and utilization-focused evaluation (Patton, 1997) to inform program improvement and decision-making. Program representatives supported this design based on a commitment to the value of knowledge translation and collaborative planning in maximizing the utility of results.

Methods

a) Quantitative methods

The demonstration phase was designed as a research study with a Randomized Controlled Trial Design. A multivariate mixed model design was used to assess the effects of study group (Usual Care, HL, HL+M) on patient outcomes over time, and health care utilization patterns.¹

b) Qualitative Methods

The perspectives of stakeholders from the demonstration phase, including patients, providers and health system decision makers were explored through numerous qualitative methods including individual interviews, focus groups, and group consultations. These perspectives were also explored through participant observation at monthly and quarterly Steering Committee meetings.

Patient perspectives

Focus groups included patients from all three study arms (including the control group) at both rural and urban sites – six were held in total (n=50).

Provider perspectives

Individual interviews were conducted with family physicians (n=10), and health lines nurses (n=3) at the end of the study.

Identification of Program-Specific and Health System Issues

Senior decision-maker stakeholder (including physician leads) interviews were conducted at 3 months and at the end of the intervention (n=20). Other key methods included participant observation at Steering Committee meetings and project Working Group meetings, and document review.

Interview and focus group questions are attached in Appendices 3, 4, and 5.

¹ More specific questions on the quantitative methods used should be directed to Dr. Alan Katz, Manitoba Centre for Health Policy

SECTION 2: PROGRAM DESIGN

Context

This demonstration project provided specialized health lines chronic disease management support to patients with CHF. It was designed and administered by the WRHA Primary Care Program, in partnership with Manitoba Health and Healthy Living and Central RHA. The intervention was operated out of Manitoba's Provincial Health Contact Centre (PHCC) located at Misericordia Health Centre in Winnipeg, and involved collaboration with several fee-for-service physicians in Winnipeg and Central RHA, as well as some involvement of the Home Care Program (especially Central RHA).

The intervention expanded the core services of the PHCC (24/7 nurse-led symptom assessment and health information system), into the more integrated area of chronic disease management, which, in 2004 when the initiative was launched, was a new area of service delivery for provincial health contact centres across Canada. At the time, most health contact centres in the country operated as an add-on service, and a Western Multi-Jurisdictional Health Lines Collaboration was exploring the use of health lines in CDM (Multi-jurisdictional Steering Committee, 2004). The Program and clinical stakeholders chose CHF, based on evidence of patient need (low QoL, and severity of illness), high health care costs associated with higher rates of health care utilization, especially hospitalizations and readmissions, and home care nursing. CHF has also been linked with innovative care delivery models (Chaudhry et al, 2007).

In the context of this Program design, integration meant that the service was conducted by health lines nurses interacting with patients over the phone, and communicating with patients' family physicians about assessments (base line and six months), action plans, and patient's health status, when necessary. This service integration was a key component of the Program's innovation in self-management support, which not only intended to increase patients' management of their condition (e.g., medications, diet, symptoms recognition, and timely and appropriate use of health services), but it was anticipated that the regular interaction between health lines nurses, family physicians and patients would improve the communication between all health services providers and patients, resulting in better health outcomes for patients. The decision was also based on family physician need for support in caring for patients with CHF, and other chronic diseases, while addressing the gap in self-management support for these patients. An evidence review prepared since the demonstration project was designed, indicates that this decision is supported by evidence that self-managed care is most effective when integrated with primary care. (Kreindler, 2008)

The overall Program design was evidence-informed to the extent that it drew on three main components of principles of chronic disease management, based on the Wagner model.

- 1) delivery system redesign, including
 - integration of health lines with primary care

- role redesign (for health lines nurses and family physicians)
- 2) self-management support, including
 - health lines nurses' scheduled and tailored interaction with individual clients on the phone and regular monitoring
 - tools developed (clinical content, education material, in-home monitoring), and additional supports for medication management, symptoms management, and co-morbid conditions, provision of weight scales and blood pressure monitors.
- 3) decision support, including
 - customized patient management plan for patient, assessment, stratification through computerized prompts.

Several key principles in chronic disease management based on recent synthesis of the evidence (Kriendler, 2008) apply to the Program.

- The strongest evidence exists for **delivery system redesign**, a category that includes changes to the organization and location of care as well as to healthcare roles.
- There is also solid evidence in favour of **self-management support** that is
 - integrated into primary care (studies of lay-led programs have yielded more mixed results when unconnected to system) and
 - targeted to patients with the greatest need
- The large literature on decision support to improve physician adherence to clinical practice guidelines has yielded less promising findings: such interventions typically have only a small impact on physician behaviour, and no impact on patient outcomes. The impact of decision support on non-physician providers has not been extensively studied.

While research indicates the value of integrating these multiple components (Kreindler, 2008), there is much that we do not know about the effectiveness of particular interventions, alone or in combination, within the local context. In fact, a number of high priority questions of relevance to Program planning and health system improvement, more generally, remain unanswered in the literature. These include (but are not confined to) the following

- How does chronic disease care compare between telephone and face-to-face encounters from patient and provider perspectives?
- Are health lines interventions more effective for some populations than others (e.g., older vs. younger, rural vs. urban; low SES vs. average or high SES)?
- Which patients constitute the patients of greatest need for this program?
- Who should coordinate health lines interventions (specialist or primary care practitioner)?

Description of intervention

All participants in the program (with the exception of the control group for the first 6 months of the demonstration phase) received the basic Health Lines intervention, which

was designed (as discussed above) to provide self-management support to patients living with CHF. An enhancement to the regular intervention was developed which provided in-home monitoring devices to patient enrolled in the program.

Health Lines Group of Patients (HL)

For the purposes of this paper, the group of participants who received this intervention without enhancement will be referred to as the **HL** group.

For all participants, the initiative involved nurses supporting patients over the phone in the management of their Congestive Heart Failure. Upon enrolment into the program, the health lines nurse would do an individual assessment over the phone with participants. Based on current medications, heart failure severity, psychosocial status, co-morbidities etc., nurses were able to stratify patients and develop a customized management plan for each one. The content of the program covered a large scope of issues relating to self-management of CHF, and included education relating to heart failure basics, diet, preventative strategies, as well as support in home monitoring of symptoms, medication adherence, and other self-care strategies. Nurses also referred participants to local support services, when necessary. After the initial assessment at baseline, each participant received a call schedule tailored to the severity of his/her disease, and was able to call the nurse any time with questions or concerns about symptoms or self-management support. Nurses made regular contact with patients' family physicians on issues related to patient assessments, health action plans, and symptoms necessitating medical intervention. The software module prompted nurses with physician alerts, based on clinical monitoring and ongoing evaluation to re-assess patient risk.

Health lines nurses worked from one central location, but patients and physicians were enrolled from both urban and rural sites. The urban patients who participated in the project resided in the Winnipeg Health Region, and their family physicians practiced within Winnipeg, and were primarily fee-for-service physicians, and a few salaried physicians working for WRHA direct operations. The rural patients involved lived within the boundaries of Central Regional Health Authority, and most of them were patients of family physicians working in one "group practice".

Health Lines + Monitoring Group of Patients (HL+M)

An enhancement to the basic Health Lines intervention for patients with CHF, referred to in the following as **HL+M**, was designed in the early phases of the demonstration phase. This included in-home monitoring devices (weight scales and blood pressure cuffs) and a computerized call schedule that prompted patients to enter in weights and blood pressures regularly throughout the year. Patients in the **HL+M** group received the Health Lines intervention described as **HL** above, in addition to the enhancement. Unlike the patients who simply received the HL intervention, these patients were provided with in-home monitoring devices, and trained to use them (by home care nurses, and/or health lines nurses) in their homes. A phone system was developed to prompt patients to receive three automated phone calls per week, during which they were prompted to enter their weights and blood pressures, and to answer (one or two questions relating to their self-rated Health Status and QoL). Unless a patient was showing symptoms or warning signs

through their telephonic submission of weights and blood pressure, he/she had no contact with the nurses beyond the regular call schedules (as described above as **HL** group). In cases where patients were showing symptoms out of the regular range, the nurses would be alerted by the software to call them and follow-up. At this point the nurses would follow-up and contact the patients' family doctor and advise the patient on where/how to seek care if necessary.

Profile and discussion of patient and physician participants

The project was successful in enrolling 106 urban patients served by 61 urban physicians and 70 rural patients served by 22 rural physicians. 51 patients were excluded from the study because they did not have a family physician willing to participate in the study.

There was a physician lead for both urban and rural sites.

As noted in the recruitment section above, most of the patients enrolled matched the eligibility criteria of

- Adults of 40+ years
- Resides in Winnipeg or Central Health regions
- New York Heart Association levels II, III and IV of CHF [severity] (NYHA Level I were excluded)
- English speaking
- No significant cognitive, physical or visual impairment
- No rotary phone, land line (no cell phones)
- Not terminally ill

The recruitment of family physician support for this project was difficult, warranting further attention in the development of further activities for ongoing Provincial Health Contact Centre (PHCC) involvement in chronic disease management in Primary care. Some of the barriers to physician participation included, lack of a history of involvement with the WRHA at the time of the launch of the demonstration phase in 2004, lack of engagement and education around the development of the intervention, and undeveloped links to CHF specialized services.

While the patient profile of the demonstration phase was diverse in terms of gender, age, and disease severity, evidence of patients who did not access the program is lacking. For example, there were some instances where patients who were younger than 40 expressed strong interest in participating in the program, and a few of them were enrolled based on individual assessment, and special consideration. Program leads from Central RHA noted that there were difficulties in recruiting patients from First Nations communities within their region. Further development of the patient profile of those who participated in the demonstration phase (with regard to age, gender, SES, ethnicity and culture, rural and urban) is warranted, as well as an understanding of who did not access the Program but could have benefitted.

SECTION 3: SELF-MANAGEMENT SUPPORT

The self-management support component of the intervention, central to the Program design, was also key to its overall success, primarily from the perspective of health lines nurses and patients. As discussed in Section 2 above, there is solid international research evidence in favour of self-management support that *is integrated with primary care* and that is *targeted to patients with the greatest need*. While these elements are integral to the most effective chronic disease management initiatives, local contextual evidence is needed to understand which elements of the program worked better than others.

Key successes of health lines self-management support

- From a patient perspective, there was stronger evidence of preference for one model of self-management support (the core HL service) over the other model with enhancement (HL+M). There was a marked difference in perspectives between the HL and the HL+M groups.
 - Patient experiences of self-management differed between the HL group and the HL+M group. The HL group expressed a more general appreciation for the comprehensive self-management content of the program, of which regular contact with the health lines nurses was key, while the HL+M group were much more focused on their CHF related symptoms (e.g., fluid retention, change in blood pressure) and how to manage those symptoms. This difference may have influenced the quantitative findings for the HL+M group, discussed above.
 - Patients describing the success of the program from the HL group indicated that it improved their overall functional status (a measure of self-report health status) and quality of life, stating, “somebody cares about you;” “it’s funny though, the study, how it makes you realize how much you want to live...To take care of yourself if you want to get, you know, quality of life...”; “somebody to keep track of you.”
 - In describing the successes of the Program, from their perspective, many who received the HL+M intervention, spoke of the comprehensive self-management support (and not enhanced monitoring), stating “and the contact with the nurses is important because you felt somebody at the other end of the line was there.”... “I was able to establish a pattern. So I presume that’s a usefulness in that. And if you deviated from that pattern, they were Johnny on the spot with a phone call.”
- The local contextual evidence showing the difference in perception of the successes of the program between the HL and the HL+M group support the international research literature that found Programs focusing on self-management support and less on monitoring are generally more successful. Despite this difference, qualitative findings indicated that patients in the HL group recognized

symptom management as part of a more comprehensive self-management support program.

- The need for regular support from a health care professional (health lines nurse/family physician) appeared to be great for many of the patients who participated in the project. Many of the patients on the program (in both the HL and the HL+M group) lived with co-morbidities (many of them serious – cancer, COPD, diabetes, arthritis), and spoke at length about the difficulty they faced in distinguishing heart failure issues from other health issues. Some also spoke of their ongoing concerns about the impact of the degeneration of a co-morbid condition on their heart health, while others were concerned about the stress associated with poor health combined with isolation. The regular contact with the health lines nurses alleviated some of these concerns, confirming the international research evidence findings that peer support programs on their own are less effective than those that are integrated with primary care.
- Many of the participants did not have a basic understanding of their condition before they enrolled in the Program, and described numerous health benefits to participating, as one patient said, “it educated me about my condition. And I didn’t panic when certain things happened and the like.”
 - A large number of patients did not know that they had a diagnosis of CHF until they received a letter from their doctor indicating they were eligible to participate in the demonstration phase.
 - A large number of patients were confused about what it meant to have CHF because they either had too much information from their specialist or family physician or not enough information, as one patient stated “and I know nothing actually about my condition except what I’m picking up from different sources and I would sooner have a sort of reliable source.”
 - This lack of understanding was exacerbated by patients with co-morbid conditions, making it difficult for many of them to distinguish which condition was making them feel ill. [this may also have influenced the way that they answered questions on the surveys]
 - “ok, I have congestive heart failure, this is what I have to do about it and I think I’ve been healthier for that because, I’m not sort of pretending that I don’t have it or acting like I don’t have it therefore getting into trouble because I can’t do the things other people can.”
- A large number of the patients from the HL group spoke of elements of self-care that they learned by participating in the Program. Some of these patients, however, were practicing elements of self-care before participating, so it is difficult to attribute all learnings to the Program. It is also difficult to determine how long these self-care behaviours continued after participation in the Program, because the study did not follow-up patients after one year.
 - Most patients appreciated the instruction about not using salt in their diet, cooking without salt, and reading labels in the grocery store.

- Many patients were also confused about how much water to drink, and benefited from advice on this (especially in terms of medication management).
 - Many patients stated that they were now weighing themselves every day
 - Some patients said they bought blood pressure cuffs when started the Program and began keeping track on logs (HL group).
 - Many became more active, quit smoking etc.
- Many patients expressed confusion over the tests that they were receiving (regular blood work) and medications, and did not always differentiate the relevant diseases for each one, or which provider they should be talking to. The nurses often assisted them to sort out some of these issues, or to know how to ask the right questions.
 - **There was general support from a patient perspective of the use of the telephone for core self-management support associated with this Program.** In fact, many patients were supportive of telephone access, especially in those living in rural areas. Some of the specific reasons for patients accepting the telephone, included,
 - The regular call schedules were critical to patients' acceptance of the health lines technology. Patients generally would anticipate the call from the nurses, which was tailored to the reality of their home lives. Tailored/scheduled call schedules was underlined by many patients in the focus groups as a key success of the program.

Discussion: self-management support

According to the WRHA Chronic Disease directional document (Kreindler, 2008); self-management programs are most effective when integrated with primary care, and targeted to the patients with the highest needs. The first of these elements (integrated with primary care) was a fundamental factor in patient and provider experiences of the self-management component of the Program (the part that was nurse-managed). This was supported by evidence of strong preference for the core HL self-management support.

Besides integration with primary care, the international research evidence, indicates that self-management support programs are more effective when targeting patients with the highest need. Based on this international evidence and emerging evaluation findings, more Program planning is required in determining the population with highest need for this intervention. Focus groups with patients suggested that patients with co-morbidities (primarily elderly, although not exclusively) and rural patients benefitted most from the intervention. It is also noteworthy that many physicians recommended specific patients from their rosters to participate in the program. In interviews many of them also indicated that these were patients who had high hospitalizations, co-morbidities, and high physician visits. The evaluation for the demonstration phase was not designed to assess the outcomes based on age, gender, disease severity, and other social characteristics of the

participants. Further evaluation or analysis of the findings based on patient characteristics is suggested to gain further understanding of differential impact.

Those patients who did not benefit as much as others, according to nurses, were patients who signed up for the intervention because their physicians suggested they participate, and were reluctant to join from the beginning. Nurses also spoke about how some of these patients ended up “coming around” (because of health scares during the demonstration phase and other reasons) to appreciating the benefit of the Program, starting out reluctantly and ending more engaged. More thought needs to be given to the reasons for these differences and what “embracing the Program” means when it comes to issues of disease management.

Key challenges of the in-home monitoring component

As indicated in the section above, evidence from patient and provider perspectives indicated the monitoring technology was not just an add-on, but changed the nature of the intervention significantly. There was no demonstrated effect on the HL+M group in functional status (e.g., working around the house or yards; doing things with family; lifting or carrying groceries), self-care behaviours or emotional or mental health. Patient perspectives supported the finding that the HL+M patients were less positive about the program than the HL group. An analysis of the difference between these two groups points to the need for further thought on the effectiveness of the use of technologies in chronic disease management. As one patient stated, “human contact is a lot better.” (HL+M participant.).

- Some of the older patients stated they had difficulty catching onto the automated system, as one participant stated, “A young person thought up the system and old folks can’t catch up to it.” (HL+M participant).
- Some of the patients in the HL+M group were monitoring their blood pressure before they had entered the program (this monitoring may have been in regard to co-morbid condition) and recalled being confused by the enhancement.
- The monitoring enhancement required that patients had the ability to punch in accurate readings of weight, blood pressure, and self-reported health measures three times a week. Some patients expressed frustration over the frequency of these calls. Others recalled that if they made a mistake in pressing the wrong number, the nurses would follow-up right away with a phone call. While many of them appreciated the quick nurse response, those who made mistakes more often, felt that the nurse follow-up was at times cumbersome (especially for those who worked or had busier family lives). Some patients spoke of their answering machines being clogged up with automated messages if they were on vacation and had forgotten to alert the Program. The PHCC made adjustments to stop calls if patients were alerted to their absence. The message that would be left on answering machines was also made shorter.

- A few patients felt that the weight scales provided as in-home monitoring devices were too large for their apartments or homes (this was discussed mostly in the Winnipeg groups). The scales provided were larger to accommodate patients who had difficulty reading the numbers.
- A number of younger patients from the monitoring group stated that they disliked being monitored so closely because they perceived their personal practices as being monitored (e.g., weight gain because of attending a wedding on the weekend etc.). Information on the severity of the illness of those patients who were concerned about monitoring is unknown.
- Many patients provided feedback to the nurses about the research survey questionnaires, complaining that they were too long and took over one hour to complete. Patients indicated that they were exhausted by filling them out; and felt that the questions were ambiguous, especially if they were stated negatively. “I cannot say that I gained a great deal by taking part in the program. I was certainly pleased that I could call the nurses and ask questions....I could not quite see that there was going to be a great deal of information gathered from them [questionnaires] (HL+M). Another patient echoed these comments: “Those long questionnaires, I found them useless. Because you don’t feel the same every day.”

Discussion: challenges of monitoring technology

The three-times a week phone call may have negatively influenced these patients’ perceptions of their health (because of monitoring too much). In focus groups they tended to speak repeatedly of symptoms such as swollen legs and feet, blood pressure etc. By contrast, the patients who received the HL care generally stressed the program enhanced their will to live and provided them with a more positive outlook on life, and spoke of activities that they were able to do (e.g., gardening, snow shoveling etc.), as opposed to the barriers. The extent to which the introduction of the in-home monitoring devices, and automated calling technologies changed the nature of the intervention, and influenced patients’ experiences of the Program, strongly indicates that much further thought needs to be given to the introduction of new technologies in chronic disease management and the frequency of home monitoring.

At what point is it best to enroll patients in the program?

Many patients indicated that they would benefit most from the program if enrolled at the time of diagnosis, but there was little consensus about what “diagnosis” actually meant (e.g., upon discharge from heart surgery, family physician diagnosis, specialist diagnosis etc.).

- A number of patients knew of their CHF diagnosis, but stated that they knew little about what it meant.
- Some patients spoke of being in “denial” until their condition deteriorated to the point where they had to do something about it.

- Many patients did not know they had CHF until they received a letter in the mail inviting them to participate in the intervention. Would these patients have “fallen through the cracks” if they had not been informed of their condition?
- Many patients had had heart surgeries or had been hospitalized as a result of their conditions. These patients had indicated that this program would have been very useful upon discharge from the hospital.
- Patients who had been living with CHF for a number of years (since the 80s) understood it to be a terminal condition – getting a little worse every day and trying to change lives to be able to live with it – and were appreciative of the self-management support at the later point in their disease.
- *Others spoke about feeling overwhelmed by information upon diagnosis and felt that the consistent follow-up with the nurses was a positive aspect of the project.* As when [male name] was diagnosed in 1999, there was so much information came at you initially. It was hard, because of the shock of being told what was wrong. There was so much information it was hard to retain everything that they told you.

Discussion: When to enroll patients in the Program

It is noteworthy that the point of “diagnosis” was not understood by all patients in the same way, and these factors need to be taken into consideration in planning further activities for PHCC involvement in chronic disease management. Some patients had been recently discharged from hospital after having heart surgery, others had been living with the condition since the 1980s, and others were not aware of the fact that they had CHF until they were enrolled in the program by their family doctor, or until they received a letter in the mail from the provincial department of Health and Healthy Living. The great need identified by patients for follow-up after discharge from hospital may be attributed to patients identifying lack of coordination with services in the community. For example, it is unknown how many patients had been referred to cardiac rehab after surgery; but those who spoke of receiving specialist care perceived great value in the service. That there was a wide variability in the circumstances upon which patients were enrolled in the program (at baseline some patients had been diagnosed since the 1970s, while others did not realize that they had a diagnosis), points to the importance of thinking critically about the health status of patients at “baseline” when interpreting findings related to impact of the service on patient outcomes. There is a need to better coordinate community services and ensure populations at risk and most likely to benefit from chronic disease management support are referred to appropriate programs, such as cardiac rehabilitation and Provincial Health Contact Centre services.

SECTION 4: EMERGING SYSTEMS ISSUES

a) ACCESS AND COORDINATION OF CARE

One of the program objectives of the demonstration phase was *to improve coordination and integration of health care providers to effectively manage Congestive Heart Failure via delivery through telephony*. Coordination of care in the demonstration phase focused on that between family physicians and health lines nurses working out of the Provincial Health Contact Centre (PHCC). Integration of the service between specialists and community-based services (e.g., peer led groups) was not in scope of the demonstration phase and may be explored in the future designs of the initiative.

How did patients perceive the Program influencing access to health care services?

Research evidence indicates that integrating chronic disease management services with primary care is a key component for designing effective programs. A strong theme emerging from patient and provider experiences of the demonstration phase was a perception that the health lines service did improve access to health care services, thus enhancing continuity of care for patients.

- Most of the participants expressed frustration about getting access to their family doctors in a timely way, indicating that waits were usually around 4 weeks for an appointment.
- Many patients with co-morbid conditions felt they had to choose between health issues for timely appointments, and would deal with different symptoms separately. They appreciated the support offered by the health lines nurses regarding their CHF and other conditions.
- Many of these patients stated the program facilitated easier access to their family doctors. “I got in next week because I am in the heart program.” Another patient said, “The best part of the program is that they notify your doctor.”
- In general, patients were pleasantly surprised with the integration of the family physicians into the program and the physician initiated follow-up that occurred at times throughout the intervention year: *“I feel, I certainly feel 900% in favour of the human contact. And you’re right about the reporting to the doctor. Because on one occasion, I almost dropped my britches when the doctor phoned me, you know. And to tell me that you be at the clinic at such and such a time and wanted to see me.”*

Did the health lines service improve coordination of care for patients?

Patients described interactions with many levels of care, including specialists, tertiary, ER, home care and primary care in dealing with their CHF and other co-morbid

conditions. Several themes did emerge from the qualitative research relating to *the role of health lines in coordination of care for patients with CHF*. Patients generally were concerned about maintaining continuity of care with a primary care provider, but found difficulty in achieving coordination within the system, as it is set up now. They spoke of family physicians being too busy to see them in a timely way, they spoke of having to confine appointments to 15 minutes and not getting to cover all questions, they spoke of worrying about lack of communication between levels of care as potentially harmful to their health, indicating that links between primary care and specialty service, advanced access and other forms of integration would enhance the appropriateness of care, improving patients' health. Many of the patients developed strong attachment to the nurses over the course of the one-year intervention, and valued this relationship

- A number of patients interviewed associated better coordination of care as a result of the health lines service with better health outcomes. As one patient's comments highlighted, *Like I made an appointment in January. And then I had to wait until, what was it, March sometime before I could get in to see him even. You know. And at that time I was very sick then and I really needed a doctor. But then I just had to go to the Emergency and, you know, it's not the same as your own doctor. I always feel your own doctor knows everything about you. So, you know, like and they were just giving me morphine and Demerol and sending me home all the time. And I was just sleeping, sleeping, sleeping. And it wasn't helping the problem. Oh that infection was there and then when they realized the infection, they had me on antibiotics like for 6 months. Like I had no, no communication with my doctor at all.*

Discussion: Patients' perceptions of access and the importance of coordination

Many patients believed that being part of the demonstration phase, increased their access to family physicians when they needed it. Participants from both urban and rural sites spoke about having to wait 4 or 5 weeks to get an appointment with their family doctor, and expressed frustration and worry about the potential impacts of long waits on their health and well-being. Many of the rural patients stated they took measures to get to see their own family doctors sooner than they were able to with regular clinic scheduling. For example, patients in the rural RHA spoke of having "spies" at the walk-in clinics to find out when their own family doctor would be working, and others stated that they used ER visits to alert their family physicians to see them sooner (a phone call the next morning to the clinic). Patients' perceptions of the importance of continuity of care (seeing their own family physician rather than a walk-in or locum) was strong, and many indicated that participating in the program gave many of them quicker access to their doctors and more desired continuity of care. This was important for rural patients and elderly patients who did not have to travel at all to access healthcare advice. These findings are supported in the international research literature that advanced access in primary care is key in meeting patients' needs for more timely and appropriate care (e.g., continuity of care) (Kreindler, 2008).

It should also be noted that the demonstration phase had envisioned the network of providers involved in the intervention to extend to home care, dieticians, ER, and specialists (at some point), however these interactions were undeveloped during the demonstration phase. There was some link to home care in both Central RHA and WRHA, and the homecare nurses were keen to assist in enhancing the process (e.g., assisting patients with in-home monitoring devices). However, integration of these services with the home care program was underdeveloped. Further thought needs to be given to the role of other providers, including specialist services as further activities are developed to enhance chronic disease management and the role of the PHCC in chronic disease management.

What were the perspectives of family physicians on what was working well and challenges of the Program?

The role played by physicians in this intervention has been recognized as one of the strengths of the design of the project and its potential for succeeding.

What was working well? Family physicians interviewed for the evaluation (n=10) were supportive of the intervention for a number of reasons, including the fact that it addressed many of the frustrations that they were having in providing quality care to patients with chronic diseases, including timely access; difficulties with ensuring follow-up appointments; medication adherence (“when get better, stop taking pills”), and 15 minute appointments for complex cases. The general sense was that this program addressed many of these concerns and that it “wasn’t a huge time commitment”.

A number of physicians felt that those patients who benefitted the most from the intervention were patients with less severe to moderate CHF –(Classes 1-3). A few physicians felt that the Program should be scaled back or tailored for patients with mild CHF; because some of them paid more attention to their illness than was warranted. Physicians also identified other patients as benefiting from the intervention including,

- elderly and less mobile patients, who had difficulty getting to the doctor’s office
- patients who use the ER frequently
- newly diagnosed patients
- potentially all patients with CHF

Challenges. Physicians identified a number of challenges with the demonstration project as it was designed, and most of those challenges related to inter-professional communication, primarily with the health lines nurses. The issues identified included,

- Many physicians were concerned with the volume of the faxes received. Some of their suggestions for improvement included, phone calls from nurses if patient requires attention; summarizes the patient updates in one page (or like a dashboard report).
- Many of the physicians interviewed suggested that the Program would benefit from more direct in-person interaction between nurses and physicians (e.g., monthly meetings)

Did the Program improve communication between health lines nurses and family physicians?

Nurses' perspectives:

- Health lines nurses highlighted the communication challenges that they had with the family physicians involved. The reasons for communications challenges were complex and numerous.
- The extent to which nurses felt part of a team with physicians in the care of the patients varied greatly and depended on the physician involved. Nurses stated that there were some physicians who embraced the project from the outset and others who came around to embracing the project after initial reluctance. A few of the physician participants did not embrace the project at all.
- Most Winnipeg physicians said that they did not feel like part of a team with the health lines nurses, and emphasized that they wanted to be more of a part of a team with nurses and other health care professionals. It is unclear whether rural physician participants felt as part of a team.
- Nurses strongly indicated that they and the patients would have benefitted from an expanded nursing role (scope of practice) to provide more autonomy over patient care in chronic disease management. For example, they often remarked on cases where standing orders from family physicians would have been helpful. While some physicians did include standing orders on the Action Plan, many did not complete the Action plans, and wanted to maintain control of patient care, while participating in the collaborative program.

Communication between providers relating to patient care

- Nurses and physicians expressed similar concern and frustration over communication processes around patient monitoring and care. Family physicians attributed the frustration to the amount of paper that they received by fax from the health lines nurses, despite the Program's response to complaints by streamlining the reporting,
- Many physicians wanted some face-to-face contact (e.g., one meeting every six months) with nurses instead of communication by fax and through telephone, and suggested that the program be "stream-lined" (e.g., less paper and more face-to-face communication with health lines nurses) to better suit their practice needs.

4b) ISSUES OF PHYSICIAN ENGAGEMENT

At the time the demonstration project was developed, there was little engagement of family physicians and the WRHA and Central RHA. Despite this lack of formal engagement with family physicians, efforts were made to design the intervention with the physician perspective in mind. The WRHA Medical Director of Primary Care was on the Steering Committee and participated in the clinical working group; the external evaluator also brought family physician expertise to the project. Expertise from other family physicians was sought through physician leads (one rural and one urban) who participated on the Steering Committee for the first year of the demonstration project.

- Many of the physicians who participated felt that this type of initiative was an appropriate way for regional health authorities to work with them and were positive about continuing that relationship, especially around issues of chronic disease management. This is especially noteworthy now as the WRHA and Central RHA are working hard at strengthening working relationships with family physicians throughout the community.
- Even though physician engagement was attempted in the developmental stages of the demonstration project, physicians felt strongly that as the initiative develops further, there should be more physician engagement in the design and implementation of the initiative. Many suggested streamlining the communication processes with nurses to better suit the reality of their practices, more face-to-face communication with nurses about specific patients enrolled in the program (e.g., regular scheduled meeting between providers), sharing of information on the effectiveness of the project (e.g., impact on patient outcomes).
- Family doctors interviewed for the study felt that chronic disease was a huge issue in their practices and welcomed leadership and assistance in dealing with this. Most of their frustrations were around high cost of medication (having to prescribe medication they know patients cannot afford); adherence to treatment (medication); lack of self-care and follow-up.
- Most physicians interviewed said they felt isolated and alone in dealing with complex cases, and welcomed the opportunity for any kind of assistance in caring for these patients.

This evidence from physician interviews for this study supports what the chronic disease management literature says works regarding the implementation of chronic disease initiatives. For example, important principles in choosing and implementing interventions, from the literature include,

- focus on one high-priority change at a time,
- ensure staff and patient engagement in order to improve the design and implementation of interventions,
- consider impacts on underserved populations

4c) RURAL/URBAN COMPARISON

While a rural-urban comparison was not identified as an evaluation question at the developmental phases, *a synthesis of the qualitative evidence gathered as part of the evaluation indicated that the Program had a greater impact in the rural site than in Winnipeg*. Rural participants in the focus groups were more enthusiastic about the program, spent more time discussing the self-management practices they learned (including cooking without salt, active living, etc.). Significantly, rural participants indicated that the use of health lines facilitated their access to health care, cutting down on travel time, and, as indicated in the section above, some of them indicated that they had easier access to their physicians. More participants from the rural sites indicated that the Program led to more timely access to physician than others. Evidence from interviews with nurses, and observational methods also supported the finding that the program was more successful in the rural RHA. Further focused research is required to be conclusive about this finding -- evidence from the research literature is lacking in comparing telephony interventions between rural and urban sites. In addition, the quantitative analysis did not compare rural and urban participants in terms of the patient outcome measures.

Some of the reasons for the better uptake in rural may have been related to the demographic and social characteristics of the participants comparing rural and urban sites. Other reasons may have to do with the fact that they were affiliated with one clinic and the communication between health lines nurses and the physicians of that clinic was generally more successful. For example, the health lines nurses communicated with the same clinic receptionists and nurses (more familiarity). There was also strong physician leadership in the rural site. In Winnipeg, there was far more diversity in physicians involved and many patients were referred through letters from Manitoba Health etc. Significantly, people living with CHF from Aboriginal communities within the rural RHA did not participate, despite targeted recruitment efforts.

SECTION 5: BUILDING ON SUCCESSES: AREAS FOR FURTHER CONSIDERATION

Key successes from patients' perspectives

The need for regular support from a team of health care professionals (in this case, health lines nurses, family physicians, and home care nurses to a lesser extent) communicating regularly with each other was important for many patients, especially those who were older and had serious co-morbidities – cancer, COPD, arthritis. The elements of self-management support that seemed to work the most was the human dimension: the follow-up, continuity (relationships developed with nurses), and “someone who cares”. Further development and expansion should build on these successful elements.

Health services utilization

The Research component of the evaluation, led by Dr. Alan Katz, focused on effectiveness in terms of patient use of health services (with the exception of Emergency Department).¹ More monitoring of the Program's impact Program on ER visits and hospitalizations as the program expands is needed, as is more thought on different health services utilization patterns for different chronic diseases (e.g., is CHF a condition with higher/different acute care use patterns than diabetes?).

Integration with Primary Care

The demonstration phase focused on integrating the Provincial Health Contact Centre health lines service with primary care by requiring patients and their family physicians to participate and by developing regular communication mechanisms between health lines nurses and family physicians around patients' health. There is strong evidence that this integration with primary care was central to the success of the Program, and improved coordination of care. More thought and evaluation of the further integration of the Program into specialty care, other points of care (e.g., ER), and community-based services (e.g., home care, and chronic disease support services) needs to be done.

Technologies

The extent to which the introduction of the in-home monitoring devices and automated calling technologies changed the nature of the intervention and influenced patient experiences of the Program, strongly indicates that much further thought needs to be given to the relative benefit of the introduction of technologies in chronic disease management.

Patient perspectives on access and continuity of care

Patients perceptions of the importance of continuity of care (seeing their own family physician rather than a walk-in or locum) was strong, and many indicated that participating in the program gave many of them quicker access to their doctors and more desired continuity of care. This was important for rural patients and elderly patients who

¹ The research results are found in Alan Katz and Malcolm Doupe, Preliminary Report of Research Findings from the Chronic Disease Management of Congestive Heart Failure via Health Lines, (unpublished) March 2009. To obtain a copy of the report, contact Dr. Alan Katz directly.

did not have to travel at all to access healthcare advice. These findings are supported in the international research literature that advanced access in primary care is key in meeting patients needs for more timely and appropriate care (e.g., continuity of care) (Kreindler, 2008).

Population of greatest need

More program thinking is required on identifying the population of greatest need for this intervention. Further development of the patient profile of those who participated in the demonstration phase (with regard to age, gender, SES, ethnicity and culture, rural and urban) is warranted, as well as an understanding of who did not access the Program but could have benefitted (e.g., some First Nations communities in the rural RHA). The perspectives of health professionals are also central to identifying these populations. Further evaluation or analysis of the findings based on patient characteristics is suggested to gain further understanding of differential impact.

When to introduce the service to patients

Many patients indicated that they would benefit most from the Program if enrolled at the time of diagnosis, but there was little consensus about what “diagnosis” actually meant (e.g., discharge from heart surgery, family physicians diagnosis, specialist diagnosis, self-diagnosis (coming to terms with illness after a few months)). Several access points is the recommendation here. There is a need to better coordinate community services and ensure populations at risk and most likely to benefit from chronic disease management support are referred to appropriate programs, such as cardiac rehabilitation and Provincial Health Contact Centre services.

Interprofessional communication

Nurses and family physicians expressed similar concerns and frustration over communication processes around patient monitoring and care. Family physicians attributed the frustration to the amount of paper that they received by fax from the health lines nurses. Some physicians also felt that the action plans were time consuming to fill out. Nurses’ expressed frustration at the difficulty in reaching many physicians offices and in getting a response back. Both groups appreciated the importance of communicating with each other regularly about patient care, but neither felt like they were really part of a team in this intervention. More thought needs to be given to address the sources of frustration and concern of providers around communication.

Family physician engagement

Recruitment of family physician for this project was difficult, for a number of reasons such as lack of a history of family physician involvement with the WRHA at the time of the demonstration phase in 2004, and lack of engagement and education around the development of the initiative. The research component may have been a barrier to some physician participation. A number of family physicians did participate in evaluation activities, and it is recommended that communication of evaluation findings to physician participants would be important. Issues of engagement and involvement of family physicians in further expansion and development of the intervention is needed.

Rural/Urban

While a rural-urban comparison was not identified as a focused evaluation question there were several findings that highlight the need for further thinking about rural and urban differences in the delivery and impact of this service. There appeared to be stronger uptake of the intervention among rural participants than urban. For example, rural participants indicated that the use of health lines facilitated their access to health care, cutting down on travel time, and facilitated access to their family physicians. A possible reason for the relative success may be associated with the fact that the rural physician participants were affiliated with one clinic and the communication between health lines nurses and the physicians of that clinic was generally more successful. Further thought and evaluation needs to be given to rural-urban comparison.

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APPENDIX 1

Questions for Nurses Focus Groups

Testing the Effectiveness of Health Lines in Chronic Disease Management of Congestive Heart Failure

Issue 1: Overall Successes and Failures of the Program

- 1. What did you see as the key successes and failures of the CDM Program?
We will begin with a discussion of the successes:*

prompts

- In terms of patient health*
- In terms of nursing roles*
- In terms of health lines*

Issue 2: Interaction with Other Providers involved in the Program

- 1. Discuss the aspects of your working relationship with other providers in this program that worked well and those that did not work so well.*
- 2. Did this program improve or impede team based care for the CHF population?*

prompts

- Physicians*
- Home Care Providers*
- Others*

Issue 3: Adequacy of the Administration of the Program

- 1. What kind of methods of getting problems addressed in the day-to-day operation of the program worked and what would you like to see changed?*

prompts

- Regarding the technology*
- Regarding issues with patients*
- Regarding issues with other providers*

Issue 4: Relevance of Program to the Patient Population

- 1. How would you describe the patient population, in terms of demographics and health status.*
- 2. How did you see this program adequately addressing the needs of the patient population*

prompts

Regarding the appropriateness of the technology
Regarding access to health services
Regarding early detection
Regarding prevention of CHF exacerbations
Regarding closer/ongoing monitoring of these patients

Issue 5:General Comments

- 1. How would you feel about getting involved in this program again?*
- 2.If you were asked to be involved in this type of program again – what things would you want to see done differently?*

APPENDIX 2

Questions for Physician Interviews

Testing the Effectiveness of Health Lines in Chronic Disease Management of Congestive Heart Failure

Introduction:

1. Discuss the key challenges that you face with patients with chronic diseases in your practice.

Issue 1: Overall Successes and Failures of the Program

1. *What did you see as the key successes and failures of the CDM Program?*

We will begin with a discussion of the successes:

In terms of patient health

In terms of physician roles

In terms of health lines

In terms of time commitment

Issue 2: Interaction with Other Providers involved in the Program

2. *Discuss the aspects of your working relationship with other providers in this program that worked well and those that did not work so well.*

Nurses

Home Care Providers

Others

Issue 3: Adequacy of the Administration of the Program

2. *What kind of methods of getting problems addressed in the day-to-day operation of the program worked and what would you like to see changed?*

Regarding the technology

Regarding issues with patients

Regarding issues with other providers

Issue 4: Relevance of Program to the Patient Population

1. *How would you describe the patient population, in terms of demographics and health status.*

2. *How did you see this program adequately addressing the needs of the patient population*

Regarding the appropriateness of the technology

Regarding access to health services

Issue 5: General Comments

APPENDIX 3

Questions for Patients Focus Groups

Testing the Effectiveness of Health Lines in Chronic Disease Management of Congestive Heart Failure

Issue 1: Overall Successes and Failures of the Program

1. What did you see as the key successes and failures of the CDM Program?

We will begin with a discussion of the successes:

In terms of your health

In terms of your using health lines

In terms of your time commitment

Issue 2: Interaction with Providers involved in the Program

3. Discuss the aspects of your relationship with your health care providers in this program that worked well and those that did not work so well.

Physicians

Nurses

Home Care workers

Issue 3: Adequacy of the Administration of the Program

3. What kind of methods of getting problems addressed in your day-to-day participation in the program worked and what would you like to see changed?

Regarding the use of health lines

Regarding getting health issues addressed

Issue 4: Relevance of Program to the Patient Population

1. How did you see this program adequately addressing your needs as a CHF patient

Regarding the appropriateness of the technology

Regarding access to health services

Issue 5: General Comments

1. How would you feel about getting involved in this program again?