three vanishing scars
Forcefully remind me
of my mortality

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

Bodily 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 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.

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 interviews, 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 Congress 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.
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.¹

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

to borrow the words of William Wordsworth
“five years have past;
five summers,
with the length
Of five
long
winters”²
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.

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, 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

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