Objectives

The Bright Eyes program is a sensory stimulation intervention for men and women suffering from advanced dementia. It has resulted in improvements in their functioning and connection with the world around them. Although sensory stimulation is part of the repertoire of many activities personnel who work with elderly, cognitively impaired people, the Bright Eyes intervention is distinct insofar as it is a well-thought-out, theoretically grounded, and empirically studied series of activities. This interview describes the process of developing and implementing the Bright Eyes program and the outcomes used to measure its effectiveness in enhancing quality of life for elderly individuals with advanced dementia.

LOW-FUNCTIONING

Bright Eyes: A sensory stimulation intervention for patients with advanced dementia

An interview with Scott A. Trudeau, MA, OTR/L

Can you first describe the unique aspects of the long-term care setting in which you work?

Although, in theory, it may appear that at our hospital we have more resources and staffing for research through the Geriatric Research and Education Clinical Center (GRECC) than found in many other long-term care institutions, the reality is that we have faced, and continue to face, budget shortfalls and staffing cuts, and we are not insulated from those by research-allocated budgets. The biggest difference between us and some of your more traditional dementia care centers is that the mindset is different. It’s sort of the philosophical approach to being able to do the research. There’s a level of investment among staff and a sense that we can make a difference in the quality of life for our patients, and that brings with it a level of optimism that may not be present in a lot of places that care for people with advanced dementia.

I think there’s sometimes a sense of futility in other rehab settings about treating elderly patients, let alone those with dementia. A lot of rehab professionals still say, “There’s nothing we can do about it. They’re not our population.” Those attitudes just blow me away... and then you add a cognitive impairment, and you lose all hope of rehab professionals being involved. My view is that these people do have rehab potential, and they do have rehab needs. It’s just that we have to understand that they’re dying eventually from this terminal illness. But that doesn’t take away that there’s potential and there’s hope and there are needs.

What led you to develop the Bright Eyes intervention?

I developed the intervention after reading the work of Carol Bowlby, who is an occupational therapist from Halifax, Nova...
The sense of smell is a very primitive sense. I mean, the neurological path from the olfactory nerve to the brain is fairly short and direct, so even someone with advanced dementia or even someone who is unconscious might still have access to that sensory pathway. Using smelling salts, for example, can rouse someone who’s passed out. It’s the same kind of effect that you can get using a less noxious olfactory/sensory cue: people with dementia become awakened, in a way, through smell.

In a given session with dementia patients, do you go through stimulating each of the senses in this order?

Correct.

Who worked with you to develop this application of Bowlby’s work?

There were a bunch of students over the years that have impacted it. But pretty much it’s been my baby.

Why do you call the intervention Bright Eyes?

It came about in the following way. I came to the Bedford VA about five years ago after having worked primarily in acute psychiatry for most of my career.

When I came to Bedford, I was actually hired as the clinical educator for occupational therapy, which meant I would coordinate student programming. GRECC had some special moneys for stipend support to occupational therapy students. But no student had ever been physically placed in the GRECC special care unit although they had done things for GRECC as part of their education. So when I came on as clinical educator, I was initially charged to spend three hours a week devoted to GRECC developing programming. GRECC had previously been cited by the Joint Commission on Accreditation of Health Care Organizations (JCAHO) for not having enough activities. So I said, “I can do an activity! Let’s figure out what one.” I started by doing
The notion of engagement is that through some form of some responsiveness, verbal or physical, there is a connection made to something outside of one's self. That may be displayed as simply as reaching for a cookie or turning and making eye contact, or as dramatically as someone who's traditionally mute speaking in the group.

arts and crafts with the patients because I had worked in acute psychiatry and that's what we had done as a rehab activity with people who had psychiatric problems. So, I started doing these craft kinds of things and found out fairly quickly that the elderly patients with dementia were not responding that well to it. They weren't connecting at all with the activities. They would do it, in sort of a perfunctory, hand-over-hand way, and sometimes they would carry out the activity, but mainly, they didn't get into it. Then I found the Carol Bowlby book and said, "Ah ha!" The whole notion of impacting the sensory experience may be more fruitful, let's see what we can do.

So, I began to structure my arts and crafts interventions around a particular theme and included other sensory experiences during the process. For instance, one fall I focused on apples for quite awhile in these activities. So, we were working on sanding and painting apple-shaped trivets and every time we met we would eat applesauce or apples or smell cinnamon, and we have stuff that was apple-y around. Compared with the intervention we are using now, it was more of a bombardment in terms of the sensory experience. At that time, I still thought that what I should be providing was purposeful activity and, bringing my own baggage to the table, what I thought was productive had to result in a product, of course. But the patients just didn't connect with the product at all. I eventually learned that you don't need the product. The product is not where it's at! It's the process that really gets you the payoff in terms of an impact on social functioning and quality of life. In my experience, when patients with severe or advanced dementia are not involved in these kinds of activities, they are often lined up around the periphery of a room staring vacuously into space. There's very little interaction that gets initiated by them. So, as I began to fashion the arts and crafts group into a more purely sensory group, I realized that we're really targeting the vacancy in these patients, their lack of connection. If we made an impact, the folks would have bright eyes, because a connection would be made. So, we call the intervention Bright Eyes.1

Is the goal of the program, then, to get people to become responsive?

Again, this is an area that I have come to learn a lot about. My goal is what I call, "engagement." Now, in the literature, engagement is fairly ill-defined, and it depends in which context you're considering engagement—social, physical, marital even. But basically, the notion of engagement is that through some form...
of some responsiveness, verbal or physical, there is a connection made to something outside of one’s self. Then, that person becomes engaged beyond their internal world. That may be displayed as simply as reaching for a cookie or turning and making eye contact, or as dramatically as someone who’s traditionally mute speaking in the group. We’ve had some very dramatic responses from people at times, which I liken to what was portrayed in the movie “Awakenings,” but those are few and far between. I don’t want to overemphasize the positive ones! And that’s what I’ve really had to come to terms with—that I don’t measure my effectiveness by whether everyone’s talking or everyone’s saying thank you or everyone’s becoming verbally or even physically involved. I measure my effectiveness by the little things that happen. For example, for the kinesthetic movement part of the sensory hierarchy, we might have a beanbag toss. Typically, what happens is that folks will throw the beanbag back and forth to the leader and they’ll focus just on the leader. A lot of times we work with primitive reflexes to get people going, so if you throw the beanbag sort of towards their face, they’ll put their hands up as a reflexive action to defend against that! They may or may not catch the beanbag. Then you work on getting them to throw it. After doing this whole routine for awhile, you sometimes see that they take the beanbag, stop, look at it, feel it, move it around in their hand a little, and then turn to the person next to them and hand it to them. Well, when that happens, I get goose bumps, and I say to students, “Did you see that???” Because these people don’t go beyond themselves. Part of that is their response to being in an institution, I think, as well as the fact that the disease is such that people become very internally oriented.

At what stage of dementia do people benefit from this intervention?

The target population for Bright Eyes is people with severe to advanced dementia, people who are often mute and possibly not ambulating, sometimes near the end of life. But it’s also been beneficial to people who are less severely impaired. People don’t mind engaging in the process even if they’re more alert and more interactive. A skilled group leader will titrate the level of intervention appropriate to the individual, and will get a range of responses depending on their degree of dementia. So, if I’m handing out pictures of Mickey Mantle and Babe Ruth when they were young players, somebody may only visually track the picture in front of them, whereas somebody else may be able to tell you they met Babe Ruth, or they remember him playing in Boston, or whatever.
Although one of our original goals for this intervention was to slow functional impairment, that has been hard to track. In fact, I once met Carol Bowlby and mentioned that that was one of our goals, and she said she thought that was not where we would see the biggest impact. And she was right.

Can you describe what happens in a Bright Eyes group session?

Approximately 10 people meet in a group for about 45 minutes. There is usually one group leader, although probably two would be ideal for a group of that size. When I am working without students, I lead the group alone; or two students may lead the group together, or one may join me to lead it. The students always say to me, “How do you get someone to smell something?” It’s very directive. You just go in and say, “Here. Smell this. Catch this. Throw me that.” For the most part, the goal is to really focus on sensory experience and to get whatever kind of responsiveness we can out of the individual during that sensory experience. It’s a very parallel group, in which the leader interacts with a single patient, then another single patient, then another. Now that’s not to say that you can’t stimulate folks to pass the bean bag to one another, or actually throw the ball across the room, or if we’re using a balloon, once lofted it will move around the room and around the group and people will become aware of one another in the group as a result of that. So, it’s not always just a parallel group, but it’s okay if it is just a parallel group.

One of the key things that I haven’t belabored enough about the actual protocol is that even though the sensory experiences are presented in isolation, they are connected by an overall theme such as baseball. Today, students led the group and the theme was babies. For olfactory stimulation, they had baby lotion. They used pink and blue balloons for the balloon volley (the movement activity). For touch, they passed around a doll in a crocheted baby blanket. The students used black and white baby pictures of their parents or grandparents to stimulate the visual sense. They played an Olivia Newton John CD of lullabies for the auditory stimulation. I don’t know what they did for taste today.

The reason why the concept of hierarchy works in terms of how this actually plays out is that there’s a cumulative effect. When you take people who are just sitting there, vacuously drooling on themselves, and you have them smell something, and then you have them move and present them with sensory stimuli around the same theme, there’s a cumulative effect. We
have found that following this intervention, very frequently, when you bring around a silver tray of ginger snaps at the end of the group and present it to people who don't feed themselves, and you say, "Would you care for a cookie?" they say, "Thank you," or they look up at you and they reach up and take the cookie and they eat it. So, that's where I think there's some functional payoff to the intervention, but I'm not sure how to measure it exactly or how to quantify it. I am currently designing a study in which I will use videotape recording to demonstrate the differences in level of engagement in the group that has the Bright Eyes intervention and in those not in the group.

How do you choose who participates in the Bright Eyes group?

It's pretty random; it's just whoever is up and available. For some people, it will be part of their treatment plan. For others who don't get up out of bed on an everyday basis, but who seem to benefit from the group, we schedule the time that they're out of bed so it coincides with when the group is being provided. So, the group composition is not completely random, but on a day-to-day basis, I tell the students to involve whoever is there.

How frequently does the group meet?

Three days a week. But there's no reason why it couldn't be beneficial seven days a week, aside from the fact that I'm just one person and there's 100 inpatients and about another 100 outpatients with whom we're involved. The group that meets regularly really only involves inpatients.

I've used the protocol in a couple of other ways. I've introduced it in a higher functioning group in our adult day care center, and because that's a group of people who are able to recognize a product, we might organize a cooking task that might include olfactory, tactile, and other sensory experiences integrated into the purposeful activity, which actually has a product as an outcome.

I've also used it to educate family caregivers who come to the hospital to visit patients and don't know what to do. If their loved one is mute ... well, if we know that they still have the reflex ability to catch a ball and throw it, we may suggest to the wife that she carry a Nerf® ball in her pocket, so when she's bored and she doesn't know what to do, and she's talked to everyone else in the room, and he doesn't seem to be responding to her,
or she's not getting anything back, maybe it would be helpful to toss the ball with him for a while . . . and it would be good for her. We've had some just wonderful effects from that. Other people seem to respond better to music. Asking the wife, when she comes for her visits, rather than just coming to visit, bring her favorite tapes or his favorite tapes and putting them in a quiet area with a tape player so they can listen to some music, or bringing in some old photos. Real family photos, and sitting and going through them. It can be very meaningful. It becomes more meaningful for the family caregiver in some ways. It makes the visit certainly a whole lot more pleasant for everybody.

*Have family members ever attended the Bright Eyes group and observed their loved one being responsive?*

Yes. But, I'm not sure how I feel about it. One reason is that there's got to be a ceiling effect on the intervention. The group works for that one hour. But, if we did sensory stimulation with the group 24 hours a day, they probably would become saturated. And, I don't know where that point is. So, one reason why I am ambivalent about family members attending the group is that, at times, they have thought, "This is great. We need more! We need more! We need more!" Another drawback is that sometimes observing the group leads family members to have unrealistic expectations and to feel hurt because the responses they observed in the group may not occur when they try to use the intervention themselves. "Well, he can do that, why can't he do this? He responded there, why isn't he doing it here? He did it for him, why isn't he doing it for me?" I've done it both ways, and at one point thought it might be nice to include families, but now I prefer to do the intervention without family there. I found that having family present was much more disruptive to the process than supportive of it, which surprised me a little bit. But for six or eight months, I chose to do the group during visiting hours because I thought it might be beneficial for family members to observe, but I no longer do so.

The other thing is that, as I said at the very beginning, my values that I brought to the table about what is productive activity are very different from what is meaningful to one's cognitively impaired elder. And I think that family members may experience a similar conflict of values; it's possible for a cognitively-intact spouse to think that the intervention is demeaning, because it's so low-level or so unproductive-looking. I think the staff had some conflicts with family because of that issue, too.
Are there any other similar programs going on elsewhere that you know of?

No. Although there are a lot of people who say they do sensory stimulation with cognitively impaired people. Activity personnel working with this population come from a wide variety of backgrounds and perspectives. So, there's a range of approaches to sensory stimulation. I don't know of anyone else who's doing it quite this way.

Are there any risks in using this kind of intervention with elderly people with dementia?

This appears to be a simple, straightforward intervention, but it's very powerful, and when you're dealing with peoples' neurologic systems and sensory experiences, and dealing with primitive reflexes, it's very easy for things not to go well, unless you're very sensitive to the cues and aware of the neurological impact of various interventions.

For example, if you use light touch instead of firm touch, you could very easily stimulate spastic muscle tone. So, if you're trying to help somebody throw the ball, and you're not doing it firmly and effectively enough, you could actually cause more tone and make the person more uncomfortable and less able to throw the ball. Really, quite easily. It's a very fine line.

What kind of impact might sensory stimulation have on people in the group who are in pain? Is there any possible negative impact to sensory stimulation for these patients?

There's always that potential, especially when you can't get accurate reporting from the subjective perspective of the individual. So, you have to pick up on the cues. The way the protocol is written, it's designed to be a pleasant experience, and any time it's not a pleasant experience, for whatever reason, then either the intervention has to shift or the person is removed from the group.

Have you studied the impact of this intervention on depression, which is common in people with Alzheimer's disease?

I believe that behavioral interventions for depression can be as important as pharmacologic interventions, but we have not done any controlled studies of this.
Are there any other barriers that you can identify to successfully implementing your approach?

I’ve wondered whether there is a more cost-effective way to do this. I can’t be everywhere; can I train somebody to do it? And, I’ve been very, very reluctant to do that because when I’ve tried to, it has been my experience that you can’t teach people how to think like a certain professional. Whoever is leading the group needs to understand the neurological and musculoskeletal effects of the intervention. There are skills involved that aren’t necessarily visible. Families sometimes don’t recognize that there are skills embedded in the activity either.

In terms of evidence for the impact of the program, can you give some examples?

One of the most significant things that’s happened, and it’s not a specific patient response, is that when I came over and said I was going to do this, staff who work directly with dementia patients told me, “You’re crazy! You’re not going to get demented people to engage in a group.” And, the reality is that even though that was where we started, this group has been ongoing for four-and-a-half years now and over time, we have seen demented people engaging in the group more and more. It does work, it can work, and people here don’t question it anymore. You can keep agitated, demented people engaged in the group for 45 minutes. You have to have some reason for them to stay, but you can do it.

Is three times a week ideal? Have you ever tried it for more, or would that be too much sensory stimulation for some people?

My gut feeling, and, it would really have to be tested, is that it could probably be beneficial on a daily basis. But three times a week has become sort of the happy medium. When I started, it was once a week, then we moved it to two times a week, and three times a week has really become the gold standard for us. It feels like there’s the potential for some carryover. One of the things that I typically do, more for the convenience of the group leader, is that I will focus on a theme for a whole week—Monday, Wednesday, and Friday. So, if the theme is the beach, I may shuffle the cues a little bit, but I stay with beach-related stimuli; instead of touching the sand, you’re going to touch a terrycloth beach towel, or rub oil on your hands, or whatever. Or, I may use some of the same cues, again, more for leader convenience.
than anything else, but it’s possible that this holds a tighter context for people; it becomes a routine . . . and certainly routine is one of the strategies we use with cognitively impaired folks.

Is there a time of day that it works best?

Morning. Without a doubt. Everything works better in the morning. The group participants tend to be more open and available in the morning to experience what we want them to get. And that time frame allows us to avoid conflicting with visiting hours.

Has this program changed staff expectations about what is possible to achieve in terms of quality of life for people with severe, advanced dementia?

Yes. Now the expectation is that you can do things with folks in a group, and that’s happening more and more. I’m no longer the only staff person here that would consider bringing a group of demented people together, where when I started, I was the only one that would consider that!

Staff in recreation therapy to some extent, and nursing to some extent, now consider group activities for their patients with dementia.

This summer, our program is going to include all of the Bright Eyes sensory experiences, but we’re going to try as much as we can to get people outside into the natural sensory world. Again, I’m not facing a lot of resistance now, whereas people used to say I was crazy.

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