

Project Report

Project Title: “Capturing and Telling Your Community’s Cancer Story”

Organization: Agency on Aging

Time Period (for project): May 2 - February 28, 2008 (includes extension)

Partners (communities involved):

- Group A
- Group B
- Group C

A. Describe each community’s project (Types of consultation provided; Timeline; Focus of stories collected and from whom in community; How stories were developed into script; Describe outputs and how selection was made; Presentations)

Story to Performance Workshop

On August 12-14 at the Holiday Inn in Norton, Virginia, two Roadside Theater trainers conducted a “Story to Performance” workshop with 11 attendees from three central Appalachian Mountain communities (Group A, Group B, Group C) and one attendee representing the University funder. (Unfortunately, the University attendee was only able to attend the first day of the workshop, as she became ill.) The “Story to Performance” workshop is one part of Roadside Theater’s community cultural methodology process developed over 30 years of practice in communities in central Appalachia and across the U.S. Through the process, ordinary citizens come together to use their communities’ strengths to name and address their communities’ challenges by telling their own stories through the public format of theater.

Workshop attendees drove to Norton and met for dinner and a Roadside Theater introductory performance on the 12th. The workshop consumed the next two days, in which participants learned by doing. With Roadside’s oral instruction and with minimal use of pen, paper, marker, and flip chart, participants learned: to collect stories orally through a specific story circle methodology; to use these stories to create simple scripts; and to produce and perform their scripts for each other on the final day. Through the process, participants got to know each other quickly and formed tight working groups through which they produced their work. Because they had physically experienced, rather than passively listened to, the process they were able to go home to their communities, collect stories, write scripts, and perform them for their own purposes. A Roadside trainer worked with the Agency on Aging to follow-up with the groups on the phone, by email, and, in Group B’s case, in-person, providing requested assistance and allocating funding.

What Happened in Each Community

****Group A, Healthcare and Cancer Center****

Cancer Storytelling Project Interview

January 15, 2009 11:00 am and March 5, 2009 11:00 am

Interviewee: Group A leader

Interviewer: Donna Porterfield, Roadside Theater, for the Agency on Aging

Production information:

- “Voices of Light,” the script, was written. The project got an extension from the University funder and mounted their production in February, 2009.
- A video production of the performance was completed by the publicity department of the Group A leader’s place of employment, a healthcare and cancer center.
- Live performances of “Voices of Light” will likely be produced in spring/summer 2009.
- Stories for the production were collected from three story circle sessions.
- The script is on-file at the Agency of Aging and the University.
- Group A applied and was approved for \$5,000 from the University funder to continue their project.

Interview (This is not a transcript, but a summary of the interview.)

Script

What was your purpose for developing the script?

We wanted to raise awareness in our community for cancer prevention and diagnosis.

How did you develop the script?

We had a team of five people working together. Most of them are cancer survivors. One was a marketing person at the hospital, who did a professional quality video of our play. To develop the script, we followed the training format. We had three story circle sessions, which were recorded. We made copies of the recordings, and took them home with us to listen to. When next we met, we came up with topics for the play. We worked together with a flipchart, picking out things we were hearing such as: cancer diagnosis, how it affected the teller’s life, and what they learned from the situation; survivorship issues; the importance of faith; turning negatives into positives; opportunities to serve others; life changes after diagnoses. We needed something to connect our stories and my daughter suggested we use stanzas from Wordsworth’s “Intimations from Early Childhood.” So, after each stanza we would have a story from a different voice: Voice of Diagnosis; Voice of Treatment; Voice of Hope; Voice of Joy; and Voice of Service. A volunteer with cancer recurrence told the Voice of Hope story, and wrote a song that we used in the play. A member of our group, put it together into script form, but, really, we all wrote it together. The writer tweaked it and transcribed some stories from the tapes.

Successes?

It was easy to do – just get a few people together and start putting it on paper. Everyone was surprised they could do it, and it was fun. Now I am incorporating story circles into the Hospital support group I work with, and that has worked very, very well. We used to have didactic lectures, but the group now asks for story circles. Group attendance has picked up. We like to share and pass on what we’ve learned. We’re opening up opportunities for actual Hospital patients to participate now.

Last December, I used story circles at my extended family’s Christmas gathering. (We usually have a game we play.) Everyone loved it so much that nobody went home until 10:30 pm. It brought us closer – a group walk down memory lane – and the kids loved listening to the stories as well. Something about the story circle process takes you back to that time in such a true way that we can actually see and feel that day again. It made us feel better to know that our stories weren’t lost – both the funny and the sad ones alike.

Challenges?

Not so far.

Anything you would do differently in hindsight?

No.

Production

Did your purpose change in the production phase?

We got an extension from the University funder until the end of February. We did a professional video of the production with backdrops and music. Our Hospital has a promotions department that worked on this. We have also been invited to perform at the Statewide Survivors' Summit in June, and we are planning live performances of the play in the community. Our group has a socio-economic mix of performers and stories, so it will work in many situations.

How did you put the performance together? Who performed?

We produced a video of the performance with the hospital marketing department. It was a professionally edited piece with backdrops and music. We paid someone to set it to music and do the editing. A University funder employee came to watch the process.

Challenges?

We were lucky to have a professional set-up at the hospital to do the video. It would have been more difficult without that asset.

Successes?

We are happy with the result. A group watched the video, and found it engaging.

Who was your target audience and how did you get them to the show?

Video will go out on the state healthcare systems internet, and we will show it at different venues within the healthcare system – board, staff meetings, support groups, etc. We have several requests to perform the play live, including at the State Cancer Survivor's Summit in June. We may use the video if we can't get our cast together then. Our target audience is the general public. We want people to come away with the idea that cancer is a difficult experience, but "out of the manure comes the rose." The rose is joy, release, and peace.

How did the audience respond?

Positively.

Anything you would do differently in hindsight?

No.

Story to Performance Workshop

What from the workshop was the most helpful to the success of your project?

Doing the hands on task of putting the skit together through the group process was crucial. We followed the process we learned in the workshop, and it worked. When we left the workshop, we felt like we could do it.

What was least helpful?

Nothing

What more could the workshop have given you?

Can't think of anything.

Future

What is the future of your project?

We will continue to show the video of the play and perform it live when we can. We will continue to use story circles in multiple ways.

****Group B, Cancer Education Project****

Cancer Storytelling Project Interview

January 10, 2009 1:00 pm and March 5, 2009 10:00 am

Interviewee: Group B leader

Interviewer: Donna Porterfield, Roadside Theater, for the Agency on Aging

Production information:

- “Hope’s Café” was performed on November 17, 2008, 6:00 pm at the First United Methodist Church; childcare was available onsite.
- The performance was sponsored by the Cancer Education Project, First United Methodist Church, and the Family Resource Network through a grant from the Susan B. Komen Foundation, the Agency on Aging, and the University funder.
- Stories for the production were collected in four community story-gathering settings with local cancer survivors, their family members, and/or caregivers.
- The script is on-file.
- “Hope’s Café” will be performed again on April 1, 2009 for the Agents of Hope Dinner, Mountains of Hope Statewide Cancer Coalition, Charleston, WV.
- The Group B Education Project has applied for \$5,000 from the University funder to continue their project.

Update

- Two additional story circles have been conducted and transcribed
- Revisions have been made to the “Hope’s Café” script; material from additional story circles will be used to prepare the script for the April 1 performance in Charleston.
- Story circle material will be used to write two new short plays – one taking place in a barber shop and one in a beauty shop. In this way the group will have a number of versions of the script to use in different ways for different settings.
- The group is purchasing a light weight digital projector, which they will use to project photos of story circles combined with a musical score.
- Roadside Theater’s Ron Short travelled to Group B’s county to conduct a publicity workshop and see the rehearsal and performance of “Hope’s Café,” on March 13.

Interview (This is not a transcript, but a summary of the interview.)

Script

What was your purpose for developing your script?

We wanted to get out the overall essence of what we had learned from the story circles to the community in a format that they would understand and listen to. Restaurants in our rural area are our local gathering places, so we decided to make a restaurant the setting for the play. Hope is a huge word to one of our members, so we named our restaurant Hope’s Café.

How did you develop your script?

We first held story circles – one at a church 12 miles from our town and one in a home at the other end of the county. We found that doing it in the home worked the best, because people seemed more relaxed. We taped the circles with the digital tape recorder we purchased with part of our Agency on Aging funding. It worked very well.

A lady in the Methodist Church had experience transcribing, so she transcribed the story circle tapes in a matter of days, and we made copies of the transcripts for each person in our primary working team. (We also had other people interested in the project who came to our meetings, listened, and gave criticism.) To write the play, we worked as a group at the First United Methodist Church in several 1.5 hour sessions. One group member offered to put our ideas together. She had never done this before. Another group member lived next door to her, so she helped. The group member’s daughter, a teenager, helped out as well. They took the stories directly from the transcripts as much as possible. Then we made changes and revisions.

There were also jokes added once we started rehearsing – for example one performer had broken her ankle, so we joked about that – and about the desserts.

Did you use music? How did that work?

Music worked really well. A group member's husband was the director of our play. (His mother died from cancer). He wrote a song, which he accompanied with his guitar, which was a tribute to his mom. Another group member's son-in-law is a tenor, and he sang a number with someone playing the piano. We would have liked to have done more music. Everyone in our area likes music, so it opened up the audience. At the end of our play, each performer stepped forward, one-by-one, and honored someone (*who had something to do with cancer – survivor, family member, deceased, etc.*). Then we asked the audience if any of them would like to honor anyone. Each audience member either honored someone or told a story. People called us days later to say how much the performance had meant to them. We had a social hour after the play, but it was cut short, because we were having a big snow storm.

Scripting challenges?

Because of the grant's time constraints and our busy lives, we had to write the play in one week. Our writer was a fulltime teacher with two children at home, so she had a lot on her plate, but she never complained. It was a challenge to be able to explain the story circle group and what it was in a way that people would want to come.

Scripting successes?

I think it was all a success.

Anything you would do differently in hindsight?

We would have put advertisements in the newspaper inviting people to participate in the story circles, in addition to calling people.

Production

Did your purpose change in the production phase?

No. We had ready access to our performance space. It was comfortable and located in the center of the county. A lot of people from the church came to the performance as well.

How did you put the performance together? Who performed?

We had a director (mentioned previously), who we recruited. There were 12 performers. Some people were going through treatment and got sick, so we wanted a big cast so we could still perform if someone couldn't make it. Some people from our work group and from the story circles were in the play. We were all non-actors. We had two rehearsals. We pasted our scripts into the restaurant menus and newspapers we held, so we could look at them if we forgot our lines.

Production challenges?

We would have liked to have had more time. Some people had to drop out. We performed "Hope's Café" in a church sanctuary, so getting that space set up as a restaurant was a challenge. We're located in a rural area, so there really wasn't another place to hold the event. But, it worked out well in the end. We wanted to video tape the performance, but we didn't have money to hire someone. We had a volunteer tape it, but the tape ran out, and we didn't get the performance.

Production successes?

Childcare – we hired 3 babysitters, and that worked out really well.

Who was your target audience and how did you get them to the show?

Everybody was our target audience! We did a newspaper article and two newspaper advertisements.

Who was in the audience?

Our performance took place on the evening of a very big snow storm, so we didn't expect to see anyone in the audience. We had 26 people, which we thought was good, considering the circumstances. They were from different parts of the county and of all ages.

How did the audience respond?

Everyone was very moved and excited by the play. We are going to do it again at a free women's screening clinic in March. We'll perform the play at a dinner that night for the nurses brought in for the clinic. It's going to be a surprise for them. We want to perform the play many more times, but getting the money to do this (travel) is somewhat of an obstacle.

Story to Performance Workshop

What from the workshop was the most helpful to the success of your project?

Learning how to do the story circles and having the opportunity to put the resulting stories in a format (*play*) that people would want to listen to was important. On the way home (*from the workshop*) we were talking about how different the performances of each group were – we really liked it. We were yearning for the information we got in the workshop, because we had seen the University funder's notice-thing, and then tried to find out more about it at every opportunity – about storytelling.

What was least helpful?

It all was helpful.

What more could the workshop have given you?

It would have been good to learn more about how to promote the story circles and the play performances. That way we could have widened our groups.

Future

What is the future of your project?

We will do more performances. We are also writing another script. We have a lot of material.

Other

Anything you'd like to say that we didn't cover?

We should have taped the conversation after the circles when people were having refreshments. A lot of good stories were told then.

****Group C, Cancer Coalition****

Cancer Storytelling Project Interview

January 16, 2009 10:00 am and March 6, 2009 11:00 am

Interviewee: Three Group C members

Interviewer: Donna Porterfield, Roadside Theater, for the Agency on Aging

Production information:

- This group collected their stories in the fall and winter, wrote the script in January, February, and made a power point presentation, which is now with the videographer, who will complete the edit by June 1, 2009. The presentation will be presented at the Relay for Life event in the county on June 19th.
- They conducted 4 story circle sessions with the local United Methodist Church cancer support group, which included non-church members. The sessions were taped and the tapes transcribed.
- The power point presentation is called "Our Never Ending Stories" and will be used in conjunction with a guest speaker from the group presenting at churches, schools, cancer

prevention events, community clubs, meetings of CEO's of hospitals and organizations, extension agents, senior centers, high schools, and churches.

- The purpose of the script is cancer awareness and cancer prevention.

Interview (This is not a transcript, but a summary of the interview.)

Script

What was your purpose for developing the script?

We want to use it for community education in churches, schools, cancer prevention events such as our Relay for Life event, community clubs, meetings of CEO's of hospitals and organizations, extension agents, senior centers; high schools; churches. "Our Never Ending Stories" is the title of our project.

How did you develop the script?

We conducted 4 story circles with cancer support groups, which we recorded. We transcribed the tapes from all the circles. We picked 9 stories to work from and eventually worked it down to 4 stories. We wrote the script as a team.

Challenges?

Hardest part of the project was to figure out how to work the tape recorder and to use it for transcription. We also worked hard on making sure that the script flowed well. The stories we collected were so different, and we were afraid they wouldn't go together. But, when we finished, we realized that the script flowed.

Successes?

Getting the script written in a way that made sense and flowed dramatically was a big success. Learning how to download the stories on a computer from the digital tape recorder was a real success! (*laughter*)

Anything you would do differently in hindsight?

We didn't have any negativity in our project; it went very well. The winter weather made travel difficult and slowed us down, but what can you do about the weather?!

Production

Did your purpose change in the production phase?

Our purpose didn't change, but we did decide to do an exclusively electronic, power point production, because our communities are so small and spread out that getting together for rehearsal and performances seemed daunting. We also feared this factor would prevent us from getting out audiences. With the electronic production, any one of us can take the performance to groups wherever they are meeting. We also think doing it this way gets an audience made up of people who need to hear the information/stories, but who might not come to a performance. (High school students are one example.)

How did you put the performance together? Who performed?

We recorded 4 distinct dramatic voices telling the edited stories we picked. We put that together with photos and music that go along with the stories. For example, one story is about a cancer survivor who decided to celebrate beating cancer by swimming from Alcatraz to San Francisco, so we put photos of Alcatraz and the San Francisco Bay with her story. Some of the stories were tragic, so we wanted to mix them with triumphant stories. We want people to leave inspired.

Challenges?

We hired an expert to do the technical end of production, our power point, so we had a very good experience. We did have to be careful to remove information that would identify each person a

story came from. We had to go over the script many, many times to make sure we had not betrayed anonymity.

Successes?

We had an incredible group of people who provided us with intimate stories; it couldn't have been done without people willing to share their stories. Hiring the technical expert was a good thing.

Story to Performance Workshop

What from the workshop was the most helpful to the success of your project?

Having someone there who really knows how to put together a script and how to direct a production and teaching it to the group was very helpful. People at the story circles we conducted really understood the rules and it made it work well. As we went through our story circles there are stories within the story so we can tell a different story every time.

Walking us through it a step at a time was also important; it seemed like a slow process, but it gelled for us that way. When we left, we knew how to do it from beginning to end. From beginning to end, the whole process was good. It helped me when Donna (Roadside trainer) stood behind us and touched us on the shoulder to stop and go when we were orally composing our script. It got it into my head how to break up the stories and mingle them together. It was important to me that Ron (Roadside trainer) told his story through song at the beginning of the workshop. I felt like I knew him that way. We all think it was interesting that Donna and Ron worked differently with their groups, but we all ended up knowing the same things. We learned how to focus on the people we were working with, the community where we are, rather than relying on a simple formula – do a, do b, do c. We learned to think and be creative with what we have, whatever that is.

What was least helpful?

It could have been longer! (laughter)

What more could the workshop have given you?

We came back overwhelmed, but when we started working we did know how to do it, so nothing was missing. The workshop gave us confidence to dig in and do it.

Future

What is the future of your project?

We want to keep presenting our program and make more power-point productions in the future.

B. Elements of Success (what was necessary to make this an effective tool in cancer control):

Elements of Success in making an effective cancer control tool included:

- **Credibility:** Community people involved in the project had first-hand experience with cancer – either as a cancer survivor, the relative of a cancer survivor, or the relative of a cancer victim. They knew what they were talking about, and were therefore more effective at affecting those listening to them.
- The power of “those with the problem being the best ones to find the solution” – each community group knew their communities intimately. They named the barriers to cancer control in their own communities, decided how they could address them, and pinpointed specific groups of people to whom they wanted their projects to appeal.

- Leadership and group process: Each group had sufficient leadership and a group process that promoted success.
- An artistic process that enabled participants to take what they knew (their own stories) and make public presentations of them in ways that drew attention to cancer issues and affected people in new and surprising ways.

C. Lessons Learned: (About involvement; Trainer; Community; Comprehensive Cancer Control Coalition (CCCC); Barriers/challenges; What you would do differently to address these next time; Costs (compared to expected costs))

When the project was conceived, it was thought that a great deal of follow-up would be necessary for the groups to carry out their projects. As it turned out, without much post-training help from Roadside trainers, the groups were able to take what they learned in the “Story to Performance” workshop and make presentations that fit their particular communities’ needs. All of the projects were different, but successful on their own terms. Group B’s project focused exclusively on live performance; Group A’s project focused on both live and electronic performance; and Group C’s project created a power-point production to overcome the difficulty of gathering people together from a widely disbursed rural population. All of the groups worked together cooperatively – their efforts were not the result of one individual but the result of a group process. Especially heartening is the intention of each group to continue their work by presenting what they have created as well as creating new productions.

Challenges included the scarcity of financial resources, which made the funding available through the Agency on Aging and the University funder very important. A lot was done with relatively little money, but without that funding not much at all would have been accomplished. This was particularly true in the mountainous, rural counties. Funding for the “Story to Performance” workshop, which also included travel, room, and board for attendees was important, because it provided an opportunity for all three groups to come together in one place, get to know each other, share ideas, and build confidence. Timing was also a challenge. From the August training to the late December deadline for completion was too short a time period, especially considering the holidays. Two groups (Group A and Group C) had to ask the University funder for a time extension, in order to complete their projects in the best way. Group B made the deadline, but then went on to hold more story circles, revise their play, and do more performances.

In hindsight, it would have been good to have the funding to get all three groups together in one place at the middle and end of the project to collaborate – to show their work to each other and brainstorm about how they could teach others to do what they had done. A future project could make these groups trainers of other CCC’s.

Another future project could be working with young people (age 16-30) to do this project. I suspect the younger generation would incorporate new media, particularly the web, to tell stories and organize their peers around cancer issues.

D. Process Questions

1) Why is the storytelling an effective means of communicating messages in the Appalachian region?

The central Appalachian region has a very strong oral tradition – of storytelling and music – which no doubt contributes to the effectiveness of storytelling as a means of communicating messages. However, Roadside Theater’s experience of working with communities in 43 states to make plays from their stories is that storytelling is an effective means of communicating messages just about everywhere. Humans are the storytelling animal. Our brains are hardwired to make stories of what we see around us, whether it’s working to explain a part of the world through scientific and/or mathematical theory or creating a play to explain to each other what cancer does to us individually and as a community. The problem is that there are not enough public opportunities for ordinary people to tell their stories in a validating way. This project worked to show folks how they can create such opportunities.

2) Describe the story circle process and identify the characteristics that make it effective in collecting stories about cancer.

Story circles, as Roadside Theater conducts them, encourage deep listening, verbal expression, respect for every participant’s story, and an appreciation for the cultural gifts and talents of diverse groups of people. They have been used successfully by medical practitioners, artists, social clubs, community groups, teachers, and many others to positively discuss and reflect upon difficult issues, to collect oral history, to write plays, to teach listening and verbal skills, to empathize with the experiences of others – to learn. Cancer stories can be difficult to tell and listen to, yet they are of primary importance in prevention and treatment of the disease. The story circle gives participants a new way to share such stories in a positive, supportive environment geared toward learning.

3) Compare the three communities and describe any differences and similarities in how they adopted the story circle process and storytelling approach to their community cancer stories?

All three communities used the same methodology and process. The difference was in their choice of vehicle to publicly present their stories. This choice was made primarily based on purpose and resources available. For example, Group A’s project had the support of a hospital with a publicity department that included professional videographers and a production crew. So, it made sense for them to create a video presentation. And, that presentation could then be seen by more people than a live theater performance. Because of the difficulty of getting a cast together regularly in a widespread rural county, Group C decided to make a power-point presentation and acquire the equipment (including a small tent) to take their show on the road to almost any setting – from a health fair to a high school to a hospital board of directors meeting. Combining live presence with electronic power-point, a group member could present the program as well as share personal stories in-person with the audience. Group B is located in a small town with few resources, so they decided to do live theater exclusively. The live process was the glue that held their group together and spurred them to take their play to other places.

The “Story to Performance” process assumes that each group is the expert on its own place and stories and on the manner in which its community’s needs should be served. The process is designed in such a way that each group can take what it learns and do something different with it

as long as it maintains the values of the “Story to Performance” methodology. All of the groups accomplished this.

E. Feedback from communities including quotes or articles.

See above A. “What Happened in Each Community” and attached information.

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