

The Official Journal of the Canadian Council of Cardiovascular Nurses
La revue officielle du Conseil canadien des infirmières et infirmiers en soins cardiovasculaires

Canadian Journal of Cardiovascular Nursing

Revue canadienne de soins infirmiers cardiovasculaires

VOLUME 26, ISSUE 1 • WINTER 2016
ISSN: 2368-8068 (Online)

Publication Mail Agreement #40051182

Canadian
Council of
Cardiovascular
Nurses



Conseil canadien
des infirmières et
infirmiers en soins
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2 Editorial Board

ARTICLES

9 Canadian Palliative Community Milrinone Infusions: A Case Series

By Ruthanne Reimche, RN, BN, and Daniel Salcedo, RN, BN

14 Psychosocial Burdens of Pulmonary Arterial Hypertension: A Discussion Paper

By Carolyn Doyle-Cox, RN, MSN, Carolynne Brousseau, RN, MScN, Heather Tulloch, MSc, PhD, Lisa M. Mielniczuk, BSc, MSc, MD, FRCPC, Ross A. Davies, BSc, MD, FRCPC, FACC, Heather Sherrard, BScN, MHA, Lorraine Clark, RN MHS

Canadian Journal of Cardiovascular Nursing

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Publishing

The *Canadian Journal of Cardiovascular Nursing* is published four times per year by the Canadian Council of Cardiovascular Nurses (CCCN).

This is a refereed journal concerned with health care issues related to cardiovascular health and illness. All manuscripts are reviewed by the editorial board and selected reviewers. Opinions expressed in published articles reflect those of the author(s) and do not necessarily reflect those of the Board of Directors of CCCN or the publisher. The information contained in this journal is believed to be accurate, but is not warranted to be so. The CCCN does not endorse any person or products advertised in this journal. Produced by Pappin Communications, Pembroke, Ontario.

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ISSN: 2368-8068 (Online)

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Column of Courage

Welcome to the column of courage, a new and exciting addition to the Canadian Journal of Cardiovascular Nursing. As your president, I have the honour and privilege to work with so many inspiring and exciting nurses across Canada and I wanted to share that with our members.



On November 6, 2015, I had the pleasure of interviewing Dr. Paula Price, Registered Nurse, Mount Royal University, Calgary, Alberta.

Can you describe how a 30-plus-year career in nursing has shaped you, as a person?

“What I have learned is that everyone has a story. Everyone is coping with something past or present: an acute or chronic illness, a family member with a problem, or challenges with any of the determinants of health. Often, others are coping with something far worse than I am. From this, I have learned about caring and listening to people and taking nothing for granted. So, I hope that nursing has made me a kinder, gentler, compassionate person after all of this time. I have also become a person who pays attention to details and strives for excellence in whatever I undertake. I think my determination to challenge myself and reach for opportunities to help others, whether in practice or scholarship, has been fostered during my career by the incredible nurses I have met over the years.”

Paula’s wish of being a kinder, gentler soul has certainly been fulfilled—she is a role model and mentor for many.

On the topic of mentorship, how does it make you feel to hear colleagues describe you as “accomplished and sincere with a unique ability to instil passion in nurses of all ages?”

“I am honoured to hear that. I have been teaching for 26 years and when I am with students my goal has always been to create an environment conducive for learning by sharing my own passion about cardiovascular and critical care nursing. Nursing is an exciting profession and I want to instil that in nurses. Nurses are in a very privileged position. Just think about what we do and the impact we have on our patients and their families. Also, very few other professions experience the changes and advances nursing has experienced in the last several decades. Consider the impact research has had on practice. Not only is nursing rewarding, it is also evolving. As for being accomplished and sincere, I have had some excellent role models during my career and I have taken on challenges that have made me grow and learn skills I never thought I possessed. I hope I am sincere, because I have always enjoyed what I do—whether at the bedside, in the classroom, or on a committee.”

Although it may sound like a cliché, I am one of those nurses influenced by Paula’s passion. I first met Paula at a CCCN board meeting and I left with the feeling of “Wow, I

want to know more about this gal” and over the years I have only become more intrigued by her methodical approach to life and enjoy her ‘voice of reason’.

Usually calm, quiet and collected, what would our membership be surprised to know about you?

“I make up silly songs and sing them to our dogs.”

This made me laugh, yes even LOL, and during our interview Paula sang me one of her silly songs. I was overwhelmed with a feeling of friendship, one that only two nurses can share. It was humbling for me and I must say look out Celine Dion, you have competition!

Registered nurses, and in particular cardiovascular nurses, are in a pivotal position to...

“... make a positive difference in peoples’ lives. Nursing’s essential contribution to health and health care, regardless of role or setting, is based on what we do. We use evidence, nursing knowledge, critical thinking and skill to understand our patients’ and families’ responses to health and illness and then we assist them by improving, maintaining or restoring health in collaboration with them and the health care team. Nurses interact with patients and families in every practice setting, at every stage of life, and every day and night. We care for highly complex patient situations and see the responses of patients and families. The impact nurses have can be profound at the bedside, organization, policy, regulatory, or political levels.”

Paula and I share the thought that nurses have extraordinary power, we just need strong leadership to unleash that power.

As a registered nurse with vast experience in the critical care and cardiovascular fields, how do you incorporate courage into your practice?

“I think it takes a lot of courage to take on a leadership role in a new venture, to try something new in the classroom or practice, or even to say ‘I don’t know.’ To quote Winston Churchill – ‘Courage is what it takes to stand up and speak; courage is also what it takes to sit down and listen.’ There are so many times I have had to incorporate courage in my practice and professional life: when I spoke with a patient and his family about advance care planning when the patient’s heart failure was becoming refractory to treatment, when I assumed the role of Provincial Director of the Alberta, Nunavut, and NWT Division of CCCN, when I assumed the role of Editor of the Canadian Journal of Cardiovascular Nursing, and when I went back to school to do graduate studies. To advance one’s knowledge and practice, one needs to take a chance and that always takes courage. Nelson Mandela said ‘Courage is not the absence of fear.’ I think it is the ability to move forward despite the fear.”

Paula, I wrote this quote for you: “Courage does not always have to roar; sometimes it is demonstrated in silence.”

Graduate studies: can you share a summary of your thesis work with our members? How and what did you learn that can be applied to current nursing practice?

“Over the years I have conducted and published several research projects that have had an impact on nursing practice. The best example is the impact our study findings had on early ambulation after PCI many years ago now. We demonstrated that the standard six hours of bedrest after a PCI was not necessary and the practice at the hospital changed to four hours after we showed data on the safety of early ambulation. Since that initial study my research focused on the impact of other nursing interventions on critically ill patients’ physiological status. While my doctoral study was not an interventional study to improve patient care, it did provide information about the physiologic effects of sitting our post-op cardiac surgery patients up for the first time after surgery.

Now, as my career is winding down, my scholarship interest is in helping others and reviewing others’ work; specifically, participating in and coordinating conferences, and reviewing and editing the work of peers.

From my research and scholarship experiences, I have learned that nurses can make a difference in practice and provide the evidence for evidence-informed practice. Research has been the catalyst for improvements in care and health outcomes in all areas of nursing practice, education, and administration. It is important that nurses continue to build capacity for both doing research and translating research to practice for a strong system of knowledge production to inform nursing practice. With my research, it was rewarding to have a clinical question, conduct a study to find a possible answer, collect data and analyze it, and finally see an answer unfold. It is also rewarding to know that in some small way, we contributed to the body of nursing science knowledge.”

I think it is interesting that Paula suggests she is helping others reach their potential, as her career is winding down. Paula, I think you have done this your entire career, you are just now beginning to enjoy the fruits of your labour.

Every program has a pioneer. Can you describe how it feels to be the longest standing faculty in the Advanced Studies in Critical Care Nursing program at Mount Royal University, Calgary, Alberta. What keeps you there?

“This is my dream job. When I started my career in the early 1980s, I completed the Critical Care Certificate Program at Algonquin College in Nepean, Ontario. I had an instructor who was an inspiration to me and I said to myself ‘I want to be just

like her.’ She was an awesome teacher. I went on to work in critical care/CVICU for several years and when the ACCN program started in Calgary I applied and was hired to develop the curriculum and then teach in the program. This has been such a rewarding career and my colleagues and mentors have helped me develop my teaching, leadership, and scholarship skills. Over the years, our program has changed and evolved, going from an onsite program to distance and then offering special condensed programs for our partners in Edmonton, Brandon, Yellowknife, Fort McMurray, and Interior Health (we are nothing, if not flexible). We pride ourselves in keeping the curriculum evidence-based, so revisions are constantly being made to the content to keep it current. Over the 26 years we keep evolving and advancing, so I am never bored. I now work with several of our graduates and in the clinical area I see so many of my current and former students. It is gratifying to see their development and the impact they have on patient care. That really matters to me and it fills me with satisfaction and enthusiasm.”

As an educator, I get excited to hear the enthusiasm in Paula’s voice as she speaks of past and present students. For Paula, pride in profession is important, and I like that she instils that in others. Thank you.

And finally. What does this quote by Maya Angelou mean to you? “One isn’t necessarily born with courage, but one is born with potential. Without courage, we cannot practise any other virtue with consistency. We can’t be kind, true, merciful, generous or honest.”

“I believe everyone is born with potential to lead a virtuous life. It takes courage to enact those attributes. It takes courage to open our eyes to what is around us and the conditions of some individuals and communities. To be truly present and cognizant of these should lead us to kindness, truth, mercy, generosity, and honesty.”

Paula, I want to express my sincere gratitude for allowing me to open a window into your life. I am richer for the experience and I wish to recognize the courage it takes to answer my probing questions. Our members will also benefit from the wise words of an experienced nurse who loves her career more with each passing year. Thank you for being an inspiration to the members of the Canadian Council of Cardiovascular Nurses. ♥

Submitted with Courage

**Susan Morris
President CCCN**

2015 Basic Life Support (BLS) Recommendations for Healthcare Providers

Component	Adult	Child	Infant
Recognition	Simultaneous assessment of breathing and responsiveness. No pulse within 10 seconds <i>The use of mobile devices is now recognized as a tool to expedite EMS activation</i>	Simultaneous assessment of breathing and responsiveness. No pulse within 10 seconds. <i>The use of mobile devices is now recognized as a tool to expedite EMS activation</i>	Simultaneous assessment of breathing and responsiveness. No pulse within 10 seconds. <i>The use of mobile devices is now recognized as a tool to expedite EMS activation</i>
CPR sequence	C-A-B	C-A-B	C-A-B
Compression rate	100 per min to maximum 120 per min	100 per min to maximum 120 per min	100 per min to maximum 120 per min
Compression depth	At least 5 cm but not greater than 6 cm (feedback device can assist in achieving depth recommendation)	About 5 cm until puberty and then not greater than 6 cm	About 4 cm
Chest wall recoil	Complete recoil between compressions is absolutely necessary, thus the upper rate limit of 120	Complete recoil between compressions is absolutely necessary, thus the upper rate limit of 120	Complete recoil between compressions is absolutely necessary, thus the upper rate limit of 120
Compression pauses	Minimize interruptions, limit pauses to 10 seconds or less	Minimize interruptions, limit pauses to 10 seconds or less	Minimize interruptions, limit pauses to 10 seconds or less
Airway	Head tilt chin lift or jaw thrust with trauma	Head tilt chin lift or jaw thrust with trauma	Head tilt chin lift or jaw thrust with trauma
Compression to ventilation ratio in the absence of an advanced airway	30:2	30:2 single rescuer 15:2 with more than one health care provider	30:2 single rescuer 15:2 with more than one health care provider
Ventilations with an advanced airway	One breath every 6 seconds	One breath every 6 seconds	One breath every 6 seconds
Defibrillation	Use an AED as soon as available, minimize compression pauses	Use an AED as soon as available, minimize compression pauses	Use an AED as soon as available, minimize compression pauses

Developed by Susan Morris, RN, BN, MEd, CNCC(C), CCN(C), BLS Instructor and Instructor Trainer

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In conjunction with the Canadian Cardiovascular Congress

Montreal, QC, October 22–25, 2016

CCCN is announcing a Call for Abstracts related to any aspect of cardiovascular and/or cerebrovascular nursing for presentation at the Scientific Sessions of the Canadian Council of Cardiovascular Nurses in Montreal, QC, October 22–25, 2016.

Abstract submissions are invited for presentation in English or French. Please indicate on the abstract form the language in which you would like to present. Abstracts are invited as four presentation options:

Workshop: Workshop presenters will offer an interactive discussion and analysis of a clinical topic or practice issue in a forum lasting 50–60 minutes. Abstracts for workshop sessions must meet the same criteria as other submissions, and must outline the educational objectives, proposed content area and method of presentation (i.e., case study, multiple choice questions) for attendees to interact with one another and the presenters.

Oral: Paper presentations will be 15 minutes in length with an additional 5 minutes allotted for questions.

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Oral or poster: Submitters are willing to have their abstract considered by the abstract review committee for an oral or poster presentation.

Submissions are peer-reviewed in one of two categories: research and non-research. An abstract submission is reviewed in the “research” category if it describes some aspect of an original piece of research, either as ‘completed research’ or ‘research in progress’.

The “non-research” category includes abstracts that do not describe an original piece of research (i.e., theoretical or clinical application).

Abstracts are considered under one of the following themes: ACS/AMI, stroke, pediatrics and congenital heart disease, dysrhythmia management, health promotion, nursing education, health services, patient safety, heart failure/transplant, cardiac surgery and other.

The submission of an abstract constitutes a commitment by the author(s) to attend the meeting and to present. All presenting authors must register for the meeting and are

responsible for their own transportation and accommodation. Abstract grading is performed by blind review and notification of acceptance or rejection of an abstract occurs by email in May–June 2016.

Students are invited to submit their abstract to be considered for an oral or poster presentation award at the CCCN Scientific Annual Meeting. Each award recognizes excellence in a clinical or research presentation. Successful candidates are awarded a free one-year membership and certificate of achievement. To be eligible for an oral or a poster presentation award: 1. Presentation must be based on work completed as a student and related to the program of study. 2. Presentation must be made within a year of graduation. 3. Student must be the lead or co-author, and the presenting author at the CCCN National Scientific Session, and 4. Student must be a current member of CCCN.

Please note: CCCN has an online submission process and all abstracts must be submitted on the website at www.cccn.ca. The online submission process opens **February 17 and closes April 4, 2016, at 2400 hours**. For more information, visit www.cccn.ca or contact info@cccn.ca

READ CAREFULLY. FAILURE TO COMPLY WITH INSTRUCTIONS WILL LEAD TO DISQUALIFICATION OF AN ABSTRACT

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1. Abstracts must be no longer than 250 words.
2. Abstracts can be submitted in French or English.
3. Abstracts will be published in the language of original submission unless provided in both official languages.
4. Abstracts must be submitted under only one of the following presentation categories and will be considered ONLY for the selected category:
 - Workshop
 - Oral
 - Poster
 - Oral or poster presentation
5. DO NOT use headings. Abstracts must be submitted in narrative (paragraph) format.
6. Common abbreviations may be used (i.e., mm Hg), but all other abbreviations must be explained the first time that they are used (i.e., “...the Heart Health Survey (HHS) found that...”).
7. DO NOT underline or use bold print within the body of an abstract to emphasize words or phrases.
8. It is recommended that abstracts be composed in a word processing program (e.g., WORD) and then cut and pasted into the abstract template. Please ensure that all spelling and/or grammatical errors are corrected before pasting into the abstract template.

B. SPECIAL ADDITIONAL GUIDELINES FOR RESEARCH ABSTRACTS

1. Authors must organize and present (do not use headings) the research abstract with the following information:
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 - Methods to collect and analyze the data;
 - Results of the study; and
 - Conclusions, including implications for practice.
2. If study is in progress and results/conclusions are not available, it is necessary to include the potential implications for clinical practice.

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 - A description of the issue/program/technique that will be presented;
 - Summary of major conclusions; and
 - Description of the significance and implications for practice.

D. POLICIES

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2. The submission of an abstract constitutes a commitment by the author to present, if accepted. Failure to present, if not justified, will jeopardize future acceptance of abstracts.
3. There is no limit on the number of abstracts that an author's name may appear on for submission.

Please note: Abstracts that have been previously presented at CCCN Scientific Sessions will not be accepted. Should an abstract be accepted for presentation at CCCN Scientific Sessions in Montreal, it may not be presented in duplicate at another national conference before or within three months following presentation at CCCN. ♥

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CCCN's abstract submission for the fall 2016 Canadian Cardiovascular Congress opens February 17, 2016, and closes on April 4, 2016. For general abstract information and to submit an abstract, please visit www.cccn.ca

Canadian Palliative Community Milrinone Infusions: A Case Series

By Ruthanne Reimche, RN, BN, and Daniel Salcedo, RN, BN

Abstract

Symptom management for end-of-life heart failure (HF) patients is a significant concern. Currently, Canadian practice does not support community milrinone therapy in end-of-life HF patients. Two patients had severe HF that was unresponsive to optimal medications. Further optimization and furosemide infusions were ineffective for symptom management. Both patients' symptoms were better controlled with optimal medication, furosemide, and milrinone infusions. A tailored discharge plan was developed to assist with community milrinone infusions. We discuss the

challenges and successes of transitioning two patients to the community. By providing symptom management and meaningful patient and family experience, both patients were able to die in a setting of their choosing. Milrinone infusions as a bridge to end of life may improve symptoms and quality of life. Select patients may benefit from milrinone infusions with resources put in place; these end-of-life HF patients can be supported in the community.

Key words: heart failure, palliative, milrinone, parenteral infusions

Reimche, R., & Salcedo, D. (2016). Canadian Palliative Community Milrinone Infusions: A Case Series. *Canadian Journal of Cardiovascular Nursing*, 26(1), 9–13.

Introduction

Recently, in a Canadian setting, we were able to assist two patients with palliative or end-of-life community milrinone infusions in our catchment area. Through the development of this process we discovered that palliative milrinone infusions had not been attempted in a community setting in Canada that we were aware of. Milrinone is an inotropic medication used to improve cardiac function for severe heart failure. The dose is individually determined and is used short term (Rettig & Schieffer, 1989). Patients awaiting a heart transplant may require milrinone infusions for longer periods of time (Mehra et al., 1997). Relevant literature and the two case studies, as well as the challenges encountered will be discussed.

Background

Heart failure is a progressive disease for which there is no current cure (Goodlin et al., 2004; Goldstein & Lynn, 2006; Howlett et al., 2010; Hopes & Images, 2013). Fifteen to 20 per cent of all adults will be diagnosed with HF and this number rises to 20% for those who are 80 years and older (Howlett et al., 2010). Ross and colleagues (2006) stated there were 500,000 Canadians with HF and approximately 50,000 are newly diagnosed every year. One of the top reasons for hospital admissions in Canada is HF; in 2005/2006 this amounted to 54,333 hospitalizations (Public Health Agency of Canada, 2009). Those patients with New York Heart Association class IV HF (New York Heart Association, 1979) have a 30%–78% risk of mortality per one year (Davis, Albert, & Young, 2005). Forty to 50 per cent of HF patients will die within five years of their first hospital admission (Hopes & Images, 2005; Taitel, Meaux, Pegaus, Valerian, & Kirkham, 2011).

As these numbers show, we need to recognize that conventional palliative treatment may not be sufficient for all end-of-life HF patients. This subgroup of the HF population may benefit from milrinone infusions for symptom

management, as patients approach end of life. Milrinone infusions for end-of-life HF patients support the palliative philosophy of symptom management and a more comfortable, dignified, and meaningful life (WHO, 2000), as milrinone infusions improve patients' quality of life rather than quantity (Packer et al., 2006). However:

The decision to continue intravenous infusions at home should not be made until all alternative attempts to achieve stability have figured repeatedly, because such an approach can present a major burden to the family and health services... (McLaughlin et al., 2009, p. 1362).

Currently in Canada, there is no process that facilitates end-of-life milrinone infusions outside of acute care of which we are aware. Therefore, end-of-life HF patients' quality of life is limited to what our health care system presently allows. In the United States, milrinone infusions outside of acute care are gaining in popularity (Goodlin et al., 2004; Mehra & Uber, 2001; Stevenson, 2003) and may also be given in hospices (Packer et al., 2006; Hopes & Images, 2013; McIntire Sherrod, Grauly, Crawford, & Cheek 2009; Pantilat & Steimle, 2004).

Both case studies highlight the challenges existing within our health care system that could prevent end-of-life HF patients from receiving community milrinone infusions. In addition, the approaches taken to overcome the limitations of our health care system and assist these patients with symptom management and increase quality of life for end-of-life HF patients are discussed.

Method

A literature review using the databases of CINAHL, MEDline, and Google Scholar was conducted and tailored to our study. To assist with development of our case study, the CARE guidelines checklist was utilized (Gagnier et al., 2014). Case studies and series are only able to discuss how

one or a few patients were affected by the phenomena of interest, namely end-of-life community milrinone infusions in Canada. Case studies are observation-based and weak on the evidence-based hierarchy, but help us to understand better how individual cases can change or adapt our ways of thinking.

Case Study #1

The first patient was well known to the cardiac function clinic and his medications were adjusted, as required, for symptom management. Hospitalization occurred when symptoms became too difficult to manage in the community. Previously, furosemide infusions, adjustment of medications, and temporary inotropic infusions were utilized to optimize his HF status, and allowed him to be discharged appropriately. See Table 1 for background information and comparison with the second patient.

His last and final admission was due to progressively worsening symptoms over the last two months. His family called emergency medical services after a syncopal episode where he was found to be significantly hypotensive. The patient was brought to the emergency department (ED) where his blood work showed hemoglobin of 76, an International Normalized Ratio (INR) of 3.6, and a creatinine level notably higher than his normal range. Doctors felt the main issues were a possible gastro-intestinal bleed and that he was clinically “dry”, as his diuretic had been increased two weeks previously. While in the ED the patient was transfused with three units of packed red blood cells, given a normal saline bolus, and his ace inhibitor was suspended. He was subsequently admitted to a ward unit. During his hospital stay, it became apparent that he required tight control over his fluid management. He was given numerous boluses to manage his hypotension, but later developed symptoms of fluid overload and required diuresis. His creatinine levels fluctuated depending on his fluid status. The patient was eventually started on milrinone infusion, as part of his tailored therapy.

The medical team attempted to wean the milrinone infusions to three days a week to allow the patient to be followed in the outpatient clinic for intermittent infusions, which resulted in increased confusion and worsening HF. It was quickly determined that the patient required more than intermittent infusions of milrinone and would possibly need continuous infusions. Palliative services became involved at this point to assist with end-of-life decision-making, which included deactivation of his ICD.

The patient and family were not interested in pursuing hospice and decided they would be interested in a continuous milrinone infusion in a home setting for their family member. A plan was developed to ensure the patient could go home on a milrinone infusion for 24 hours a day with support from his family members, palliative home care, and his cardiologist to avoid future hospital admissions.

Discharge planning took approximately three weeks and required meetings with the patient, his family, and key

stakeholders. After this was accomplished, the patient was discharged home with family support and passed away four weeks later in his own home environment, as per both patient and family wishes.

Case Study #2

Our second patient was also well known to the cardiac function clinic. Previous admissions to hospital involved furosemide infusions, adjustment of medications, and temporary inotropic infusions to optimize his HF status and then discharged appropriately. See Table 1 for background information of this patient.

His recent hospitalization, the third within the last six months, was due to acute decompensated HF and cardio renal syndrome that required intravenous diuretic and inotropic management. During his rural emergency and inpatient admission, the patient was given intermittent and continuous furosemide infusions, which were ineffective. He remained short of breath with expiratory wheezes with no significant improvement. The patient was eventually transferred to a tertiary care centre for HF management.

The medical team tried high doses of furosemide, which resulted in minimal diuresis, worsening dyspnea, ascites, weight gain, and increased creatinine levels. Treatment options included starting intravenous nitroglycerin or milrinone infusion and/or deactivating his ICD. After discussions with the patient and family, it was decided to move forward with the milrinone infusion and deactivation of the ICD. Palliative service was engaged; the goal was to transition back to community with intermittent milrinone infusions with a palliative approach to his care.

Discussion regarding suitability of the care plan involving milrinone in the small community hospital where the patient was originally from involved identifying resources and limitations. The care plan involved intermittent furosemide and nocturnal milrinone infusions five days a week to allow the patient a reprieve from the hospital setting on days and weekends.

Although our team knew this patient would be transferred back to his community hospital where the medical staff knew him well, we anticipated similar challenges, as with our first patient. The community hospital was not familiar with inotropic infusions.

Planning took approximately three weeks to ensure the patient was safely transferred back to his community hospital. The patient felt we supported and honoured his wishes to be closer to friends and family at end of life. He passed away peacefully five weeks after being transferred to his local community hospital.

Challenges

Process

The first patient’s wish to spend his remaining days at home with family rather than a hospice or acute care setting

Table 1: Background information and treatment		
	Patient A	Patient B
Demographic Information	80-year-old Middle Eastern male	73-year-old Caucasian male
Past medical history	coronary artery disease congestive HF internal cardiac defibrillator (ICD) chronic kidney disease chronic atrial fibrillation diabetes hypothyroidism anemia	coronary artery disease cardiomyopathy congestive HF ICD chronic kidney disease chronic atrial fibrillation, diabetes hypothyroidism anemia
Symptoms	Class IV	Class IV
Psychosocial history	Lived with son's family	Lived with his wife
Diagnostics	Echo – Ejection Fraction <20% CXR	Echo – EF 20% CXR
Pertinent Medications on admission	Allupurinol 100 mg Clopidogrel 75 mg Enalapril 20mg am 30 mg pm Ezetrol 10 mg OD Furosemide 60 mg bid Insulin sliding scale Imdur 120 mg Levothyroxine 75 mcg Metoprolol 12.5 mg Pantoloc 40 mg Potassium chloride SR 1500 mg Salbutamol inhaler prn Warfarin 2–3 mg OD	Advair diskus 1 puff bid Allopurinol 100mg OD Atorvastatin 80mg OD Carvedilol 6.25mg bid Furosemide 100mg bid Hydralazine 75mg tid Isosorbide mononitrate 60mg OD Insulin glargine 28U OD Insulin Humulin R 12U qam Levothyroxine 150mcg OD Potassium chloride SR 3000mg qid Salbutamol inhaler prn Warfarin 4 mg OD
Other options attempted	Wean off Milrinone Set up with intermittent milrinone infusions in the community Morphine Continuous and intermittent furosemide infusion	Continuous furosemide infusion
Teaching required	Use of intravenous pump What to do if patient becomes more symptomatic Who to call for medical and palliative issues	Information about milrinone, side effects, how to manage the medication, and who to contact were given to the community hospital
Pertinent medications on discharge	Allupurinol 100mg Clopidogrel 75 mg Furosemide 60 mg bid Insulin sliding scale Imdur 120 mg Levothyroxine 75 mcg Metoprolol 12.5 mg Milrinone 0.25 mcg/kg/min continuous Morphine 1–2 mg sublingual prn Pantoloc 40 mg Potassium chloride SR 1500 mg Salbutamol inhaler prn	Advair diskus 1 puff bid Allopurinol 100mg OD Amiodarone 300mg OD Atorvastatin 10mg OD Carvedilol 6.25mg bid Furosemide 100mg IV M-F am Hydralazine 75mg tid Insulin glargine & sliding scale Ipratropium inhaler prn Isosorbide mononitrate 90mg OD Levothyroxine 150mcg OD Metolazone 5 mg M-F qam Milrinone 0.3 mcg/kg/min M–F for 8–12 hrs nightly Potassium chloride 3000mg qid

prompted us to explore all options to assist in this goal. Options were conventional palliative therapy such as morphine or intermittent milrinone infusions in an outpatient clinic. Neither of these options were enough to manage his end of life HF symptoms and so a continuous milrinone infusion was deemed to be the best option.

As there was no existing process in Canada to facilitate community milrinone infusions as bridge to end of life, the medical and nursing team needed to collaborate closely with our community partners including the HF team, palliative home care, pharmacy, and the home parenteral therapy program (HPTP) to develop a simple, effective, and meaningful

discharge plan. The key elements of this plan included defining goals of care, who would manage the milrinone infusions, as well as the palliative goal of symptom management.

Finances and drug availability

Milrinone is readily available in acute care, but not in the community setting. The cost of milrinone, as an inpatient, is considerably lower than in the community (Chua et al., 2011; Hopes & Images, 2013). Chua and colleagues (2011) stated that the cost of home milrinone with home care equipment and supplies was \$183–\$383/day. Possible means of coverage to assist with the cost of milrinone were explored to no avail, as milrinone is not on the community formulary. As a result, extensive collaboration with the inpatient and outpatient pharmacies assisted in providing the milrinone in a pre-mixed and stable intravenous form at a significantly reduced cost.

Even though the medication was available at a reduced cost, there was still a financial burden because of the uncertainty in how long milrinone would be effective for the patient, and could impact their ability to pay for the infusion for a prolonged basis. The family was assured that milrinone would not prolong life, but would improve the patient's quality of life. In the second case the cost of milrinone was covered by the hospital where the infusion was given.

Equipment and home supports

There was no community access to equipment, such as IV pumps. To the best of our knowledge, IV pumps are not available to be rented or privately purchased in our catchment area. The closest existing IV community support was the HPTP, which is focused on the provision of for-home antibiotic infusions and, after much discussion, they were able to support our patient by allowing access to their equipment.

As the first patient was nearing end of life, there was not enough time for our community partners to familiarize themselves with milrinone or follow the process required to add this medication to their existing formulary. Therefore, the attending cardiologist had to be responsible for making any HF management and symptom control decisions.

Education

As milrinone is currently not on the formulary for palliative home care, or HPTP, there was a lack of understanding and hesitancy by our community partners of the benefits of milrinone infusions for these particular patients. There was also a lack of time to have this added to the formulary for our first patient and, so, education was necessary.

Therefore, with the first patient, the nursing team had to effectively transfer knowledge to the patient's family member who was identified as the main caregiver, by developing a teaching plan. He was taught how to use the pump, prime the IV bags, and troubleshoot any issues, as he would be responsible for maintaining the IV infusion. Once the nursing team was comfortable with this family member's skill, the discharge plan proceeded.

In the second case, information was provided to the community hospital regarding milrinone. They were given information about what to do if the patient developed significant side effects. Patient care was managed by their in-house medical team, with support from the tertiary care HF physician.

Palliative Care

At present, our standard process in managing end-of-life HF patients is to transition them with a palliative focus and palliative home care or hospice, if they qualify. In the U.S., patients may have the option of being sent home or to hospice with end-of-life milrinone infusions. In Canada, the only instances we were able to find in regards to outpatient milrinone infusions were for patients awaiting a heart transplant, as noted by Chua and colleagues (2011) in British Columbia. Of note, this program is still in effect but, due to advancements in ventricular assist devices (VADs), it has been four years since they sent a patient home with a milrinone infusion (personal communication D. Chua, May 28, 2015).

In both cases, we were able to assist our patients during their palliation by providing the option of milrinone infusions in a community setting. The wishes of both of these patients were accommodated and respected to die in a place of their choosing rather than an acute care hospital.

Implications for future practice

Inotropic infusions such as milrinone are not the answer for every patient with end-of-life HF, but are an alternative for symptom management in a select group of patients. Prior to choosing this option, a transparent discussion with the health care team, patient, and family should be completed for an informed decision (Mehra & Uber, 2001). Part of this discussion should include the supports required for the expected emotional, financial, and physical effects of continuing this therapy and reviewed regularly in cases where therapy is prolonged. Patient- and family-centred care focus is paramount to end-of-life care and assists with providing a tailored therapy.

For future cases, it would be necessary to develop a program similar to the HPTP program where equipment, such as IV pumps, is available for our end-of-life HF patients. It is also important to ensure that community partners are aware of the benefits of milrinone for end-of-life care for HF patients and how it can assist with symptom management.

Strengths

One strength of this case series is the community partners' willingness to have discussions and assist these families with their options. The first case study showed a family who was very engaged and willing to learn what was needed to honour their family member's wish to die at home. In the second case study, the community hospital was willing to assist the patient and family with the milrinone infusions. Both patients had strong support systems that allowed this alternative approach to end-of-life care.

Weaknesses

One of the weaknesses of this case series is that our team had limited time to develop a standardized process, as our patients were nearing end of life. A second weakness is that at present we have only encountered two patients requiring community end-of-life milrinone infusions.

Limitations

A limitation is that this case series only deals with two patients in our catchment area in a new process. In addition, the high cost of milrinone in the community and the lack of a defined process to enable patients to have access to resources make this challenging. A final limitation is that milrinone is not on the list of approved medications for the palliative formulary.

Conclusions

Both of our case studies were about HF patients who were given alternative end-of-life milrinone infusions in the

community, a practice that has not been previously documented in Canada. Problems were identified and effective solutions were developed in collaboration with community partners to assist with the patients' final wishes. Key features of developing a care plan for end-of-life HF patients include collaboration with key stakeholders, adherence to the palliative philosophy and, most importantly, being patient- and family-centred care focused. ♥

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Psychosocial Burdens of Pulmonary Arterial Hypertension: A Discussion Paper

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Abstract

Pulmonary arterial hypertension is an uncommon and devastating chronic illness with no known cure. Little is known about the disease, and even less about the psychosocial burdens. While it is important to create awareness about the physical aspects of the disease, it is equally important to create awareness about the psychosocial burdens patients and their families face. We reviewed the literature to better understand these psychosocial burdens, which include impact from physical limitations, emotional strains, financial burdens, social isolation, lack of intimacy

in relationships, and an overall lack of information. The findings can be used to assist health care providers to understand the psychosocial challenges that are being experienced by patients and families in order to better provide supportive care. The creation of a standardized tool to assess the psychosocial burdens at each clinic visit can benefit health care providers by addressing challenges faced and facilitate subsequent referral to appropriate specialists.

Key words: PAH, anxiety, psychosocial, support

Doyle-Cox, C., Brousseau, C., Tulloch, H., Mielniczuk, L.M., Davies, R.A., Sherrard, H., & Clark, L. (2016). Psychosocial Burdens of Pulmonary Arterial Hypertension: A Discussion Paper. *Canadian Journal of Cardiovascular Nursing*, 26(1), 14–18.

Introduction

Pulmonary hypertension (PH) is the elevation of the pulmonary artery pressure to greater than 25 mm Hg. This is often times a result of respiratory and/or cardiac diseases (Simonneau et al., 2013). In its most severe form, PH can be presented as pulmonary arterial hypertension (PAH), which is idiopathic or heritable or can be caused by connective tissue diseases, associated with certain drugs and toxins, HIV, congenital heart diseases and portal hypertension (Simonneau et al., 2013). Common symptoms include shortness of breath during routine activities of daily living, pre-syncope or syncope, fatigue, chest pain and, if in right heart failure, peripheral edema and ascites (National Heart, Lung, and Blood Institute, 2011). The prevalence of PAH is reportedly estimated at 15–50 cases per million (Peacock et al., 2007). In high-risk groups such as those with the connective tissue disease scleroderma, the prevalence is significantly higher and has been reported between 7% to 12% (Hachulla et al., 2005; Mukerjee et al., 2003). The disease can affect people of any age and with a higher prevalence among females (Manes et al., 2012). If left untreated, the prognosis for patients is poor, with estimated median survival rate of 2.8 years, with one-year, three-year, and five-year survival rates of 68%, 48%, and 34%, respectively (D'Alonzo et al., 1991).

Pulmonary arterial hypertension (PAH) is a life-altering and progressive disease that has no cure. Beyond the pathophysiology and subsequent symptoms, this illness affects the patient, the caregiver and the family in a multitude of ways. Medical therapies currently available are directed toward prolonging life, slowing disease progression and improving the quality of life of these patients, not cure. Anxiety and depression are known to be common with PAH patients

and psychological distress increases as the disease advances (Löwe et al., 2004). There are many identified psychosocial burdens associated with this chronic terminal illness, such as financial burdens, social isolation, and adaptation to new roles. In this discussion we will focus on psychosocial support by reviewing the limited current literature on the psychosocial burdens faced by patients with PAH, describe why it is important for PAH health care professionals to assess psychosocial coping between outpatient clinic visits, and provide a discussion around developing a short questionnaire to identify maladaptive coping in order to refer patients and family members to the appropriate sources for assistance. At this time there are no standardized tools for assessing the identified burdens patients can possibly face.

Aim

The aim of this position paper is to discuss the identified psychosocial burdens patients and their significant others suffer and explore ways to effectively assess these burdens, possibly by utilizing a short screening tool at the time of each outpatient clinic visit. It is recommended by the 2015 ESC/ERS Guidelines for the diagnosis and treatment of pulmonary hypertension to assess and manage these issues/burdens in order to be able to refer to the relevant disciplines, as needed, e.g., psychiatry, clinical psychology, welfare and social work. At this time, there are no standardized tools for assessing the identified burdens patients can possibly face.

Method

A review of the literature was completed to determine the psychosocial burdens of PAH on individuals living with this chronic illnesses and search for a burden assessment tool.

The search for relevant manuscripts was performed using MEDLINE primarily, followed by CINAHL, and PubMed. The key words used in the search included PAH, psychosocial, support, stress, depression, isolation, employment, caregivers and family relations.

Following initial searches, the results were combined with the operand AND. The reference lists were analyzed and a few more articles were kept for greater analysis. A total of 213 articles were discovered and 15 articles were kept for greater analysis based on their titles, abstracts and their content that was related to psychosocial burdens and PAH. A total of eight articles met the selection criteria and were included in this review.

At present, a significant number of studies have been conducted to examine the effects of pharmacotherapy. Multiple randomized controlled trials have been performed resulting in regulatory approvals of nine PAH-specific therapies (Rosario et al., 2014). Several studies have also been conducted in regards to the physiological disease process (Rabinovitch, 2012), while only a few have been conducted on anxiety and depression (Löwe et al., 2004) and quality of life (Shafazand et al., 2004; Taichman et al., 2005; Mereles et al., 2006) associated with PAH. Unfortunately, little is known about the psychosocial burdens of PAH and, at this time, no standardized tool was identified for assessing psychosocial burdens.

In order to live with PAH successfully, these patients deserve to receive a more holistic treatment, but, as a first step, we must better understand their psychosocial burdens. Left untreated these burdens can lead to depression (WHO, 2014). In order for health care professionals to refer patients to the appropriate specialist, it is important to be able to distinguish what these burdens are and to assist all with better coping mechanisms. By addressing these burdens we are meeting some of the unmet psychosocial needs, which links into best practice guidelines, as described by the current European guidelines for PAH treatment (Galiè, Humbert, et al., 2015).

Discussion

Impact of PAH on the physical and practical aspects of daily living

Many patients find that the disease has a significant restricting impact on their physical activity and impacts work and employment, household chores, social outings and travel, and their relationships (Guillevin et al., 2013). In Canada, 85% of patients' activities of daily living are affected by their symptoms such as walking up a flight of stairs, having a telephone conversation, or walking a short distance (Pulmonary Hypertension Association of Canada, 2013). Caregivers similarly were impacted, as they expressed feeling exhausted from having to complete the extra tasks that patients were unable to complete (Guillevin et al., 2013). Caregivers often spent more than 50% of their time caring for the patient (Pulmonary Hypertension Association of Canada, 2013). Weber

et al. (2011) reported a case study describing one mother's experience while living with PAH. This person's primary concern was raising six children and those challenges associated with parenthood while accepting the physical limitations of the disease, mainly fatigue, dyspnea and exercise intolerances, which interfered with her life. In another study, it was discovered that many patients experienced varying levels of sleep disturbances that worsened with the progression of the disease (Matura, McDonough, Hanlon, Carroll, & Riegel, 2014).

Financial burden

Patients and caregivers reported that PAH affected their work, resulting in reduced household incomes (Guillevin et al., 2013; Hwang, Howie-Esquivel, Fleischmann, Stotts, & Dracup, 2012). The Pulmonary Hypertension Association of Canada (n.d.) discovered that nearly half the patients surveyed had their income reduced by more than 50%. An estimated 60% of patients had to reduce work or stop working completely and 40% of caregivers were forced to change their work to accommodate the patient. Only 20% of patients reported that work was not affected while on therapy (Pulmonary Hypertension Association of Canada, n.d.).

The cost of travelling to specialty PAH clinics can be costly. For example, in Ontario there are only five PAH clinics located mainly the southern area of the province. This is a similar situation across Canada. Hesselgrave (2003) reported travel for follow-up visits cost up to \$15,000 annually for one family.

Rubens et al. (2009) identified the influence of health insurance coverage of pharmaceutical drugs on a patient's well-being. The cost of the pharmacological therapies for PAH can be significant with substantial patient variations. For example, Treprostinil, a prostanoid, can cost between \$18,000 and \$70,000 annually per patient, depending on the dose (Canadian Agency for Drugs and Technologies in Health, 2006). Not every country, including Canada, covers fully the costs of these therapies. The sudden loss of a job and associated health insurance can cause a patient to feel a loss of independence and a loss to family contributions (Wryobeck, Lippo, McLaughlin, Riba, & Rubens, 2007). In the Weber et al. (2011) case study, a patient had expressed concerns regarding the financial implications of the illness including the cost of required medication and medical equipment and fear of her insurance reaching its annual limit. This is consistent with the literature that indicates these concerns added to the patient's overall stress. In order to overcome job loss due to illness limitations, a majority of patients seek medical or social security disability (Wryobeck et al., 2007).

Intimacy challenges

Intimacy affects both patients and the sexual partner. A loss of intimacy or sexual relationships was found to correlate with a decline in functional classification (Guillevin et al., 2013). Patients reported feelings of low self-esteem

and inability to physically exert themselves, while partners reported fears of exacerbating the symptoms that patients experience (Guillevin et al., 2013). Patients who are being treated with prostanoid therapy either required a central venous access device or subcutaneous catheter to deliver medication, which can impact a persons' confidence. Weber et al. (2011) described a patient who not only experienced facial and leg rashes, a side effect from one of the PAH therapies, but also received scars from several infected central venous access sites and, subsequently, developed subcutaneous hematomas when switched to the subcutaneous route of the prostanoid therapy, which made her feel self-conscious. The altered body image lowered her self-esteem and interfered with intimacy.

For couples in their childbearing years, the fear of getting pregnant impacts intimacy and decreases the desire for intercourse (Wryobeck & Rubenfire, 2012). Due to the high maternal-fetal morbidity and mortality of pregnancy in PAH, the only guideline that exists is that it is certainly contraindicated (Sahni et al., 2015). Current recommended treatment guidelines suggest the need for birth control for couples of childbearing years (Galiè et al., 2010). Suggestions made by PAH centres often include double contraceptive methods. Pregnancy comes with a high risk of morbidity and mortality for women with PAH (Pieper & Hoendermis, 2011).

Emotional and social well-being

Patients reported feelings ranging from frustration, anger, low self-esteem, being misunderstood and feeling worthless—all of which have a negative effect on their emotional and social well-being (Guillevin et al., 2013). Caregivers were frightened by the future for the patient and stressed from caregiving (Guillevin et al., 2013). Matura, McDonough, Aglietti, Herzog, and Gallant (2013) reviewed online patient discussion boards and identified four themes that patients discussed: (a) to seek support from each other, (b) to discuss their uncertainties and various concerns, for example, going to diagnostic procedures, costs and side effects of medications, (c) to obtain guidance and validation for their feelings and thoughts, and (d) to refocus their lives.

Lichenstein, McDonough, and Matura (2013) reviewed caregiver online discussion boards and summarized four themes that caregivers discussed; (a) to verbalize their fears and frustrations, (b) to voice questions and concerns, (c) to have someone to listen to them, and (d) to support with moving on with their lives. One case study illustrates how sensitive issues must be discussed privately, as one entire family required counselling therapy when a younger member of the family overheard a health care provider discussing the prognosis of the patient and used the word death (Hesselgrave, 2003). Matura and Carroll (2010) found there was limited literature on how family members cope with PAH.

Patients attempt to cope with the uncertainty of their illness, life, and treatment in various ways (Flattery, Pinson,

Savage, & Salyer, 2005). Through semi-structured interviews describing lived experiences with PAH, the authors identified the following ways patients learned to cope with their illness: (a) seeking information via internet and their health care team, (b) creating memories with such activities as painting, (c) humour, (d) spirituality and faith, (e) support group meetings, (f) resuming life activities and doing what they have to do.

Patients using intravenous epoprostanol experienced initial shock following diagnosis and treatment (Hall, Côté, McBean, & Purden, 2012). Often, patients adapted through trial and error while the caregivers continued to struggle with the daily pressures of preparing and administering the medication (Hall et al., 2012). It is important to care for the caregivers, as they play an important role in the patients' daily lives. For instance, caregivers have a 14% chance of developing depression (Hwang et al., 2012).

Social isolation can also occur. PAH can be viewed as an invisible disease, since many of the symptoms are hidden and there is a lack of general information and awareness in the community resulting in misunderstanding of the illness (Guillevin et al., 2013; Rubenfire et al., 2009; Wryobeck et al., 2007).

Information

Patients and caregivers require information regarding their disease, as well as the wider impacts such as the psychosocial impacts, including the emotional impacts of depression, treatment options, consequences of PAH, and support groups (Guillevin et al., 2013; Hesselgrave, 2003; Hwang et al., 2012; Lichenstein et al., 2013; Weber et al., 2011). Often this information is requested in a staggered approach to help lessen the burden of information overload (Guillevin et al., 2013; Tsangaris, 2014).

In summary, psychosocial burdens affect both patients and caregivers. These burdens include physical, practical, emotional and financial domains of patients' and caregivers' lives. Health care providers should take into account the added stress on the physical illness that psychosocial burdens have.

Conclusion

PAH is a devastating and progressive chronic illness with no known cure and carries with it a high mortality rate. Patients and their caregivers may experience many psychosocial burdens that are not often addressed at the time of clinic visits with their PAH health care providers. Left unaddressed, patients and caregivers suffer many forms of emotional distress. While many clinics do not have social workers or psychologist, a simple questionnaire assessing psychosocial burdens and maladaptive coping is suggested at each clinic visit in order to refer patients to appropriate services for assistance in their local community. Offering psychosocial support is best practice for PAH patients. After reviewing the

literature and identifying seven types of psychosocial burdens that patients and caregivers experience, psychosocial issues should be assessed at each visit and referrals offered, if needed. These burdens are too numerous and too significant to ignore.

Relevance to Clinical Practice

As a health care professional, it is important for nurses to monitor patients for the additional stress that this illness has on their daily lives (Gin-Sing, 2010; Tsangaris, 2014). Adopting a holistic and team approach will allow for a better supportive environment and help reduce anxieties and depression induced by PAH (Gin-Sing, 2010; Tsangaris, 2014). Nurses should offer continual psychosocial support where needed (Galiè et al., 2010; Ghofrani et al., 2011) and refer to specialists for further assessment and care.

Psychosocial assessments consisting of questions addressing the identified burdens given to patients with PAH can be helpful when monitoring psychosocial status and should be conducted at each clinic visit in order to identify ineffective coping, with referrals to appropriate specialties, as needed. The creation of a short standardized tool to assess these burdens would be beneficial. Researchers agree that assessing this population for psychosocial distress is important, yet no formal tool or system currently exists to guide health care professionals in assessing and providing support for this population.

Treatment guidelines should be updated to include the caregiver as a patient resource and how caring for the patient and the caregiver is beneficial to both parties.

Further research is required to assess the possible and unique burdens, which are not identified as of yet, experienced by children with PAH and children of PAH patients. Little information is known on how a family copes as a unit when faced with a loved one being diagnosed with PAH. ♥

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Acknowledgements

The authors gratefully acknowledge the assistance of Dr. George Chandy, Dr. Duncan Stewart and Dr. Vladimir Contreras-Dominguez for providing general support, drafting and editing of the manuscript.

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Canadian Journal of Cardiovascular Nursing

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Discourses relevant to cardiovascular nursing, including position papers and critical reviews of particular bodies of work, which do not contain empirical data or use systematic review methods are also welcome. The text should be arranged as follows:

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