

SEEING CAMBODIA: A New View of the Research Process

This article describes our research with Cambodian refugee women suffering from psychogenic blindness as a result of war trauma. We describe our process of learning about the client's functional blindness, their trauma and their culture. It is a story fraught with joy and challenge; it is a story of seeing the world in new ways, through the eyes of women blinded by what they had seen.

by **Patricia D. Rozee and
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This is the story of the hardest, and the most rewarding, research we have ever done. It is a narrative of the process of studying a group to which we do not belong, a country to which we had never been, and a psychological process rarely observed. The research examined trauma-based psychogenic blindness among older Cambodian refugee women, women so physically and emotionally traumatized by the Khmer Rouge takeover of Cambodia that they literally went blind so as not to see the horror of the killing fields.

We discovered the phenomenon in 1984 when Gretchen began to see Asian females referred from the Social Security Administration for assessment of reported vision loss at the eye clinic. Each woman was seeking state disability benefits for blindness. Gretchen was responsible for assessing brain activity by means of visual evoked potentials. The test objectively determines if the brain is receiving visual input from the eyes, even if the individual cannot communicate (as with an infant or comatose patient) or is unwilling to speak accurately (as in the case of the

person trying to fake blindness or malingering).

The women reported severe loss of vision, ranging from legal blindness (20/200) to no vision at all. Most were referred with a diagnosis of malingering since all previous eye examinations had been normal. Generally, malingerers know that their reported vision loss is feigned. Some people feign blindness for the primary gain of obtaining money, either through a lawsuit or worker's compensation claim.

Because vision loss is fabricated, and most people are unaware of how the truly blind behave, many malingerers try to show the examiner their level of vision loss by "acting blind." The malingerer might tap the wall, feel the floor while walking, walk into a wall, or carefully trip over a wastebasket. In most instances the person with organic vision loss can ambulate through a room with relative ease. Only in cases of severe organic vision loss does the person need to be guided through an unfamiliar environment.

At first Gretchen, too, thought these women might be malingering, until she found that

like those who are truly blind, none of the Cambodian women displayed behavior typical of malingerers. In addition, Gretchen started to hear the same trauma story told and retold. She learned that her Asian clients were actually Southeast Asian, when one woman told a horrific story of witnessing her husband's death by disembowelment in Cambodia. He had been slain in 1976 by one of Pol Pot's Khmer Rouge soldiers. After she saw her husband die with such cruelty, she cried and cried. When at last she stopped crying, she could no longer see.

Through an interpreter, Gretchen asked the next Southeast Asian woman with similar symptoms if she were from Cambodia. She replied "yes," and reported a gruesome trauma history before the onset of vision loss. The woman sat on the examination table, head bowed, affect withdrawn, and answered questions in the softest voice. In great pain with tears rolling down her face, she reported her life under Pol Pot. She recounted witnessing the death of one person after another, of working twenty hour days, and of eating less than one cup of watery rice per day while her captors ate their fill.

Gretchen started seeing more and more Cambodian women in the clinic. Each one claimed severe vision loss, reported a similar history of trauma before the onset of vision loss, tested normal on the brain evoked potential test, and presented with a typical demeanor. Like the first woman, each

shuffled slowly into the clinic, head bowed, totally withdrawn. Each walked as if medicated, as seen in the so-called "Thorazine shuffle," yet none were on psychotropic medications. No matter how hard she tried, the only emotions Gretchen elicited from the women were either fear or extreme sadness.

A pattern of severe trauma prior to the onset of vision loss started to emerge. The women reported being beaten, starved, severely mistreated and had witnessed the death of a loved one immediately prior to the onset of vision loss. It seemed as if there was no way to reach them. And, their numbers kept increasing.

After about one year, Cambodian women accounted for sixty percent of Gretchen's clients with unexplained vision loss. Usually, unexplained vision loss is observed in individuals from all walks of life, and from all ethnic and racial backgrounds. This sudden disproportion of Cambodian refugee women seemed unusual. There were several questions that remained unanswered. Were these women malingerers as was thought by some who had examined them, or was the trauma history the cause of the blindness? Why were women the ones who were affected? If these women believe that they cannot see, but their evoked potentials reveal that they can probably see, should they be denied disability benefits? Finally, how widespread was the problem?

It was at this point that Gretchen contacted me. We were

old college friends. I was working in Nashville, Tennessee, at Vanderbilt University.

We discussed the information told to us by the translators that accompanied the Cambodia women to the clinic. There was a consistent background among these clients of severe trauma, beatings, starvation, forced labor, death or disappearance of loved ones, and witness to abuses and sometimes violent deaths of friends and family. Could such trauma be responsible for their functional blindness?



After our discussion, we decided to investigate the disproportionate representation of Cambodian women among the functionally blind. We knew little about psychogenic blindness and even less about the history of Cambodia under Pol Pot, the leader of the

Communist Chinese backed Khmer Rouge forces. We searched the literature for other examples of trauma-based blindness and perhaps to find an explanation. We examined literature on plane crashes, catastrophic floods, earthquakes and other disasters. Nothing. We looked at the psychological literature on the survivors of various wars. A few anecdotal reports were found on blindness among holocaust survivors, WWI veterans, and Vietnamese civilians during the Vietnam War.

We needed to know more about the trauma background these women revealed through their translators. We designed an interview protocol and set out on our separate journeys.

Gretchen went back to the clinic to systematically explore the women's trauma histories. I went back to the library to try to find a theoretical explanation for the phenomenon, and to study Cambodia during the period 1975-1979.

Although the Khmer Rouge figured prominently in the women's stories, they all reported that the onset of blindness was during the Pol Pot reign, I found surprisingly little information on Cambodia during the Pol Pot years. What I did learn from the few reports submitted mostly by freelance journalists was shocking.

This period in Cambodia's history is known as the "Reign of Terror." Somewhere between one and three million Cambodians were killed by the Khmer Rouge.

Forced to work with

little or no food, they were tortured and killed by young Khmer Rouge boys known as "Angka" (they carried automatic weapons). Only one in two Cambodians that tried to escape were successful in making their way to the Thai border—our clients were among them. All of our clients had lived in border refugee camps for years before being allowed into the United States.



Back at the clinic, with interview schedule in hand, Gretchen went ahead with the task of discussing with the women their experiences in Cambodia. Although the stories they revealed were gruesome, the women were more than willing to share them. Even the interpreters wanted to share their stories living under Pol Pot. The minute Gretchen showed that she knew something of Cambodia, usually accompanied by a phrase in Khmer, the language of Cambodia, she was allowed into their world.

She was told of many atrocities. One woman had her fingers cut off for not obeying Angka, another was repeatedly forced to watch while disobedient people were beaten.

One woman reported that the Khmer Rouge soldiers frequently sewed the eyelids of young children shut, so that the child would become absolutely dependent on the Khmer Rouge. Another woman had escaped from the soldiers into the jungle and gave birth to a stillborn

child. Soon after, her vision became severely abnormal.

One after another, Gretchen's clients told of the similar atrocities committed against them. In my review of the literature on psychogenic blindness, I found that psychology had found little new to say about the topic since Freud's early notion of "hysteria." Since Freud's theory of hysteria was rooted in childhood psychosexual anxiety, it did not seem to fit our data. Later theorists reported that it was probably due to extreme suggestibility, or even that it was just another example of the "California Syndrome," i.e., trying to get something for nothing from the notoriously generous California welfare system. None of these theories adequately explained the systematic and severe traumas we observed in our clients. We decided that we were dealing with a unique clinical entity that we labeled "war trauma syndrome" or psychogenic blindness caused by the traumatic loss of self, kin and country. From our initial interviews we began to define the syndrome. We discovered that the more time the women had spent in work camps in Cambodia and in the refugee camps in Thailand, the worse their reported visual acuity and general psychological adjustment. The women reported severe depression, feelings of isolation, daily crying, intrusive thoughts and nightmares about the Cambodian soldiers, mental confusion and inability to concentrate, and extreme fear.

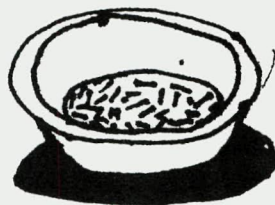
Many of our clients were

so fearful that they rarely, if ever, left the house. At this point we realized we had to do more. We wanted to do something about the problem, not simply describe it. We wanted to give something back to these women for what they had given us by simply sharing their trauma stories. We felt that lack of social support, isolation, and inability to resume accustomed social roles allowed the blindness to continue long after the cessation of trauma. I had relocated back to California so we were able to set up two intervention groups at the psychology clinic on my campus: a therapy group, a skills building group (e.g., using public transportation, emergency phone calling and so on); and a control group. We wanted to compare the relative efficacy of the two interventions in improving visual acuity and psychological function compared to the no-intervention control group.



Because we did not speak the Khmer language, we knew this was going to be difficult research. Although we studied Cambodian culture and religious traditions, we learned the social mores the hard way. For example, we had not been able to learn the language, so I applied for and received a small in-house grant to pay translators.

We discovered that our male interviewer would not ask questions regarding sexual assault or other personal questions, due to cultural mores prohibiting such discussions between the sexes. So we set out to find Khmer-speaking female social service workers to work with us. I also contacted Cambodian and other student groups to enlist their help in the project. It was about this time that we got our first lesson in Cambodian etiquette. We set an



evening appointment and invited our assistants to join us. One came very late, while another did not show up at all. From that experience we learned that in Cambodia it is considered impolite to say "no" to an honored person or a person in authority. Thus, everyone whom we asked to assist in the project said "yes" even when they had no intention of participating, so as not to offend us!

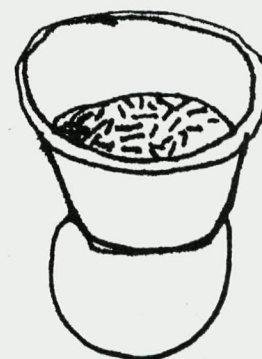
We learned other harder lessons. Onetime when we arrived to interview a client, the whole family had moved away. They moved out of fear for their lives. When a Khmer Rouge authority asked a person to come with him to help his/her country, the person was never seen again. We were shocked to learn that we might have contributed to the very trauma we sought to alleviate. Once we

discovered this, we spent more time building trust with clients. We continually reassured the family of our purpose, and later assigned just one student driver to each woman to reduce the number of strangers with whom she had contact.

The abject fear with which many Cambodian refugees live was evident when we attempted to get a signature on the informed consent form. Since our clients were preliterate, they were unable to read the consent letter.

Although the translator read it to them, they did not believe the benign purpose of the document. Since many had been tricked into signing contracts, they were afraid of what they might be signing away.

We learned the lesson that in Cambodian culture the male head of the household grants permission and needs to do so in order for the women to participate in the study. We often spent a good deal of time trying to express our good intentions to the male of the house. Sometimes the woman would want to participate and he would not allow it.



When it finally was time to begin the groups, the

condition of the women when they arrived at the clinic was heartbreaking. They hung on to the arm of their student driver as they followed her into the elevator to the second floor clinic. Their body language can best be described as a walking fetal position. Hunched and withdrawn, with heads bent down they very slowly shuffled along. We questioned our own ability to help such traumatized individuals. Were we just arrogant privileged white women sticking our values in where we had no business being? It was a time of humility. We saw the enormity of the task we had undertaken.

Each Saturday morning my students would arrive at the homes of the women and drive them to the university. For some of the women, the weekly visits included participating in group therapy sessions. The sessions were run by a Cambodian social worker, named Santa Smith. Santa helped the women to tell their stories and to explore the demons that haunted them. The women learned that they were not alone in their sorrow or feelings of shame. They learned that there were others like them, who had experienced similar things. They learned that they could share with the others and that such interactions could be beneficial. One woman abused by her husband, had never before told anyone of the abusive situation. All of the other women in the group offered the battered woman a place to stay after she told them her experience.

For the other women, their weekly visits included

participation in skill building sessions. Conducted by a Cambodian rehabilitation counselor named, Canthi Kans, the women were taught how to use the telephone and dial "911" for emergency assistance.

Acting as mock-operators, the students and Gretchen would speak to the woman who "needed" 911 assistance. The women learned to tell the "operator" that assistance was needed from fire, police, or medical personnel. When not engaged in more serious business, the students took to drawing large objects on the blackboard and pronouncing the English word for it. The women would chime in with the Cambodian word—they wanted us to learn Khmer too!

As the weeks went by we noticed a wonderful thing happening. Now as the women walked into the clinic they stood straight. Some of them walked up the stairs with their student guide, rather than using the elevator. While they sat in the lobby awaiting their group, they chattered among themselves in Khmer. We discovered a love of humor—the women enjoyed teasing each other, and us! They started to like the group sessions, and more important, each other, and us.

They called us "daughter" as a sign of endearment and talked with each other outside group sessions. One woman, who was very uneasy at first, became so excited about coming to group that she would stand on the sidewalk ten minutes or so before her student driver was to come.

After ten weeks the therapy group got wind of the fact that the skills group was learning to dial 911 and insisted on being taught to use the telephone. We showed one woman how to phone home. After she dialed the number we held the phone to her ear. When her brother answered the phone, she got so excited at the sound of his voice she screamed and dropped the phone and all the other women started teasing her until the whole room was in an uproar.



On the last day of group we conducted exit interviews. It was a sad leave-taking, as we had all grown quite fond of each other. With one or two exceptions they walked from the building laughing and smiling with their heads held high.

They had made measurable improvement in visual and psychological function. Sixty percent of the women in the intervention groups showed improved visual acuity and improved psychological well-being compared to no change in the control group. We were funded for only ten weeks of intervention! We learned the lesson of caring. You can move incredible mountains and cross

great distances if you care enough.

We began to talk to the ophthalmologists in Los Angeles who conduct the eye examinations for those applying for blind disability benefits. Previously those that were not physiologically blind, as measured by the brain evoked potential test, were told to go home and rest, and that their condition should improve in a week or so. The assumption, of course, was that they were malingering. We have now been able to demonstrate, rather than malingering, such functional blindness may be trauma based, and though psychogenic, cannot be left untreated. Thus, such patients are now commonly referred to a psychiatrist and become eligible for psychiatric benefits from the state.

The challenge of this research had just begun. Little did we know that we would soon be put in the position of protecting our clients against hoards of reporters eager to see women blinded by the killing fields. We published two scholarly papers about our research (Roze-Calker & Van Boemel, 1989; Van Boemel & Roze, 1992). The first article won the Distinguished Publication Award from the Association for Women in Psychology. About this time the New York Times heard about our work through a short article in the Los Angeles Times about a Cambodian conference at which we presented our research. They sent a reporter to talk with us. Our story was picked up by the wire services and soon we were

being asked by everyone from the *New Yorker* to the TV program 20/20 to do interviews. Of course they all wanted to interview some of the Cambodian women with whom we had worked.

We initially resisted this idea. We were afraid to compromise the hard won gains in mental health we had seen among our clients. But we wanted the plight of Cambodian refugees to be brought out in public. There is a population of 50,000 Cambodian refugees in our city alone. All of them were in need of some social services and very few were receiving them due to lack of appropriate programs, translators, and transportation. Lack of knowledge about the needs of Cambodian refugees and lack of services in general were also contributing factors. So we compromised and cooperated with the media we thought would have a particularly large effect on public support and fended off the rest.

We selected the healthiest of our clients and allowed a few interviews. We soon learned that most of the reporters had little background in Cambodian culture. We taught many of them such courtesies as taking their shoes off before entering a home, and placing the hands as if in prayer and slightly bowing the head as a sign of respect and greeting.

Most reporters were respectful and caring. Some were incredibly rude and displayed disrespect by walking into people's homes as though they were their own, tracking dirt in

on their shoes, rearranging knickknacks and furniture to make room for equipment, and so on. One reporter shaved himself with a battery operated razor while standing over the family's Buddhist altar. Some we turned down would not take no for an answer. They went around us to search out the clients without our knowledge.

We had two goals when we started this research. First, we wanted to demonstrate that even a short intervention could result in positive changes in mental health. Second, we wanted to change the way in which trauma-based psychogenic blindness was handled by ophthalmologists, who are often the first to come in contact with such clients. We accomplished much more. We have spoken to dozens of reporters over the last three or four years. Stories on TV, in magazines and newspapers raised awareness of the holocaust in Cambodia and of its victims. A United States Congress Member used our research to argue against a Khmer Rouge role in the new Cambodia. I was asked to consult on a United Nations document about interventions with war-traumatized individuals. Gretchen has worked as a consultant on Cambodian health benefits with the State of California. We have recently been contacted by a playwright working on a play about Cambodian women and psychogenic blindness.

We are consulting with a Hollywood director making a feature length film on psychogenic blindness.

What started as the curiosity of two psychologists ended up enabling us to have experiences few researchers ever get to have. We were able to influence international, national and statewide public policy; affect public opinion; and provide positive changes in the lives of our clients.

Best of all we gained a depth of knowledge that sometimes only comes by learning it the hard way. We have seen Cambodia through the eyes and minds of women blinded by the experience.

REFERENCES

Rozee-Koker, P. & Van Boemel, G. (1989). The psychological effects of war trauma and abuse on older Cambodian refugee women. *Women and Therapy: A Feminist Quarterly*, 8, 23-49.

Van Boemel, G. & Rozee, P. (1992). Treatment efficacy for psychosomatic blindness among Cambodian refugee women. *Women and Therapy: A Feminist Quarterly*, 13, 239-266.

Footnotes

Both authors contributed equally in the preparation of this paper.

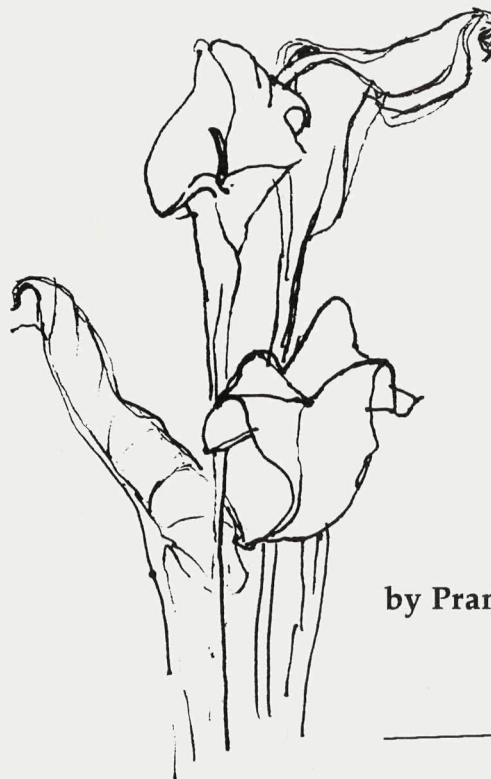
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THE COLOR and SOUND of DREAMS

You've added color and sound
to my dreams; a longing that lends
to a krait in the monsoon as it twists around
a banyan tree; a future that bends
through some mists unknown: eavesdropping nights
peering through the door; a wish to make sense
and swing it out in rhyme;
a wish to be mime
and let go of my voice; a wish for the lights
of comets far away at elliptical heights.

You're the cries of a crocus in a darkness dense!



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