

Living Life to the Limits

Dragon Boaters and

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Tout en reconnaissant que l'expérience du bateau dragon est un élément important pour les patientes en rémission dans la gestion du stress relié au cancer, l'auteure indique qu'il faut d'autres recherches qui examineraient l'hypothèse que le bateau-dragon comme sport d'équipe, incite au jeu dans un contexte collectif tout en revalorisant la santé émotionnelle et physique des patientes en rémission du cancer du sein.

Dragon boat racing is the fastest growing team sport in North America. This dynamic, team water sport arises out of an ancient Chinese sport, also known as Asian Long-boating, dating back more than 2000 years. Each boat has a traditional dragon's tail and dragon's head, they are 13.5 meters long and weigh between 800 and 1360 kgs. Twenty people paddle vigorously in unison with a steersperson in the rear and a drummer in front. Dragon boating involves 22 individuals working synchronistically and vigorously as a team to advance the boat.

Recently, an unusual group of women have taken up dragon boating. They are all living with breast cancer, a group of women who are literally and figuratively all in the same boat in the race against breast cancer. Dr. Don McKenzie, a sports medicine physician at the University of British Columbia, is the recognized founder of the breast cancer dragon boat phenomenon in Canada. He conducted a study (McKenzie) with a group of breast cancer survivors that challenged the myth that strenuous post-surgical upper body exercise in women treated for breast cancer would in-

Women are attracted to the positive nature of the sport that brings them into community with other women who also have breast cancer and who are moving on with their lives.

crease their risk of lymphedema (a painful and chronic swelling of the arm and chest area).

Each year, more than 19,500 Canadian women will develop breast cancer and an estimated 5,500 women will die of this disease (Canadian Cancer Statistics 2001). Because breast cancer tends to occur earlier in life than other cancers and affect women earlier than other major causes of death such as cardiovascular disease, it is the greatest cause of years of life lost by Canadian women (Canadian Cancer Society). As incidence rates climb and mortality rates stabilize for breast cancer, it is critical to consider the factors related to living with breast cancer and women's quality of life post-treatment. This study on women's experiences of dragon boating investigates the psychosocial impact of dragon boating and the potential of this team sport to contribute to post cancer treatment rehabilitation both physically and emotionally.

Research objective and methodology

The dragon boat study was designed to describe the experience, meaning, and psychosocial impact of dragon boating on women with breast cancer. A participatory (Green, George, Daniel, Frankish, Herbert, Bowie and O'Neill), qualitative methodology was therefore chosen to draw upon the rich, descriptive, personal narratives of the dragon boat experience. Participant Advisors (Survivor/Dragon Boaters from the Thunder Bay and Toronto teams) were involved throughout all aspects of the research. Dragon boaters critiqued and refined the research questions and design, and were involved in an advisory capacity throughout all phases of this participatory research from design to analysis, writing, and dissemination.

Method and data collection

An ethics review was approved by Sunnybrook and Women's Health Sciences Centre. Face to face open-ended interviews were conducted with a 12-question interview guide used to focus the interviews. Participants were asked questions in order to elicit descriptions of: their experience of dragon boating and the physical, emotional, mental, and social impact of dragon boating. The order of the questions varied within each interview as the interviewer followed the lead and flow of the participants. Each interview was between 1 1/2 and 2 hours long. The interviews were taped and transcribed. Each transcript was checked for accuracy against the tape and then again by

Breast Cancer



Second place winners, Women's Open, International World Championship Dragon Boat Races, Philadelphia 2001.

each participant who reviewed her own transcript offering edits to the interviewer.

Criterion and convenience sampling (Patton) were used in recruitment for the pilot interviews. Founders of each team were identified from the participating dragon boat teams. The founders then each selected two active team members under the age of 45 at diagnosis, an older member of each team then self-identified to be interviewed for a total of six pilot interviews, N=6. Participants range from 43-75 years in age and were diagnosed as recently as 1999 and as long ago as 1974. On the whole the participant sample is somewhat homogenous; however, there is considerable variance in racial/cultural backgrounds as well as in education, income, and relationship status as well as a geographical difference given the size of the sample.

The interview transcripts were entered into N Vivo, a computer software program for qualitative data analysis, to assist in data management. A Phenomenological-Hermeneutic approach informed by the

methods of Grounded Theory was used in the analysis. Data was read line by line and open coded using the participants' own language. Thematic analysis within each transcript and across the six interviews was conducted in which experiences and perceptions, common throughout the interviews, were organized into themes and categories and then conceptually mapped into a visual model. Participants' key quotes and the conceptual model were shared with the Advisory Group for critical review before the analysis was finalized.

An examination of the transcripts revealed nine main categories within the data that begin to describe and illuminate the experience, meaning, and psychosocial impact of dragon boating. The nine categories a) Hopeful Mission; b) Common Base; c) Paddling and the Environment; d) Camaraderie; e) Regaining Control; f) Embracing Life; g) Facing the Disease; h) Having Fun; and i) Being Focussed and Moving On are described and then illustrated with participant quotes.

Hopeful mission

Entering into the sport of dragon boating after a diagnosis of breast cancer represents the embodiment of hope. Women are attracted to the positive nature of the sport that brings them into community with other women who also have breast cancer and who are visibly active, having fun, and moving on with their lives. Women who participate in dragon boating are placing themselves in a challenging athletic arena. The physical demands and the public nature of dragon boat racing inverts the perception of self and others that women, who have had a diagnosis of breast cancer, are deficient in some manner. Dragon boating dramatically refutes the myth that women who have surgical treatments for breast cancer cannot engage in strenuous upper body exercise and demonstrates women's determination, emotional and physical strength, and their power and ability to have fun following a diagnosis of breast cancer. The participants spoke of giving hope to their family members and to other



Photo: Gwen Stott

women who have been diagnosed with breast cancer and demonstrating to themselves and others “that there is life after breast cancer.”

I feel that hope is, that's what we're giving is hope to others. When you have walked a path and you can see the end of the tunnel, I think they often see where maybe if I work at it and continue it as a team member that they do see that “My golly, I couldn't have done this last year, but look at me now!” They see their own self-maturing in the progress from when they've been diagnosed.

A symbol of hope to those who need it ... I think we're a highly visible symbol of successful breast cancer treatments to a lot of people ... That is an enormous symbol of hope for people who are newly diagnosed.... We're a very, very, visible example of a group of women who are doing something and having fun doing it and living life to the fullest.

It's important for them to see us out there to see that there is a life after breast cancer. When you're in the midst of the treatments, you can hardly see ahead. You think you're going to die. It's really im-

portant for other women on the shore or watching it at home on TV. I think we've been an inspiration to lots.

The paddlers in one team extended their vision of hope to women in treatment by inscribing a paddle and placing it in the chemotherapy room in their regional cancer center.

Finding a common bond

Women found a place of connection with other women who were negotiating the enduring effects of a breast cancer diagnosis as well as surgery, chemotherapy, and/or radiation on their lives. Women speak of a silent bond, a comfort zone that comes from knowing that the other women “know.” There was a common base for all of the team members, a sense of connectedness based on different yet shared experiences of the cancer journey and an increased ease with their physical changes or their temporary loss of hair in the company of other survivors.

It's being a part of a group ... where they'd be accepted because we have this common bond. And a lot of women, after being diagnosed... speaking for myself, we're different now. We're different

from normal women now. In whatever way, and it's overcoming that.... Meeting the other women, talking about, oh, it was our first day. How long ago were you diagnosed? How long has it been for you. The whole building of, sort of finding out about one another and knowing that we're all, no pun intended, but we're all in the same boat. We've all experienced something very similar.

Paddling and the environment

Dragon boating is a sport that requires ongoing commitment to a team, dedication, and year round training. It is a sport in which women push themselves to their limits regardless of whether they are extremely athletic or whether they have never previously participated in a team sport. They find themselves training outdoors in extreme temperatures and paddling with a mental and physical intensity that they have never experienced in any other sport, or any other time of their lives.

Lake Ontario in April ... bundled from, you know, head to toe in rubber, [laughs] to try and keep the water out, you still got wet. It was freezing.

Cold, wet, my butt is sore. Those hard little wooden seats, no paddling on them and you have to sit because you're leaning so far ahead your sitting right on those bones after an hour of practicing you can hardly walk.

There is also the description of the exhilaration of being in synch with 21 other women.

It's an awesome feeling. You're paddling and you know that everybody else is doing exactly the same as you are. And you know if you don't it's like paddle cracking, it's water flying so it's a really exciting feeling knowing that you're altogether. And you holler

out, "Stroke, stroke, power, power" you're just hollowing out and it builds that real intense feeling that we're in this together and we'll work and win, we're going to do our best.

You can't compare it to hockey, you can't compare it to baseball, except for the fact that there is the overall team commitment. If you're looking at the team aspect of it. But the actual participating in the activity, you're all doing the same— it's like a machine. I always think of that big engine, what is it, the big wheel on the train, you know how it goes around together? And that's how we're paddling, all in unison together. Because if someone's off synch, it slows the boat down.

The feeling of racing, giving it your all using every ounce of muscle that you possibly you have. That feeling of strength, the camaraderie. Getting us all together. You can do it if there's 22 people in the boat, you can go anywhere. It's everybody, all working paddling the same...

While many women are winning races and increasingly demonstrating greater and greater heights of athleticism the focus is much larger than winning individual races. Women say that they have won as soon as they step into the boat. Just as being in the boat together with 21 other women with breast cancer is symbolic so is racing. As participants often put it "Yes we're winning this race, hopefully winning both races."

Camaraderie

The six study participants described a tremendous sense of camaraderie with their team members as they paddled in unison and supported each other through their cancer journeys, especially at times of reoccurrence or loss. The degree of



Photo: Otto Zogola

safety experienced in being on a breast cancer dragon boat team and the amount of pleasure that was experienced in participating in the sport of dragon boating far outweighed the challenges of the emerging group dynamics or conflicts about levels of competitiveness. Participants spoke of a powerful sense of camaraderie that arose from women being engaged in an exciting physical challenge together in which talking about breast cancer and support were secondary to their reason of being together.

I don't know if I would call it support, but I certainly got a lot of friendship. It was overwhelming. .. I wasn't looking for support but I got a lot of caring. I felt a lot of people cared and I saw a lot of friendships and the grief at the outpouring of grief at the funeral of [name] and [name], [name], it was overwhelming really.

... and you can laugh. You can laugh with them. And we can all laugh together, and we can share our stories and we can cry. And when we go through a loss in our team, we're all there to support each other. And that's really important. And as we go through that, a loss is a reality check. I

always say that, everytime. I think, oh, reality's kicking us in the stomach again. Because it is. We have fun, we get together, we paddle, we have fun, we go our races ... and then something happens within the group, we lose someone or someone has a recurrence. And we pull together for them. And again, that brings us right back to, to what the forming of this group is all about, in some sense, the awareness issues....

What I see is the distinction in this is that the support is secondary to the reason for us coming together. We're coming together for the experience of Dragon Boating and paddling. We're not coming together as a support group, we're going out and paddling. So the support happens, but it's not the primary focus and I think that's a very powerful tool and a very powerful learning out of the Dragon Boat experience. Certainly we have team members who are members of the support groups, absolutely, but we have a lot who never have been. It's a very different level.

Regaining control

Women are confronted with their

mortality and the fear of death when they are diagnosed with breast cancer. They endure harsh treatments, hair loss, extreme levels of fatigue, and other negative physical, emotional, and social side effects. Life is in the shadow of the big “C” that many initially experience as a death sentence. The women often feel that their bodies and their lives are out of their control. Dragon boating provides a positive focus for women, a goal that emphasizes health and vigor, and epitomizes living to the limits. The physical and mental preparation for dragon boating requires discipline, commitment, and a focus on one’s self that entails a challenge to the body and spirit that enables women to regain a sense of control once again. As the physical training advances and women begin to see the changes in their strength and their health and see the power of the dragon boat team working in unison there is an overall sense of regained power and control.

Chemo sucks you dry. By the time you’re finished, you have a shell of your former self. Just the disease, all the emotional and psychological things but physically I was not prepared for that ... So I started running the first of May and started the weights the end of May and I went to the support group meeting and they were doing the Dragon Boat thing. They were going to get in shape and I felt that this was perfect. Everything was falling into place. Then I had a goal; I’m going to get strong so that I could go into this Dragon Boat race... Women are taking control. That’s what it was. The cancer I can’t control that but this was something I control. I could get stronger and I could be a part of this team. I could paddle in this boat. So it was good.

I lost a lot of energy, I felt I lost control over my sense of wellbeing... And going into dragon boating, I think it opened a lot of doors

for me in the sense that it made me feel that I could be strong again. It empowered me in a way that I’ve never felt before, in some ways. Maybe because you’re being involved in a group, doing this sport, all women, who have all been diagnosed with breast cancer. And it is a lot of energy, it is demanding, and it’s a different feeling. It’s almost a feeling of, well it is, I think empowering is probably a good word, because you feel like, you can take anything on now, when you’re doing that... dragon boating has given me the opportunity to regain control in my life, to feel strong again. To be able to do things, to be able to feel that sense of aliveness.

Embracing life

Being confronted with one’s own mortality is a critical incident in a woman’s life that is often responded to with an increased focus on the self with a changed overall perspective on life and living. For some women there was a sense of living life more fully, more consciously, than they had before their cancer diagnosis.

When you’re faced with something like a life threatening illness, all of a sudden, life becomes so precious to you. You want to live every minute to the fullest. That’s me, I’m sort of a crazy. I don’t want to have a day that I’m not doing something meaningful to me. That’s why I’m job sharing and not working full time because I like work but I don’t want that to be my life, I want there to be time to do other things that I enjoy. It’s changed me for sure. I’ve become more mindful. I look for the diamonds and everyday they’re there. You become more appreciative of the small things. Doesn’t have to be big things, just little things. Sparkle of the sun, the water. The wind in the trees... You sort of wake up.

We’ve gone through what we’ve gone through, and look where we are today, we’re in boats paddling. And paddling hard and paddling strong. And feeling alive and feeling that you can do anything, that you can take on the world. It’s a real sense of accomplishment.

Women are also pushing themselves harder than they ever have physically and mentally in the dual race against the other dragon boats and the empty lane that they call cancer. While paddlers are reaching new heights of physical challenge they are also increasingly attending to the immediate, to the moment, and to the beauty in their environments.

It’s just a very, very nice environment. The sunsets are exquisite along there and whether the weather is cold or cloudy or rainy or beautiful and sunny, it’s gorgeous. It’s a beautiful location. You see birds along there, everything about it is lovely.

... just going out in the evening and the sunset and the water’s so calm and you’re out and you’re seeing and you look back in and it’s just beautiful. It’s just beautiful seeing the sun going down. And in the fall, we used to go out in the Humber River and there’s a nip in the air and it was on a Sunday morning. It’s just beautiful. Some people call it a spiritual experience.

Facing the disease

Women are attracted to the symbols of hope and the image of health and vitality that dragon boating presents. Paddlers are often survivors who do not participate in breast cancer support groups and who do not want to focus on the disease. The breast cancer dragon boat teams emphasize the physical challenges of training and racing as a team rather than directly

talking as a group about their breast cancer experiences. The dragon boaters' positive focus on a shared sport rather than talking about breast cancer, however, indicates neither complacency nor denial about the disease and its impact in their lives. The teams perform a ritual at the end of the Survivors' race in which each team member tosses a flower into the water for those women who are unable to paddle due to current treatment and in commemoration of those women who have lost their lives to breast cancer. While paddlers are ferociously racing against the disease, personally and as a team, reoccurrences do occur and team members do succumb to the disease. When the race is done and the petals are tossed each woman and the team as a whole pause to face the disease.

And the last race is also the Survivor Cup. The Breast Cancer Survivor Cup Challenge. And it's all breast cancer survivor teams. And [sighs] you start to sort of regroup and think, why the reason we're doing what we're doing, and what really is it all about, again... starting the race we all paddle out with our carnations in hand. Well, I find it very emotional. And like I said, it's really realizing what I've been through. And you stop and think about—you're having fun. You know, you're really having fun but really it stops, stops you in your tracks and says, OK, it's a reality check here. You've gone through something quite serious. My mother was also a survivor, so she had breast cancer too, and I think about that as I'm tossing my carnation. And remembering, you know, those people, team members that we've lost to the disease. And you only hope, I only hope, that one day that there will be a cure. And that our team won't have to be growing so much.

One individual found facing reoccurrence in and loss of team members overwhelming and decided

to leave her survivor team but to continue dragon boating on a community team. Another participant however found great personal meaning in witnessing and being with women who are teaching her a great deal about both living and dying with cancer.

Having fun

Despite the physical and emotional challenges of participating in a breast cancer dragon boat team, fun was the most central aspect of the participants' experience. Fun was emphatically described by all participants in terms of the mechanics of the sport itself, being in the company of women who share a common experience, the humour and bawdy insider jokes, the excitement, pride, satisfaction and thrill of the races, and the pleasure of being outside on the water.

If I were to describe my personal reaction to Dragon Boating in the first season, it was with a reminder of the fun of playing on the water... It was relearning what fun that is. That was sort of personal for me, as a personal gain out of all of it was the fun of it... For me, that's the fun part of it, so there's sort of the pleasure of the environment and the activity and the enjoyment that people get out of it. That just goes all together into the pot of having fun. I just find as an adult, we don't make a lot of opportunities for ourselves to have fun ...

But it's fun, I mean it really is fun. For example, I think I would have died and wanted to crawl into a hole in the ground... Three years ago if someone said to me, all right, (name) "hooters to the hull!" [laughter?] You know? I would've just thought, how are you saying that? But those are things that come out, and that we can laugh about. And so you can take the seriousness really, and we're not ... (but) you can take the serious-

ness of the disease and overlook it and sort of look for humor in certain things that we've been through this, we know ... we talk about ... like they'll say, hooters to the hull, you know, put your best breast forward. Or things like that. And we can laugh.

Being focused and moving on

Women became so focused on getting in shape, on the challenge and fun of paddling, that breast cancer began to recede into the background of their lives. Dragon boating is a new and positive focus within a physical and social environment that increasingly enables women to focus on life and living rather than breast cancer. The women benefit from no longer focusing on the fear of premature death, though this may still be a reality for some team members, no longer focusing on treatment related losses, the breasts, hair, fertility, or other cancer related losses in their lives. Instead women increasingly focus on the present, on their physical strength, on their emotional and physical wellness, on pushing limits and being all that they can be. There is an admirable focus on the present, on an increased sense of being in the moment, of moving on from the weightiness of the cancer experience to an enhanced sense of "mindful" living and aliveness.

But from the beginning, it's just, all I wanted to do was get in the boat and paddle. And when I did, everything else was left outside. I never focused on anything else. I never and I liked that feeling. I liked the feeling that when I went to paddle down in the water I left all my worries behind. I focused on the moment, and it was paddling in the boat with these women. And I liked that feeling.

... the dragon boating has helped me get over worrying about whether I'm going to have lymphodema or not. You know,

worrying about what's going to happen, because I've had little side effects, with my arm. And so it's helped me move on, say, OK, deal with it, you've got to deal with it. But don't quit because of it. Don't say, oh, because my arm's bothering me or hurting, you're going to stop paddling. Just keep going. And I think that that it helps you to say, you can do it. You can be strong. It gives you, it gives me such great satisfaction, to be involved and be a part of it.

Discussion

Despite a variety of personal circumstances of the study's participants there were notably no discernible differences in the participants' experiences of, or responses to, dragon boating. Half of the participants in this study live in Toronto and are not members of breast cancer support groups. The other half live in the northern community of Thunder Bay where they were all a part of a survivors' support group. The participants were in very different places in their cancer journeys, being from three years to twenty-seven years post diagnosis, ranged from 43 to 75 years in age, and were in varying life circumstances in terms of work and family. All of the participants, regardless of age, years since diagnosis, or life circumstance, talked about the meaning and importance of dragon boating in their lives. The individual who left her team to paddle with a community team was particularly emphatic about the positive impact of dragon boating in her life as a survivor of breast cancer. All of the participants spoke of increased physical and emotional health, and a sense of aliveness, of living life to the limits.

As a team sport, dragon boating, has inherent in its structure and processes some important variables that have in other circumstances been shown to mitigate cancer related distress. In particular, dragon boating provides exercise, social support, and

a sense of increased control. There is considerable evidence that exercise in general has a positive impact on the health status of women with breast cancer. Several studies have demonstrated that exercise improves women's functional status after breast cancer (MacVicar, Winningham and Nickel) as well as their quality of life (Young-McCaughan and Sexton; Mock *et al.*). Social support and emotional expression, both integral to the breast cancer dragon boat experience, have been shown to mediate many of the negative psychosocial aspects of breast cancer such as anxiety, denial, anger, depression, and altered self-image (Oktay); (Spiegel, Sephton, Terr, and Stites); (Classen and Butler).

Dragon boating as a team sport provides survivors with a community of women with an unspoken knowing. The comfort and safety that comes from the camaraderie of women who are "all in the same boat" combined with physical training and challenge provides promise as a powerful antidote to the sense of loss and difference, lack of control and fear, that often follows a diagnosis of breast cancer. For the women I interviewed the balance of Facing the Disease and Embracing Life was clearly positive. Dragon boating is fun and inspiring, it fills participants, their family members, and spectators with hope. For some facing the possibility of reoccurrence and death has promoted an integration of their beliefs and feelings about death. This in turn produced a freeing up, a letting go, that has enabled them to live more in the moment and to understand that living is dying, and that very few of us choose our time of death. There was an increased honouring of the dignity in living in the moment and entering a journey of learning how to embrace both life and death to the fullest.

You've got a lot of women who have come through a life-threatening experience... It's an invasion in your body, it's, you know,

there's all those things. And these women get together and we have this commonality, this common thing that's happened to us in our lives. Overlooking it, or sort of putting that now to the side and saying, OK, we're all here for the same reason let's do what we have to do but let's make the best of it and let's have fun. And so it's building friendships and camaraderie. And the whole aspect of sportsmanship on a team, and being involved in these dynamics, it's [laughs] an experience. But it's fun, I mean it really is fun.

Dragon boating will not ensure that there will not be a reoccurrence, it will not necessarily contribute to increased length of survivorship; however, it has for this small sample of women, increased their sense of wellbeing and enhanced their quality of life.

Conclusion

This pilot study is the first study on the psychosocial impact of dragon boating on women with breast cancer and therefore adds considerably to the limited understanding of mechanisms of psychosocial support for women living with breast cancer. The study indicates that dragon boating as a team sport provides hope and focus and enables women to move beyond the spectre of breast cancer not only to survive but to increase their sense of well-being and to enhance their lives. The unique nature of support as a secondary outcome of participation in a dragon boat team is poorly understood and will need further investigation. Given the small number of research participants and their specific roles as participant/advisors, further investigation of the findings of psychosocial impact is needed with a larger sample of dragon boaters. The increasing popularity of dragon boating suggests that this team sport is already perceived as a promising vehicle for enhancing the quality of women's lives after a diag-

nosis of breast cancer. From its beginnings with the Vancouver Abreast In A Boat team, to the present participation of over 1000 paddlers living with breast cancer from coast to coast, dragon boating has captured the imagination and spirit of breast cancer survivors across Canada. Further research is required to test the hypothesis that dragon boating as a team sport provides a powerful communal context to engage in adult play while enhancing the physical and emotional health of breast cancer survivors as they race individually and together against breast cancer.

This study would not have been possible without the support and active involvement of the Dragon Boat Advisory Group made up of members from the Toronto and Thunder Bay dragon boat teams, Dragons Abreast and Dragons of Hope, and the breast cancer survivors who gave so willingly of their time and life experience. We also wish to acknowledge the support of Dr. Margaret Fitch and Dr. Ross Gray and funding from the Canadian Breast Cancer Research Foundation Community Research Initiative.

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Eleanor Nielsen is a nurse who spent the first half of her working life in hospital management. For the past ten years she worked in a variety of positions at the national office of the Canadian Cancer Society. She retired from this position in June 2001. Eleanor

was diagnosed with stage 2 breast cancer in 1989. She is a Reach to Recovery peer support volunteer and has conducted volunteer training for the Canadian Cancer Society for three years. She is the co-founder of the Toronto breast cancer dragon boat team, Dragons Abreast.

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PATIENCE WHEATLEY

Kissing Under a Winter Sky

You expect nothing
and the surprise of it tips
you into the thought

Why was *this* so enjoyable?

like the mild shock sometimes
encountered at New Year's Eve
parties
meaningless yet intriguing that
can fit you under the bow of Orion
shove you under the kilt of
Perseus, and the square belly of his
horse.

Cassiopeia weeps, Andromeda
laughs.

And you think perhaps
you're as young as they are

*Patience Wheatley's poetry appears earlier
in this volume.*