

A mixed method study of a peer support intervention for newly diagnosed primary brain tumour patients

by Douglas Ozier and Rosemary Cashman

ABSTRACT

Purpose: The purpose of this pilot study was to investigate the impact of an intervention designed to enhance quality of life in newly diagnosed primary brain tumour (PBT) patients. The intervention involved a structured, one time meeting between newly diagnosed PBT patients and trained volunteer “veteran” PBT patients.

Methods: Two volunteers met for a single, one-on-one meeting with a total of 10 newly diagnosed PBT patients. A combination of questionnaires and interviews were used to investigate the impact of the intervention for both the new patients and the volunteers.

Results: The intervention appeared to be of substantial value for both groups of participants. Analysis revealed that the newly diagnosed patients experienced a range of benefits, including those related to the themes of: increased hope, valued guidance, hearing what it’s really like, overcoming aloneness, and receiving a wake up call to what matters. Only relatively minor adverse effects and challenges were reported.

Conclusions: The findings provide initial evidence that the developed intervention has the potential to be a safe, useful means of enhancing psycho-social well-being in newly diagnosed PBT patients.

Further investigation into the potential of one-to-one, peer support for brain tumour patients is an important research priority.

Key words: cancer; brain tumour, peer support, quality of life, volunteer

INTRODUCTION

The diagnosis of a primary brain tumour (PBT) is a devastating occurrence. This profound impact is reflected in the fact that PBT patients exhibit significantly impaired quality of life (Taphoorn, Sizoo, & Bottomley, 2010), highly elevated levels of existential distress (Pelletier, Verhoef, Khatri, & Hagen, 2002), and rates of depression that are up to three times higher than those found in the general cancer population (Wellisch, Kaleita, Freeman, Cloughesy, & Goldman, 2002). There is an evident need for the development and validation of psychosocial interventions that can help to enhance quality of life and decrease distress in the PBT population.

In response to this need, our research team consulted with the members of our Patient and Family Advisory Council (PFAC), a volunteer body of brain tumour patients and family caregivers that provides input to the British Columbia Cancer Agency’s (BCCA) neuro-oncology care program. PFAC members recommended the development of a pilot program for newly diagnosed PBT patients through a single meeting with a “veteran” patient who would be trained to provide support and information. New patient participants (NPPs) would be matched to volunteer veteran patients (VVPs) based on whether they had high grade (III and IV) or low grade (II) tumours.

A review of the literature revealed ample evidence to support this project. First, research findings suggest that while cancer survivors who attend a support group derive strong benefit, only a small percentage of cancer survivors ever actually attend such a group (Grande, Myers, & Sutton, 2006). For example, a group of authors (Sherman, Pennington, Simonton, Latif, Arent, & Farley, 2008) found that only 8% of the 425 cancer survivors they surveyed had attended a support group. Therefore, one-to-one peer support interventions would seem to offer an alternative to support groups, perhaps appealing to cancer patients who might not feel comfortable accessing support in a group setting. Further, we wondered if offering a positive peer interaction early in the disease course might empower new brain tumour patients to more actively access other support services, such as support groups.

Second, a review of 19 one-to-one, peer-based support interventions conducted in an oncology setting suggested that these programs tend to be “well received and have benefits, including improving well-being and/or reducing anxiety”

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(Macvean, White, & Sanson-Fischer, 2008, p. 22). For example, a group of authors (Dunn, Steginga, Occhipinti, & Wilson, 1999) researched the impact of the “Reach to Recovery” program, which organizes meetings between trained, veteran breast cancer survivors and patients who have recently undergone a mastectomy. The new patients receive a single, brief visit from their volunteer. Despite the brevity of these interactions, on average, the 245 new breast cancer patients found this intervention to be “very helpful” and felt “significantly less anxious” after the meetings.

Third, adaptation to a cancer diagnosis occurs over time and with effort. The development of a sense of mastery has been cited as an important element of adjustment to a life-threatening condition (Hagopian, 1993). We postulated that the provision of guidance to new patients would not only be helpful to new patients, but it might also promote a sense of mastery in the veteran patients and, thus, foster their psychological strength and adaptation.

Finally, despite the clear promise of one-to-one peer support interventions in psycho-oncology, relatively little research has been done in this area. This has led authors in the field to call for further work to be undertaken (Macvean, White, & Sanson-Fischer, 2008; Hoey, Ieropoli, White, & Jefford, 2008). In this article we report on the impact of the peer support intervention that we piloted between June and November, 2012. Our inquiry focused on the following questions:

- Were there benefits and/or adverse outcomes experienced by the new patient participants?
- Were there benefits and/or adverse outcomes experienced by the volunteer veteran patient participants?
- What other information was obtained from this study that could result in improvements to the intervention?

METHODS

Participants

Volunteer veteran patients (VVP). Four VVPs were recruited from within the Vancouver brain tumour community; all were active members of our PFAC and had completed initial treatment for a PBT (see Table 1).

The first author provided 15 hours of individual training to each VVP over a period of six weeks. These training sessions focused on: clarification of the role; emotional management; and the intensive use of role play to integrate the relevant skills. Protocols for a variety of possible boundary issues (e.g., dealing with suicidal ideation and “doctor bashing”) were also created.

Three VVPs completed the training. Unfortunately, the fourth volunteer, Ann, experienced a recurrence of her tumour after her first training session and withdrew from the study.

New patient participants (NPP). As part of her initial assessment of newly diagnosed brain tumour patients at their first visit to the BCCA Vancouver centre clinic, our neuro-oncology social worker invited all eligible patients to participate in the study. Criteria for participation included: a new diagnosis of a grade II, III or IV glioma; English fluency; and a Karnofsky Performance Score ≥ 70 . The first author then conducted screening calls with all of the new patients who expressed interest in participating in the study. After informed consent was obtained, each NPP met with a VVP until a total of 10 individual meetings had occurred.

Recruitment occurred between April 1 and August 29, 2012. During this period, 31 English-speaking patients with a new diagnosis of a high grade glioma appeared for treatment at the Vancouver Centre. Of these:

- 8 were excluded due to inadequate functional status
- 23 potential participants were invited to have a screening call
- 13 of these 23 people declined the offer
- all 10 of the interested parties were successfully enrolled (see Table 2).

During the accrual period, no new patients with low grade brain tumours who met the inclusion criteria appeared at the clinic. Therefore, in order to maintain our goal of matching VVPs to NPPs by tumour grade, all of the meetings were conducted by those VVPs who had a diagnosis of a high grade glioma (Mike, six meetings; Yves, four meetings).

Intervention

The intervention involved a one-hour, private meeting. The meetings were held in a meeting room at the BCCA Vancouver Centre four to eight weeks after the NPP’s initial diagnosis. The VVPs structured the meetings to include introductions, time for the new patient to freely initiate topics or ask questions, and a brief period at the end in which the VVPs reviewed a list of relevant supportive resources. The VVPs were trained to make use of a prompt list if the NPPs seemed hesitant to generate their own questions. An example prompt from this list was, “A lot of new patients are worried about treatment side effects, are you?” Overall, the VVPs’ emphasis was on active listening, provision of emotional support, and the sharing of personal experiences as a successful survivor. The VVPs were explicitly trained never to offer any form of medical advice. The NPPs filled out response questionnaires immediately following the intervention.

Pseudonym	Gender	Age	Ethnicity	Profession	Diagnosis	Years Post-Diagnosis
Yves	M	38	Caucasian	Scientist	glioblastoma/Grade 4	9
Mike	M	39	Caucasian	Former lawyer/counselling student	anaplastic astrocytoma/Grade 3	4
Arnold	M	66	Caucasian	Semi-retired academic	oligodendroglioma/Grade 2	6
Ann	F	41	Caucasian	Former occupational therapist/ stay-at-home mother	oligodendroglioma/Grade 2	4

NPP	Age	Gender	Ethnicity	Marital Status	Glioma WHO grade
Gerry	48	M	Caucasian	Married	3
Mona	59	F	Caucasian	Married	4
Gary	54	M	Asian	Married	4
Jake	54	M	Caucasian	Married	3
Robert	48	M	Caucasian	Single	4
Bradley	57	M	Caucasian	Married	4
Dwayne	65	M	Caucasian	Married	4
Shawn	68	M	Caucasian	Married	4
Shirley	47	F	Caucasian	Common-law	3
Alan	51	M	Caucasian	Single	4

Psychometric measure

The study response questionnaire, a 10-item, Likert style, self-report measure, was adapted from the Post-Meeting Participant Response Questionnaire (Ashbury, Cameron, Mercer, Fitch, & Nielsen, 1998) to quantitatively assess NPP's responses to the intervention.

Follow-up interviews

The first author met with the NPPs one week after the intervention for a digitally recorded, follow-up interview. Six weeks later, the first author contacted the NPPs by telephone for a second interview. The first author also conducted interviews with the VVPs at the end of the data collection period. All interviews included quantitative, ranking style questions; closed questions; and exploratory, open ended questions (see Appendix A, which lists select interview questions).

Supervision and support of the VVPs

The first author held an individual supervisory session with each VVP after every two NPP meetings that the VVP conducted. These hour-long supervisory meetings involved problem solving, coaching, and the provision of emotional support.

DATA ANALYSIS

Quantitative analysis. The ranking style interview questions and the questionnaire responses were analyzed using descriptive statistics.

Qualitative analysis. Analysis of the NPP interviews followed the general approach to qualitative analysis described by Vilhauer (2009). First, all of these interviews were professionally transcribed. The first author then read and re-read the transcripts from the initial NPP interviews to identify all portions of these transcripts that were related to one of the previously defined domains of inquiry: benefits, adverse effects, valued topics, and suggested improvements. This process revealed that the questions related to the domains of valued topics and suggested improvements resulted in relatively straightforward responses. Responses in these categories were therefore not thematically

analyzed, and are instead reported in list form with frequency counts. Analysis further revealed that only two adverse reactions were reported. Therefore, each of these events is discussed individually. Alternately, the NPPs' responses regarding derived benefits prompted a rich, diverse set of narrative data. Therefore, this data was thematically coded into units of meaning. The constant comparative method (Strauss & Corbin, 1990) was then used to group these data into emergent themes and, where appropriate, sub-themes.

The described process was also performed on the second NPP interview data. As with the time one data, only the responses related to perceived benefits resulted in data amenable to thematic analysis. Comparison of the benefit related data across the two time points revealed that no new benefit-related themes emerged from the second interviews. Therefore, the benefit-related data from the two time points were merged for subsequent analysis.

Once all of the benefit-related data had been coded and assigned to a theme, a naïve rater re-sorted a randomly selected 30% of this data (Wimmer & Dominick, 1991). Following this, the themes were further refined. This process was repeated until an inter-rater agreement kappa of at least 0.7 was achieved, representing a "good" level of agreement (Altman, 1991). One theme (increased hope) was assessed to contain sub-themes. Therefore, the described re-sorting and refinement process was repeated at the sub-theme level with another naïve rater, again until a kappa of 0.7 or greater was achieved.

In regards to the VVP interviews, the analysis process again began by having both interviews professionally transcribed. The PI then identified all portions of the transcripts that were related to one of the previously defined domains of inquiry: benefits, adverse effects, challenges, and responses to training/support.

Ethics

Ethics approval for this study was granted by the BC Cancer Agency Research Ethics Board. Informed consent was obtained from all individual participants included in the study.

Statement	Item Mean ranging from 1 (strongly disagree) to 5 (strongly agree)	Standard Deviation (SD)
I felt comfortable discussing my illness with my volunteer	5	0
I felt that I was well matched to my volunteer	4.7	0.7
I felt that my volunteer was sensitive	4.9	0.3
I felt that my volunteer was comfortable discussing my illness with me	4.9	0.3
I felt that the volunteer was non-judgmental	5	0
I felt that the volunteer was responsive	5	0
I felt that the volunteer was helpful answering questions	4.8	0.4
I felt that that the visit was soon enough after diagnosis	4.1	1.0
Overall Mean	4.8 (closest to strongly agree)	-
Overall Mean of SD	-	0.38

*Adapted from the Post-Meeting Participant Response Questionnaire (Ashbury, Cameron, Mercer, Fitch, & Nielsen, 1998)

RESULTS

Questionnaire responses

See Table 3.

Responses to ranking style questions

During the first interview the NPPs were asked to answer the question, “Overall, how helpful was this meeting for you?” on a four-point scale (from 1: “not at all helpful” to 4: “very helpful”). The average answer was 3.35 (with a standard deviation of 0.57), closest to “quite helpful.” The NPPs were also asked to answer the question, “Overall, how negative was this meeting for you?” on a four-point scale (from 1: “not at all negative” to 4: “very negative”). The average answer was 1.15 (s.d. 0.38), closest to “not at all negative.”

During the second interview (approximately six weeks after meeting the volunteer) the NPPs were again asked to answer the question, “Overall, how helpful was this meeting for you?” The average answer was 2.9 (s.d. 0.86), closest to “quite helpful”. Finally, the NPPs were again asked to answer the question, “Overall, how negative was this meeting for you?” The average answer was 1.05 (s.d. 0.15), closest to “not at all negative”.

Responses to close ended questions

During the first interview the NPPs were asked a number of closed ended questions.

- In response to the question, “Was one meeting with the volunteer enough for you or would you have wanted follow-up meetings? (If more meetings were wanted) How many more would you have wanted?”
- Four (40%) respondents said one meeting was right for them; three respondents (30%) said they would have wanted one follow-up meeting; one (10%) respondent said they would have wanted two follow-up meetings; one respondent (10%) said they would have wanted three follow-up meetings; and one (10%) respondent said they would have wanted unlimited follow-up meetings.

- In response to the question, “Do you feel it was important that your volunteer was a brain tumour survivor instead of a survivor of another form of cancer?”
 - All 10 (100%) respondents said “yes.”
- In response to the question “Do you feel your partner (or other key support person) would find it helpful to have a similar meeting with a volunteer who was the support person of a veteran brain tumour survivor?”
 - Eight respondents (80%) said “yes”; one (10%) respondent said “no” due to a language barrier; and one (10%) respondent said this was not relevant as he did not have a key support person.
- During the follow-up interview, the NPPs were asked the following question: “Has your meeting with the volunteer, including anything you talked about or the booklet of resources he shared, had any impact on how you have accessed supportive resources since then?”
 - One respondent (10%) said “yes.”
 - Nine respondents (90%) said “no.”

Responses to open ended questions

During the first interview the NPPs were asked about valued topics and suggested improvements. Their responses are listed below with frequency counts of how many participants mentioned each item.

- Valued topics:
 - Hearing others’ story (3); Adjusting to changed life priorities (3); Dealing with career transition (3); Recommended life style changes (2); Specific coping strategies (2); Treatment side effects (2); Exercise (2)
- Suggested improvements:
 - More structure (3); Meeting should have been held earlier in the diagnosis (3); More personal disclosure by volunteer (2); Longer meetings (2)

Benefits reported by the NPP

Regarding NPP reported benefits, the process of re-sorting and refinement at the theme level was conducted by three naïve raters, when a kappa of 0.701 was achieved. In total, seven benefit-related themes were identified. Only the five themes that were alluded to by at least four NPPs are reported here (see Table 4). Re-sorting and refinement at the sub-theme level (only conducted within the “increased hope” sub-theme) was stopped after rating had been conducted by a single naïve rater, as a kappa of 0.745 was achieved.

Increased hope. The strongest form of benefit to emerge from the data was that of increased hope, with nine of the 10 NPPs making at least one statement to this effect. Four distinct sub-themes emerged within this theme.

Theme	# of NPP who reported theme
Increased hope	9
Valued guidance	7
Hearing what it's really like	6
Overcoming aloneness	5
Receiving a wake up call to what matters	4

1) The first hope related sub-theme was, “hope for a longer life than expected”. Eight of the NPPs expressed the feeling that, through meeting the volunteers, they felt more hopeful that they would live longer than they had allowed themselves to believe was possible. This hopefulness arose from the experience of sitting with a brain tumour survivor who was doing well, which provided tangible proof that this was a possible outcome following treatment. Mona said:

“I wasn't allowing myself any kind of future, I wasn't allowing myself to say, ‘Next year I'm going to do this’ ... I was restricting myself; it was almost like I had a barrier around me... And Mike gave me hope...I wasn't even thinking up 'til Christmas... I've got more hope now that I will be (here at Christmas)...that's where the hope comes from. Because if you don't have any hope and you're ill ... your sense of living, your well-being, everything changes.”

2) The second hope related sub-theme was, “hope inspired by the volunteer's example of living with the diagnosis”. Six of the NPPs reported that the VVP's personal example of successfully meeting the challenges of living with a brain tumour encouraged them to believe in the possibility of a similar outcome. Mona said:

“And the things that he's done since he has been diagnosed—he's travelled, he's had a child, it's just amazing. It's given me hope... (to) reach a stage like his.”

3) The third hope related sub-theme was, “hope for a better medical outcome than feared”. Three NPPs found that meeting with the VVP had fostered a sense of hope that the medical implications of their disease would not result in severe decrements to their quality of life, as they had feared. Gerry said:

“...you picture people who are altered mentally because they have had the operation... You think that they're going to be like Jack Nicholson at the end of One Flew Over the Cuckoo's Nest, and that there'll just be nothing left, or they'll be a completely different person. So, it's good to know, just from meeting Mike...that it hasn't changed him.”

4) The final hope related sub-theme was, “hope that could be conveyed to loved ones”. Two NPPs said the meeting had provided a mechanism for restoring hopefulness to their loved ones, who were also highly anxious as a result of the diagnosis. Gerry said:

“Yeah, because I worry more about my wife and... about my aging parents more than I worry about myself in a sense, and I was able to tell them about Mike's situation, and I think that made them feel better.”

Valued guidance. Seven of the NPPs expressed that they benefitted from receiving concrete recommendations from their VVP. Gerry said:

“I recall Mike saying that it was either massage or acupuncture in terms of stress that made him feel better, and that made an impression on me...”

Hearing what it's really like. Six NPPs found it encouraging and demystifying to hear an account of the volunteer's day-to-day experience of living with a brain tumour, particularly in regards to treatment and tumour effects over time. Several of these NPPs reported that even though they believed their own tumour-related experiences would be unique and, therefore, inevitably different from those of the VVPs, it was helpful to be given some sense of the challenges they might expect. Alan said:

“To hear it from somebody who's gone through it rather than a doctor who says, ‘You might experience this.’ I mean to hear somebody say, ‘This is what actually happened to me, you know?... it's more concrete...”

Overcoming aloneness. Half of the NPPs made statements that reflected a greater sense of connection and shared experience after meeting with the VVPs. Some alluded to a sense of overcoming a pervasive existential aloneness that had troubled them since the diagnosis. Gerry said:

“...I found it helpful because...when you find out about this, it's as if...something goes up between you and the rest of the world, like a Plexiglas wall... So, it's good to talk to people like Mike... Whether they experience it that way or not, they're kind of a part of a merry band of brothers, you know?”

In a related exchange Mona said:

“...You just feel so alone inside, even though there are so many people here and they're so wonderful and they're so supportive...You can have everybody in the world love you and support you, but you never feel that that fills the emptiness that you have inside. And he (the volunteer) felt the same way... (it's) you know, some gentle relief.”

Receiving a wake up call to what matters. Four NPPs related that the VVP meetings had prompted a greater sense of the importance of prioritizing what mattered most to them in their lives. Gerry, who has a longstanding love of music, but was pursuing a degree in gerontology at the time of his diagnosis, said:

“(The VVP) said to me that the place is there for him in the law firm, but he’s not sure whether he ever wants to practise law again...It just rang a bell... I mean when you know you might have limited time, you want to use that time doing what you really want to do.”

Adverse impacts reported by the NPPs

Two adverse events were reported by the NPPs. In one case, the NPP Gerry was surprised to learn that his VVP had been given an estimated life expectancy, while Gerry had not. This led Gerry’s VVP to speculate that the “real” reason that Gerry’s medical team had not offered him a concrete prognosis was that medical practice has changed and oncologists no longer feel it is helpful for patients to be given a specific life expectancy. In response to this speculation Gerry said,

“...I guess maybe that is a negative thing that I took away from it...is this a five-year thing. I keep remembering it, that that’s what they told him.”

VVPs are explicitly discouraged from engaging in interpretation or explanation of medical advice and opinion because this may lead to incorrect assessments. In addition, it has the potential to produce anxiety in NPPs and to lessen their faith in the integrity of their medical teams. However, this event seems to have had a relatively limited negative effect on Gerry, reflected in the fact that, one week after the intervention, he only gave a 1.5/4 negativity rating, versus a 3/4 positivity rating for the meeting.

The second adverse event involved the NPP Shirley, who expressed the perception that her VVP had become emotionally triggered several times during their meeting, and that during these episodes he had inappropriately shifted the meeting’s focus toward his own emotional needs. This caused Shirley to leave the meeting with some negative feelings, as reflected in her comments:

“...because he sort of got choked up a bit... (so, I felt) just a little negative, because I somehow assumed the roles would be reversed...(and that he was) wasting my time a little, just for a moment, you know?”

However, the impact of this event seems to have been quite mild for Shirley, as evidenced by her initial negativity rating of 2/4, versus a 3/4 positivity rating for the meeting.

Benefits reported by the VVPs

Collectively, the two volunteers identified three specific benefits that they had derived from participating in this study.

An increased sense of accomplishment and positive meaning. Both VVPs expressed the feeling that working as a guide to newly diagnosed patients had helped them to feel a heightened sense of self-worth and positivity about their own experiences. Yves said:

“...it just feels good to have that kind of impact on others... for me, it wouldn’t feel right to have survived this and then forget about it, and not be able to leverage that to help others. So, it places meaning behind my continued growth, so to speak, of where to take my experience.”

Mike expressed similar feelings:

“It’s given me huge benefits... I feel really great after the meetings. I feel that I’ve presented hope to a patient...”

Decreased anxiety. Mike expressed the belief that volunteering had helped to strengthen his belief in his ability to handle stressful aspects of his condition:

“There’s a whole variety of factors, but since these meetings have started my anxiety level has gone dramatically low. I experience almost no anxiety about my side effects now. I experience no anxiety about the MRIs—or little anxiety about the MRIs. I think it’s just given me perspective...”

Mike also made comments that suggest his participation in the volunteer program helped him to achieve a greater sense of peace and equanimity, even as he confronted the fears related to his own mortality.

“...Mortality is always on my mind whatever I do...whether it’s playing video games or exercising or whatever...but in this place of really being present with another patient who is suffering a brain tumour, and its early stages for them, and I remember all that fear that I had, and it’s just like, ‘Yeah, I can handle this’... I have to remove my masks. And I think that being in that place of being authentic really helps me. So many times I’ve put on a brave face and I feel fear and anxiety.”

Increased communication skills. Yves felt that the training process had made him a more thoughtful and better communicator, particularly at work.

Adverse impacts reported by the VVPs

Upon inquiry, Yves did not identify any adverse impacts as a result of volunteering. Mike, however, identified a single, mildly adverse impact. In the early stages of the project Mike found that discussing the topic of seizures with NPPs provoked an anxiety that he was having seizures even when he was not. However, with support and supervision, this anxiety quickly diminished and ceased.

Challenges reported by the VVPs

Both VVPs expressed general confidence in their ability to manage the meetings effectively, and in their ability to regulate their own emotions in order to better support the new patients. Mike did identify one challenge in this domain, however, as reflected in the quote below:

“Sometimes I got emotional about my wife and my son and then typically, older men would jump in and try to caretaker me and I would have to say, ‘This is about you and this is your meeting and the focus really should be on you.’ ... that seemed to put the meetings back in order.”

VVP responses to the training and support/supervision

Both of the VVPs said that they were strongly satisfied with the training, support and supervision they received for their volunteer role, and they particularly valued the experiential, role-play aspect of the training.

DISCUSSION

This study involved the development and implementation of a one-to-one peer support intervention for newly diagnosed PBT patients. Patients who had previously completed initial treatment for a brain tumour were trained to offer support and information to the new patients.

The most significant finding to emerge from the study is that the intervention was found to be beneficial for the NPPs and caused no serious adverse effects. This conclusion is supported by both the quantitative ratings of the intervention and by the eloquent observations of NPPs regarding its positive outcomes. This finding underscores the value of a peer support program for newly diagnosed PBT patients and also supports the conclusion reached by previous researchers (Macvean, White, & Sanson-Fischer, 2008) about the value of one-to-one peer support programs for cancer patients more generally. This result is particularly salient in light of the findings of a literature review on the psychosocial and supportive care needs of glioma patients (Ford, Catt, Chalmers, & Fallowfield, 2012) which found that patients were dissatisfied overall with communication with their health care providers. The reasons for this dissatisfaction were varied and included a lack of positive messages and a failure to prepare patients for life after treatment. The NPPs who received our study intervention explicitly mentioned the benefits of meeting with successful VVPs who served as positive role models and led them to have a more hopeful attitude about life after treatment.

In addition to being beneficial for the new patients, the intervention also resulted in positive outcomes for the “veteran” patients, again without causing any significant detrimental effects. This finding is consistent with recent evidence that cancer patients derive psychological benefit from serving as peer volunteers (Pistrang, Jay, Gessler, & Barker, 2013), but contrasts with an earlier study that did not find this to be the case (Giese-Davis et al., 2006).

The fact that our VVPs derived benefit from this experience, even as they were forced to confront existential fears, suggests that the effort of supporting others may have facilitated the development of an increased sense of personal control. This hypothesis is consistent with research showing that controlled exposure is a powerful means of lessening the anxiety associated with highly charged psychological situations (Hayes, Strosahl, Wilson, Bissett, Pistorello, Toarmino, et al., 2004).

The brevity of the intervention bears discussion, as the reported benefits were accrued despite the fact that the intervention only involved a single meeting. This result is consistent both with the previously cited results of the “Reach for Recovery” program (Dunn, Steginga, Occhipinti & Wilson, 1999) and also with the surprisingly potent effects of single session psychotherapy (Bloom, 2001). At the same time, however, the majority of the NPPs did express a preference for at least one follow-up meeting. Hence, future iterations of this intervention should potentially include the option of a follow-up meeting for those new patients who want one.

It is also worth noting that, although the NPPs benefited from the intervention, there was a very limited increase

in NPPs’ subsequent uptake of other supportive resources (with only 10% of NPPs agreeing that the meetings had had an impact on the way in which they had accessed supportive resources in the following six weeks). This finding went against our expectation that having a positive peer interaction during which they were offered information on relevant support resources would increase the NPPs subsequent resource-seeking behaviour. It is possible that a single interaction with a VVP was not sufficient to increase the NPPs’ motivation to seek other forms of support. On the other hand, perhaps this intervention did lead to an increase in the NPPs subsequent uptake of other support services, but this occurred following our brief, six-week follow-up period. Ultimately, establishing the extent to which this kind of very brief volunteer intervention can encourage new brain tumour patients to more actively access support services is an important question for future research.

On another front, almost all of the NPPs said they felt that a similar intervention would have been helpful for their partner or key caregiver. Our findings, therefore, suggest that caregivers of newly diagnosed brain tumour survivors, who are also burdened with anxiety, distress, and uncertainty (Janda, Steginga, Dunn, Langbecker, Walker, & Eakin, 2008), may similarly benefit from meeting with veteran caregivers who have successfully met these challenges. This is particularly relevant in view of the potential cognitive and physical deficits of PBT patients, and the resulting importance of family caregivers in patient decision-making and care provision.

Finally, the importance of patient engagement in the development of neuro-oncology care programs cannot be overstated. This study is a demonstration of the fact that our PFAC members provide invaluable insight into the needs of brain tumour population and guidance about the most effective ways to meet these needs.

Limitations

There are a number of limitations to this research that impact both its internal validity and its ability to be generalized. The study required the development of a training program for VVPs, was conducted by a research counsellor, and required a significant degree of staff effort and supervision. This may be beyond the purview of less well resourced cancer centres. This may still prove to be the case, even if the number of training and supervision hours involved in this intervention can be lessened without degrading its efficacy or safety.

In a similar vein, we were able to recruit two outstanding VVPs. In fact, one of our VVPs had a special interest in counselling and had begun a program of training in this field. Staff at other centres may find it difficult to recruit such highly qualified, motivated volunteers to a program of this nature.

All NPPs and VVPs were the second author’s patients and also received special attention during the program from the first author. It is therefore possible that these relationships may have caused the NPPs and/or VVPs to overstate the benefits derived from the intervention.

Our inclusion criteria restricted access to the intervention to those patients who were medically most well and who spoke English. Furthermore, all but one of the new patient

participants were Caucasian. These factors decrease the representativeness of our sample and thereby lessen the generalizability of our findings.

The intervention was conducted by only two VVPs and, as such, the outcomes may have been different if other individual VVPs had been involved.

Finally, although efforts were made to ensure inter-rater reliability, it is possible that the themes that emerged through qualitative analysis may have been different in the hands of another research team.

Summary

Trained, veteran brain tumour patients may provide a meaningful source of support to newly diagnosed patients. The experience of serving as a successful role model may also benefit the veteran patients and promote a sense of self-efficacy, integrity and coherence in a life that has been disrupted by a devastating illness. This model of support is aligned with an increasing interest in patient advocacy and self-determination, and may respond to unmet needs for better communication and support. The findings of this pilot program are preliminary, but suggest that further research into peer support for brain tumour patients, as well as their family members, is important.

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Appendix A: Selected interview questions

Open Ended Questions for the NPPs

- Was the meeting with the volunteer helpful for you?
- (If so) In what ways?
- Was the meeting with the volunteer a negative experience for you in any ways?
- (If so) In what ways?
- Were there any topics that were especially helpful for you to talk about?
- Are there any improvements to the program that you could suggest?

Open Ended Questions for the VVPs

- Has this experience benefitted you in any way? If so, how?
- Has playing this role been a negative experience for you in any ways? If so, how?
- What challenges did you experience in facilitating the meetings?
- How well did the training prepare you for the role?
- How well supported did you feel by the staff?