

## ESSAY

## Narrative accounts of recovering at home after heart surgery

three vanishing scars  
Forcefully remind me  
of my mortality

what if my heart ...  
what if my chest ...  
how would I ...

**B**odily markings, sensations and feelings of vulnerability following heart surgery often permeate patients' thoughts. It is during the home period of recovery that patients begin to ruminate about what can be a traumatic and life-changing event. And yet, the home phase of recovery following surgery receives the least amount of attention in the cardiovascular literature. In addition to introspection during this phase, patients must assume a significant and active role in terms of self-management<sup>1</sup> related to exercise, diet, medication and stress management, as well as adhering to guidelines concerning lifting, driving and sexual activity.

This article presents the results of an arts-informed narrative study of patients' experiences of the home period of recovery. Sixteen adults, 59 to 85 years of age, scheduled for coronary artery bypass graft and/or valve repair or replacement were recruited from a preoperative clinic. Individual interviews were conducted at 48–96 hours following surgery, and between 4–6 weeks following discharge. The methodological approach is new, and extensive details of the analytic and creative process appear elsewhere.<sup>2</sup>

To highlight the experiential qualities of patients' stories, we translated the study results into poetry and photographic images. The first author extracted words and phrases from inter-



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Image 1

views, and compiled them into poetry. The research team derived concepts from the patients' stories that informed the images, which metaphorically represent participants' experiences. The photographed subjects are volunteers and are not the actual research participants. These images provide viewers with an immediate and sensory lens to enter into the patient's journey of heart surgery and recovery.

The 13 poems and images, which follow the patient's journey through surgery and recovery, were originally displayed in 2011 at Toronto General Hospital and at the International Con-

gress of Qualitative Inquiry in the United States. This article highlights three of those poems and four images concerning the first six weeks following discharge.

Image 1 focuses on the feet, the only body part visible in the intensive care bed, where the person is almost completely concealed by a heating blanket, iodine, and tubes and wires. In this image, the feet metaphorically represent the way that patients undergoing cardiovascular surgery become marked and carry their experiences of heart surgery with them throughout their life.

## Thrown to the wolves

This poem is based on participants' descriptions of engaging in self-management behaviors. Once participants returned home, they detailed their feelings of insecurity as they struggled to interpret and apply strict regimens to the particularities of their own bodies, lives and homes. The figure in Image 2 reflects this uncertainty as he stands alone in a boat where the horizon is barely visible.



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Image 2

I wonder  
what are my limits?

don't want to do anything  
that would undo,  
whatever-they-did-to-me

carefully follow,  
instructions  
do exactly as they say  
no lifting  
no reaching  
no bending  
no driving

but I don't know  
what to do, I don't know  
    how to do it, left  
    with questions, left  
    to figure it out, like I was thrown  
    to the wolves, left  
    to follow instructions to the dotted  
    line, follow  
    exact procedures, but listen  
    to my instincts, faithfully  
    take medications

but don't become addicted  
do exactly as they say, but listen  
to my body, don't  
push myself, but Force, myself to walk

can't  
rush it, told to breathe  
    ten times every hour  
    how long do I do this?  
    am I to do it when I walk?  
    they say nothing  
    can happen, but maybe  
    I do something  
    wrong, maybe     it rips  
open

I do the prescribed walks  
but have to judge  
my body, have to follow  
their orders  
    but they're not inside me

they don't know  
how — I — feel  
left with these things  
    "don't lift anything heavy"  
    for how long?  
    when can I return to work?  
    should I walk fast?  
    slow?  
    does it matter, as long as I walk?  
    how do I do this?  
    how can I live?  
    will I get back  
    to my old self?  
    when will I be "normal"?

like I was thrown  
to the wolves, I'm left  
to figure it out

## These things prey on one's mind

This poem reveals feelings of turmoil and isolation that participants felt. They described a moment-to-moment/day-to-day physical and emotional struggle in which they lacked support and wished for more communication with practitioners. In Image 3, a figure situated alone in a forest symbolizes feeling lost and caught in an emotional spiral.

the mind is a strange animal  
catching  
the spirit off guard  
can make a heaven of hell,  
a hell of heaven.<sup>3</sup>

I had one black  
day

one emotional black  
black  
day  
one really dark  
down  
depressing  
day  
I couldn't shake it

they said there'd be days  
like this, I was warned  
they said there'd be mood swings  
dark moods  
despite a host of warnings  
all  
of a  
sudden,  
it came over me

I had no reason,  
to feel blue  
I was alive

I think it had to do with the medication  
the invasion  
of my body, having to hold  
onto walls when I walked, restricted  
by the things I can do, despite  
expectations of aches and pains  
one sees such aches and pains as possible indicators  
of something-seriously-gone-wrong

as days  
passed  
didn't feel like doing anything  
didn't feel like walking  
I'm not used to this



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Image 3

these things Prey  
on one's mind

they all say  
"you look fine"  
I don't feel fine  
can't walk  
can't do anything  
my mind sometimes thinks  
I can do things  
but my body won't let me  
I don't have energy  
I feel like crying  
I'm useless  
helpless

I'm learning  
to deal with restrictions, the body  
doesn't repair so quickly  
goes at its own speed, forces  
me to follow, I can't  
do all the things I used to, my patience  
evaporating

to borrow the words of William Wordsworth  
"five years have past;  
five summers,  
with the length  
Of five  
long  
winters"<sup>4</sup>.

## Not the demon I thought it would be

This poem reflects participants' realization that the process is tolerable. As they began to look beyond their current state, participants described a renewed sense of clarity regarding recovery. This is portrayed in Image 4, with a figure standing tall in an open field of snow with hints of foliage emerging. Although the window pane acts as a separation between the figure and outside world, he stands with confidence and readiness to move forward.



Image 4

three vanishing scars  
Forcefully remind me  
of my mortality,

wish I could talk  
to someone about how I feel  
about what's going on inside

I'm not sure if my chest will split  
open, afraid  
to cough and sneeze, scared  
I might fall

can't sleep through the night  
I want to beat the records  
I just have to Suffer  
through it, discovered  
I can't rush it, have to work  
my way up, I feel sorry  
for myself, worried  
scared, nothing  
is progressing, I feel  
Static

frustrated  
I'm in no walking mood, I can't  
breathe, I can't  
drive, I can't  
walk, I can't  
do anything,  
I'm tired  
exhausted

lethargic, I can't  
help myself, I can't  
Stand it, my hands don't  
work, I don't  
feel like reading, I don't  
feel like walking  
I Still.  
Get. Pain.

but, in the cold light of logic  
my current condition is better

I'm breathing  
my heart's beating  
I'm not what I used to be  
get reminders from my Body when I overdo it  
that's the way it has to be for now  
an incremental return, to normalcy  
I have to Hurt to get better  
Build myself up  
look how far I've travelled  
how fast it has gone  
I'm getting stronger  
it's Worth,  
what I did, worth  
the pain  
the anxiety  
the inconvenience  
I had my first glass of red wine in five weeks —

it's not the Demon  
I thought it would be

the pain was bearable

under the glare of surgery  
that of Lesser consequence  
assumes its status

I am fortunate  
this experience has brought perspective

I'm loved  
I'm wanted  
I'm sheltered

Poetry and imagery provide insight into the embodied, emotional and psychological elements of recovery. Once home, contact with practitioners is infrequent and of short duration and the content is not always structured according to patients' needs. This narrative evidence indicates that patients' struggles are impromptu and distressing, leaving them feeling anxious and uncertain. They have difficulty inferring whether their physical sensations are normal parts of recovery.

Our work, and that of others,<sup>5</sup> confirms that patients lack education, communication and supportive interventions tailored to their needs in the home. The move towards a system that encompasses a patient-centred care philosophy demands that we consider all phases of therapeutics including the home period of recovery.

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## References

1. Fredericks S. The influence of country of origin on engagement in self-care behaviors following heart surgery: a descriptive correlational study. *J Clin Nurs* 2012;21:2202-8.
2. Lapum J, Ruttonsha P, Church K, et al. Employing the arts in research as an analytical tool and dissemination method: interpreting experience through the aesthetic. *Qual Inq* 2012;18:100-15.
3. Milton J. *Paradise lost*. Cambridge (UK): Cambridge University Press; 1952.
4. Wordsworth W. *Tintern Abbey*. Boston (Mass): Houghton Mifflin Company; 1919.
5. Lie I, Bunch E, Smeby N, et al. Patients' experiences with symptoms and needs in the early rehabilitation phase after coronary artery bypass grafting. *Eur J Cardiovasc Nurs* 2012;11:14-24.

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