“It’s Hard to Paddle Upstream, When You’re Caught in the Current…”

Supporting Self-Management in Rural Older Adults with Heart Failure

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- Heart failure (HF) is complex, progressive chronic condition that is expected to reach epidemic proportions by 2030 (Heart & Stroke Foundation, 2003)

- Effects 400,000 Canadians & 6-10% of those over 65

- Leading cause of hospitalization, readmissions & death from CV disease in older adults

- Outcomes: higher rates of mortality, hospitalization & higher likelihood of *not* receiving appropriate pharmacological management (CIHI, 2006; Johansen et al., 2003; Jin et al., 2003)

- Due to to a complex interplay of social, economic, health care & cultural determinants (Chow et al., 2005; McKibbon et al., 2008): higher proportions of older adults residing in rural areas, lack of access to health care, lower SES & a lack of resources to effectively diagnose or manage HF

- Most HF SM occurs at home in the community over the long term (Hicks & Holm, 2004). Estimated 80% of HF provider care occurs in PHC settings. Evidence for the effectiveness of SM support integrated into PHC settings is strong (Brownson et al., 2007; Kreindler, 2009)

- Primary SM & nurse-led HF disease management interventions have been proposed as strategies to reduce the burden of HF in rural communities (Caldwell et al., 2005; Clark et al., 2008).

- Evidence for integration of HF disease management interventions into PHC is equivocal/inconclusive.

- To describe the need for use of SM by rural older adults with HF & the support for SM provided by PHC providers
- From the perspectives of those with HF, their caregivers and PHC providers within the rural context
- Based on self-regulation theory encompassing SM as health promotion measures within chronic disease prevention & management continuum.

- Concurrent, embedded mixed methods design with qualitative methods dominant

- Semi-structured interviews based on qualitative descriptive methods conducted to provide an interpretive description of the SM needs of rural older adults with HF & impact of SM support from PHC providers. Content analysis used to identify emerging themes.

- Quantitative data gathered using the Patient Association of Chronic Illness Care (PACIC) survey (Glasgow et al., 2005) to describe elements of SM support.

- Setting: Rural SW (Grey-Bruce) & SE Ontario (Lanark, Leeds-Grenville)

- 6 PHC sites recruited to ensure diversity of regions & provider make-up: small to medium community clinics & FHTs in communities designated medically under-served

- Rural defined in terms of geographical locations that pose difficulties in accessing adequate healthcare services due to distance from regionalized centres, where the small population size promotes challenges in providing care, & where much of the healthcare services are reliant on informal care providers (Crosato & Leipert, 2006).

Convenience purposive samples recruited through PHC sites. Interviews conducted until saturation achieved.

Inclusion criteria:

- Men or women ≥ 65 years of age, living in rural communities in a home setting, diagnosed with HF, able to participate in/direct their own care, literate in English
- Their nominated primary caregivers
- PHC providers directly caring for clients with HF

Study Sample Characteristics

Clients (n = 10)	
Mean age (years)	77.5
Mean HF history (years)	7.6
Men (%)	50%
Married (%)	50%
Caregiver involved (%)	80%
NYHA Class III – IV (%)	80%
2 ≥ other chronic conditions	90%
10 ≥ prescribed meds	50%

Caregivers (n = 6)	
Mean age (years)	68.5
Men (%)	66.6%
Spouse (%)	83.3%
2 ≥ chronic diseases	50%
15 hrs. ≥ /week caregiving (%)	83.3%

Providers (n =11)

Mean age (years)	50.4	Range 38-66
Female (%)	81.9%	
Profession (%)		
Family physician	18.2%	
RN (EC) – BScN	45.5%	
RN (EC) – Master’s	18.2%	
RN	27.7%	

All using interdisciplinary team approach

Comparison of Themes - Goals

Client & caregivers	PHC providers
Live for today *Control HF* Moderated by *resilient/reticent-resigned acceptance*	*Stability & control HF to stay at home* Through compliance & motivation

Self-management Needs

Client & caregiver	PHC provider

Client & caregiver

- Symptoms
- Medication management
- Balance between losses/ limitation & maintaining daily life
  - Pragmatism
  - Partitioning roles
- Managing co-morbidities

PHC provider

- Symptom recognition & control
- Medication management
- Losses/limitations & lifestyle adaptations due to limitations
- Motivators
  - Fear of HF progression
  - Negative emotions
  - Provider knows “best”

Facilitators

Client & caregiver	PHC provider
• Caregiver support • PHC provider relationship & support • Being monitored/checked on • Access & support from PHC & HF program, if available • Needs conveyed & help requested directly	• Caregiver support • Provider support Provider/team relationship Monitoring tailored Client empowerment strategies Timing of intervention based on readiness to learn/to accept support

Barriers

Client & caregiver	PHC provider
• Low expectations • Retention & difficulties adhering to recommendations • Lack of emotional outlet or support • Conflicting/competing priorities • Burden of treatment plan • Concerns over quality & consistency of care	• Needs conveyed reactively, when urgent/symptomatic thru narrative story-telling • Or thru provider assessment & use of probing questions • Non-compliance/adherence leading to provider taking control/deciding for client • Lack of knowledge/retention/ confusion • Lack of self-awareness/ recognition of symptoms

Barriers continued

	PHC provider
	• Fluctuating course & burden of HF • Burden of medication regimen • Integrating & sustaining behaviour changes • Competing/conflicting priorities • Fixed income impacting compliance • Delays in seeking/requesting help

Rural Issues – may serve as barriers or compound other issues

Client & caregiver	PHC provider
• Distance • Travel • Weather • Lack of PHC providers – physicians & NPs • Lack of access & availability to HF programs • Lack of adequate home care resources • Lack of family support • Independence/pride	• Travel, distance, cost • PHC provider shortage led to reliance on emergency depts. • Home care nursing shortages resulted in urgent issue & task focus • Lack of physician time in settings impacted care received from NPs • Lack of specialty resources such as HF program in own communities • Issues of clients living alone & isolation from family & friends

Rural Issues Continued

PHC provider

- Unpredictable winter weather
- Lack of transportation systems
- Making tradeoffs (Wong & Regan, 2009)
- Rural characteristics of hardiness, self-reliance & stoicism

- Results only apply to study sample & may not be generalized.
- Measures constructs used to support SM – patient activation, delivery system/practice design, goal-setting or tailoring of goals, contextual problem-solving & follow-up coordination.
- Total average score for client mid-range rating. Provided objective measure that some support for SM was occurring.

PACIC Results Continued

- Design/practice setting & contextual problem-solving were elements with highest ratings. Patient activation was mid-range.
- Goal –setting and follow-up coordination had lowest ratings.
- Subgroups – single, older than sample average (> 77), lower SES (income < $20,000), PHC provider relationship < 6 mon. had lower overall ratings on all elements except contextual problem-solving.

- Adults are living longer at home with more advanced HF

- Recent studies by Clark et al. (2008; 2009) demonstrated that for rural elders, knowledge is only a part determinant of HF SM & contextual issues play a large component in delays in help-seeking behaviours.

- The contextual issues in this study are different than those from Clark et al.'s. This study adds to the evidence that personal values, beliefs expected outcomes & added rural characteristics & context issues play into into SM decision-making. Providers must take time to assess these aspects & tailor interventions.

- Confusion, negative emotions & lack of retention impacted use of SM & delayed requests for help. Need to ensure that recommendations are “boosted” regularly & cognitive impairment & depression are regularly assessed.

- We can do more emphasizing clients’ priorities & using mutual goal-setting to avoid power-value conflicts & move away from acute care paradigm.

- We must recognize that competing/conflicting priorities exist for clients especially with co-existing chronic illnesses. Can we responsibly focus only to HF? How do we address HF & 2-4 other illnesses? Are disease-specific interventions in PHC the way to go?

Conclusions Continued

- We must recognize that caregiver support is essential as HF progresses & “self & family management” is a real phenomenon (Grey et al., 2006).
- Rural characteristics & context perpetuate the traditional “sick role” & acute care paradigm for clients & providers & serve as barriers to the integration of SM support & chronic disease prevention & management into PHC particularly for lower income older adults without caregiver support.
- As we develop or adopt primary SM interventions or SM elements bundled in disease management programs, we must investigate & analyze the target population, setting & context through pre-intervention research to ensure interventions are tailored to the needs of recipients & users.

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