Neil Samuel Ghiso Fellowship Final Report

Eric Zwemer
HMS Class of 2010
Castle Society

I. Summary

Throughout the eight primary weeks of my fellowship, my daily activities were split between three primary tasks: working with the Pediatric Advanced Care Team (PACT), performing and teaching magic tricks, and assembling tricks for my magic booklets.

A. PACT Team Medical Student

As a reminder, the Pediatric Advanced Care Team was formed in 1997 by members of Children's Hospital Boston and the Dana-Farber Cancer Institute. The PACT team works with medical teams, pediatric patients, and their families with the goal of "helping children live as well as possible for as long as possible" (PACT, 2006). Although the team began by serving specifically children with cancer, it now sees patients with a wide variety of life-threatening illnesses. The main goal of PACT patient care is to develop a "cohesive palliative care plan" which is distributed to all members of the treatment team as well as to the family. This plan encompasses the "physical, psychosocial, and spiritual needs of the individual and the family" (PACT, 2006). Currently, the PACT team serves approximately 130 children and their families (Duncan, Spengler, & Wolfe, In Press). The main members of the PACT team include Dr. Joanne Wolfe (PACT Attending), Dr. Tamara Vesel (PACT Attending), Janet Duncan (PACT Nurse Practitioner), and Marsha Joselow (PACT Social Worker).

As the PACT Team Medical Student for 6.5 weeks, I assisted and followed the team in all of their daily activities. These included but were not limited to morning rounds on patients, initial patient contact meetings, family meetings, home visits, all patient writeups, ethics consults, and full medical team meetings. Typically, I would arrive at Children's Hospital Boston at 8 AM to prepare a list of updates on inpatient children for the PACT team when they arrived at 9 AM. When the remainder of the team arrived, I would accompany them on whatever meetings they had scheduled for the day, which typically included at least one new patient, two or three family meetings, and a meeting with a medical team on one of the Children's Hospital floors. In addition, I would spend anywhere from 1-3 hours each day preparing patient writeups for new patients, specifically focusing on gathering the child's past medical history from their file and summarizing it for PACT team members. I also accompanied the PACT team on four home visits where we met with the patient and family as well as observed the patient in their home environment. Finally, in meeting so many children and their families, I was often asked to stop by and check up on children and families who seemed to particularly enjoy my presence. These children ranged from a 13 year with Cystic Fibrosis to a 5 year old with congenital heart disease. On two occasions, I traveled with Dr. Joanne Wolfe, my mentor, to meetings of the Partners Transitions for Kids program, which is an in-home pediatric palliative care program for children separate from PACT. My day typically ended at 6 PM, when the last scheduled (or unscheduled as the case often was) meeting ended.

B. Performing and Teaching Magic Tricks for Children

During my rounding with the PACT team, I was often asked to perform magic for children that the team thought would particularly enjoy my magic tricks. As such, I walked around the hospital with my pockets bulging with a variety of tricks. Although I will go into more detail about specific children below, I performed on average for at least one child a day. In addition to my daily routine performances, I also ran a magic workshop for the Spinal Muscular Atrophy (SMA) Conference held in April of 2007 as part of my Ghiso Fellowship. In preparing for this workshop, I met with Erica Sanborn, a genetic counselor at CHB, to discuss what functional limitations children with SMA have that my chosen tricks would have to accommodate. The ability to perform magic even with their motor deficits empowered these children, and I watched many of them brag to their parents at the end of the conference about their newfound skill. Finally, in addition to this Conference, I went on two “Magic Home Visits” with a nurse from the Partners Transitions for Kids program, where I arrived at the child’s home to perform and teach magic for them. The purpose of these visits was to bring magic right into the child’s home, and both children and their families were unbelievably appreciative of our efforts.

C. Assembly of Magic Booklets

For the 1.5 weeks that I was not working full time with the PACT team, I spent the time collecting magic tricks I wished to include in my booklets. In order to do this, I read through more than 30 books of magic tricks to isolate those which I thought would be particularly suited for my goals. These tricks included those that were easy to perform and involved items that would be easily available to children or physicians within the hospital. Unfortunately, due to the time constraints of my summer as well as the pressures of medical school, I was unable to do much more than choose which tricks I wanted during the summer, and I have been working in my spare time since the summer to write up these tricks. At present, I have collected all of the tricks and written the instructions up; I am now only waiting for my consultant photographer to take pictures for my booklets. After this, my current plans include distributing the booklets to the PACT team to give to their inpatient children, as well as distributing the booklets to my medical school classmates before they begin their pediatrics clerkships in third year. In addition, I am strongly considering taking a fifth year of medical school to work with the PACT team for a greater length of time doing clinical research, and I plan to spend parts of this fifth year perfecting my magic booklets and distributing them to a greater population as an extension of my Ghiso Fellowship.

II. Benefit to Involved Populations

A. PACT Team

In working with the PACT team for 6.5 weeks, I was able to contribute to their daily work in many different ways. In terms of lessening their workload, I took on the task of assembling the Past Medical History of almost all new patients during my time with PACT, producing notes which served to update PACT members on a child's history and which were later placed into the child's medical chart. In addition, I was responsible for writing the Home Visit PACT notes on two of the four home visits I went on, which summarized the conversation we had had with the child and family as well as gave suggestions as to the next steps to take. Finally, I worked with Rita Fountain, the PACT team coordinator, to maintain the PACT computer database of patients, adding new patients after our initial consult.

Aside from the written work I performed, I played many other roles in my work with the PACT team. First, I was often asked to sit with the child in the hospital room while the PACT team had a discussion with the family and other medical professionals. Secondly, as the new PACT team resident arrived in July midway through Fellowship, I was asked to help orient and train the resident in PACT team writeups as well as how to use the PACT database. Finally, I spent much of my last two weeks with the PACT team involved in handling Quality of Life issues for our patients. Just as palliative care does not imply only end-of-life care, the PACT team works with children and families to improve almost every aspect of their life, regardless of how trivial or small a child or family's concern might seem. Noticing, however, that the PACT team could not address every one of a child or family's needs, I took on the responsibility myself of addressing those that I could. These included but were not limited to: advertising at local colleges to solicit Big Brother-like figures for our patients, purchasing and delivering gifts for our patients (e.g. balloons, video games, etc.), and assembling medical information packets for our families.

B. PACT Team Patients

In addition to assisting the PACT team with my work, I also feel that I benefited many of the PACT team patients and their families. Interestingly, children and their families were incredibly appreciative not only for the active tasks I performed, but also simply for my presence as I got to know the child and the family. Although I cannot hope to cover all of the children I met during my Fellowship, I would like to highlight a few instances where I feel that I truly made a difference. (Note: names have been changed for confidentiality purposes).

i. DJ

DJ is a 14-year-old boy with cystic fibrosis who currently spends about half of each month in the hospital for recurrent lung infections. Unfortunately, DJ’s mother is a single parent who works two jobs in order to support DJ and his younger brother. Due to her hectic work schedule, she is unable to visit DJ very much while he is in the hospital. In addition, as children with CF are particularly susceptible to infection, DJ is not able to spend time with other children while he is in the hospital. Due to his relative isolation, the PACT team was initially consulted on DJ for Quality of Life issues such as loneliness and depression. As DJ was a young male whom the PACT team thought I would interact well with, I was charged with the task of serving as the liaison between the PACT team and DJ. Thus, I stopped by every day for about 30 minutes while he was in the hospital, during which we usually just talked, played Boggle, or watched TV. Over the course of the next several weeks, DJ opened up to me about many aspects of his life, including his frustration at not being able to attend school, his nervous excitement about girls, and his thoughts about the future possibility of receiving a lung transplant. Since medical school began, DJ is the one patient with whom I have kept in regular contact with, and I usually visit him at least 1-2 times per week while he is in the hospital. As he is quite tired of the Children’s Hospital food by this point, my visits usually involve bringing him the food of his choice, typically his favorite chips and salsa. In addition, I arranged a “Movie Night” earlier this year for DJ and I, where we watched a movie and gorged ourselves on junk food. Although I cannot do anything to lessen his medical course and the complications of his illness, I believe I have at least made his time in the hospital more enjoyable.

ii. Angela

Angela is a 5 year old girl with complex congenital heart disease who was in the hospital with severe pain and infection during my time with the PACT team. More than any other patient, Angela taught me how to adapt my magic to a child who is scared and in pain. When we first arrived at her room, she was very nervous about the group and did not want her mother to leave her side. When the PACT team members asked her if she wanted to see a magic trick, she shook her head quickly to indicate “no”. Suspecting that she was merely scared of me, I asked Angela if it would be all right if I performed a trick on her mother, which she quietly agreed to. Children of Angela’s age tend to appreciate tricks that are short and simple to understand, so I performed a trick in which a red sponge ball travels from my hand to the spectator’s hand. Now nervous myself, I watched Angela’s face as I finished the trick. Her face remained impassive for ten seconds, after which a small smile broke out and she exclaimed, “Do it again!”. This was to become her catchphrase over the next 30 minutes, as I performed this same trick approximately 10 times on the adult of Angela’s choice. When I arrived the next day and asked Angela if she would like to see a magic trick, she quickly said yes and let me perform for her alone, a drastic change from her understandable apprehension the previous day. While doing a trick that involved her drawing a picture on a playing card, I noticed that Angela was enjoying this task of drawing. Rather than continue with more magic tricks, we spent the next half hour simply coloring on playing cards, after which I left Angela with a stack of cards she could color on her own. I was later informed by the PACT team, who saw Angela recently, that she still has her “magic cards”. In working with Angela, I learned the value of letting a child watch you perform a trick for someone else before you try it on him or her. In addition, children of Angela’s age often enjoy simple coloring just as much as anything else, and it is important to adapt to their personal interests rather than pressing on with your own agenda.

iii. Lindsey

Lindsey is a 16 year old with Mucopolysaccharidosis Type 6, a rare metabolic disorder resulting in stunted growth and chronic lung and heart disease, accompanied by a normal intellect. I was first asked to perform magic for Lindsey by Janet Duncan, the PACT team Nurse Practitioner, who noted that she would most likely greatly enjoy the company and the entertainment during her required weekly transfusions of the enzyme she lacks. In reviewing her medical history before I visited Lindsey, however, I noted that she was also legally blind, a deficit that would tend to detract from many of the tricks I had prepared for her. During our first meeting, I performed two tricks that were very tactile, meaning Lindsey could feel the props to understand what was happening rather than needing to see the trick. I then taught her and her mother how to make a spoon float behind a napkin, which brought a huge smile to Lindsey’s face. She proceeded to call in each of her nurses and doctors to see her new trick. For the next two months, I visited Lindsey almost every week during her transfusions, during which time I would usually perform two tricks for her as well as teach her one trick. This proved to be one of the most challenging but rewarding tasks that I have undertaken, as it often took me quite some time to choose which tricks would be best suited for Lindsey. The challenge was well worth it, however, as I am now confident that I could perform magic for any other blind children that I happen to encounter in my medical career.

iv. Abby

Abby is a 24 year old with mental retardation, cerebral palsy, seizures, and severe lung disease leading to respiratory distress and chronic aspiration. I met Abby on my first day working with the PACT team, when I was asked to purchase a balloon for Abby's hospital room. Although arriving with a giant butterfly balloon certainly put me in Abby's good graces, her mother was also extraordinarily appreciative of the gift, and we talked about Abby for the next half hour. Luckily, Abby was discharged soon after, and I did not see her again until the PACT team went on a home visit to her house. On arriving there, I first noticed that Abby still had the butterfly balloon hanging in her room. During the course of a two hour discussion with her parents, many of their concerns about Abby's future came up, some of which related to her worsening respiratory status. Specifically, both parents were worried about knowing when they should call an ambulance to take Abby to the hospital. Abby's mother in particular noted that although she felt confident in her ability to take care of her daughter, she lacked confidence in accurately assessing Abby's respiratory status by listening to her lungs. On arriving back at Children's Hospital, I took the task of assembling a list of websites that had normal and abnormal lung sound samples on them, after which I emailed the list of websites to Abby's mother so that she could train herself in discriminating between the different sounds. Although this was a relatively small task, Abby's parents were very appreciative of my efforts, and Abby's mother is now more confident in her medical skills. Along with countless other experiences like this throughout my summer, I learned the value of even small tasks in reassuring families. As a physician, I hope that I am able to incorporate the PACT team’s philosophy of doing everything they can for a patient and their family, outside of only handling the medical tasks.

v. Devon

Lastly, I would like to discuss my relationship with Devon, a 17-year-old girl with Trisomy 21 (Down’s Syndrome) and interstitial lung disease. At the time that I met Devon, she was being hospitalized frequently for episodes of respiratory distress and hypoxia. After I was introduced to Devon, she quickly offered me a seat and insisted I watch an episode of her favorite show, “Star Trek: Enterprise”. Although Devon’s vocabulary was somewhat limited, it quickly became clear which of the show’s characters was her favorite, as she would make kissing noises every time one particular character came on the TV. Over the next two weeks, I watched about 10 episodes of this show with her, all the while learning more about her likes and dislikes through her facial expressions and actions. In addition, Devon took it as her responsibility to introduce me to everyone she saw, including those people just passing by in the hallways. Her mother would often use the time I was there as a reprieve, allowing herself to leave the hospital room for a trip to the cafeteria. In addition to spending a great deal of time with Devon, I also talked with her mother on many occasions, both with other PACT team members and on my own to see how she and Devon were doing. Thinking that Devon would enjoy a poster in her room, I ordered her a Star Trek poster online, hoping to surprise her with it on my next visit. Unfortunately, due to the worsening degree of her respiratory disease, Devon passed away in the hospital on a day that I was not present, though she was surrounded by her family and friends as she died. As this was the first death of a pediatric patient I had experienced, I had a particularly difficult time dealing with

Devon's passing, particularly since I had not been able to be present on the day she passed away. During a follow-up phone call with Dr. Tamara Vesel, however, Devon's mother told her that my last visit before Devon's death had been the happiest and most animated she had seen Devon in quite a while, and that she was very grateful for the time that I and the PACT team had spent with her daughter. Although I do not believe I did anything particularly special for Devon, her mother's comments reminded me of the power that simple presence can have for a patient and their family during difficult times.

C. Children with SMA

As noted above, I ran a magic workshop for children whose parents were attending the Spinal Muscular Atrophy Conference at the New Research Building of Harvard Medical School and Children's Hospital Boston. As children with Spinal Muscular Atrophy have mild to severe motor deficits, I selected magic tricks which involved only minor movements to perform. In addition, I assembled 20 bags of magic materials so that the children at the conference could take their tricks home with them at the end of the conference. On that specific day, I instructed ~10 children in 4 different magic tricks, which the children enjoyed a great deal. Beyond anything else, the workshop empowered these children to try a new hobby which they may otherwise have felt they were unable to do. After the conference, I received a thank you note from Erica Sanborn, which read:

> "Thank you again for participating in our Boston SMA Day. The kids that worked with you loved it! I hope next year we can collaborate again and have you work with more of the kids. Your work and vision is special and I hope the rest of med school only strengthens it."

D. Hospice Magic Home Visits

Also noted above, I went on two "Magic Home Visits" with a nurse from the Partners Transitions for Kids program, an in-home pediatric palliative care program for children living with life-threatening illnesses. Specifically, I first visited Emily, a 3 and ½ year old girl living with a brain tumor, and her 5-year-old brother Jason. As Emily was a bit young to understand my magic tricks, I ended up performing more for Jason, but both of them were entertained by the various tricks. In addition, as Emily was particularly fascinated by one of my magic scarves, I left it with her to use as a blanket for her stuffed animal. We visited Sally during the second visit, a 10 year old with mitochondrial disease and Asperger's Syndrome. As Sally was quite interested in Japanese Anime cartoons, I tried to incorporate these cartoon characters into my magic tricks (e.g. having her draw an anime character on the back of a card instead of merely signing her name). After showing Sally a few tricks, I taught her and her mother a few tricks, which excited both of them. After these home visits, Dr. Wolfe, my mentor, received the following email from Michelle Papazian, the Program Director of the Partners Transitions for Kids program:

"Just wanted to give you some feedback re: Eric Z. Cheri took him out yesterday to see some of our kids and left me a lengthy message about what a HUGE hit he was with the kids. The fact that one child (Emily) was actually willing to get off her mother's lap during his visit and participate in his tricks, was extremely significant. Apparently he ended up giving her his " magic scarf" which was also huge for her. As you know, there's so much symbolism in magic for kids, and also what a wonderful way to engage kids who might otherwise be so terrified, mistrustful, physically miserable, etc. I think he's on to something fabulous here. Perhaps we should suggest that Developing a Pediatric Magic Bag should be a mandatory course at Harvard Medical School!! Please let him know that he made a difference yesterday."

III. Data/Evaluations

Although my project did not involve any research or data collection, I have attached two documents at the end of this report to illustrate my written work during this Fellowship.

A. *Home Visit Report*

As noted above, I was often responsible for writing up the PACT team notes following a meeting. The attached is an example of a Home Visit summary entirely of my own authorship following one such meeting, with the identifying information removed to protect confidentiality. This note was approved by the PACT team, distributed to the patient's family and health-care providers, and then placed into the patient's chart. In particular, this note exemplifies the vast range of concerns that families and patients have when they meet with the PACT team.

B. *Magic Trick Instructions*

In addition, I have attached my written instructions to all of the tricks I selected for my two magic booklets. I am currently waiting to meet with a consultant photographer to take pictures for these tricks. After this, I will assemble the tricks into a more complete booklet and begin the process of distribution to PACT team patients and medical students.

IV. Successes and Challenges of the Fellowship

A. *Successes*

First, I was able to integrate myself with the PACT team very quickly, allowing me to begin helping the team as opposed to just observing them. In part due to this integration, I was able to receive an incredibly wide exposure to the field of pediatric palliative care, which I plan to pursue as my career following this experience. I worked with children suffering from a wide range of life-threatening illnesses, and in doing so I was able to critically think about and explore all of the major topics in pediatric palliative care.

Secondly, although I did not have the time to achieve many of my goals regarding my magic, I did achieve a great amount of success with my magic on an individual level with children. As illustrated above, I was able to make a difference in the lives of many children with my presence and with my magic. In addition, performing and teaching magic to children with such different illnesses and deficits strengthened my ability to adapt my magic to drastically different audiences, a skill that will surely be useful in my future career as a pediatrician.

B. Challenges

My major challenge was that I simply took on too much for the primary 8 weeks of my Fellowship. I cannot stress how valuable the 6.5 weeks I spent with the PACT team were, but the remaining 1.5 weeks of my fellowship did not allow me to complete my magic booklets. Although I would have liked to have spent most of the fall working on this project, the rigors of medical school classes from 8:30 to 5 almost every day prevented me from achieving much progress on this project. After spending a significant amount of time writing up tricks over the past holiday break, I am now only waiting for my photograph illustrations before I can compile and complete the booklets. In addition, I believe I could have used a magic mentor in addition to my PACT team mentors, as this would have allowed me to meet with someone and specifically discuss this aspect of my fellowship. I believe it would be helpful for future applicants to have a more realistic goal for their Ghiso Fellowships based on the period of time they have allotted for the fellowship. As noted above, I will most likely take a 5th year working with the PACT team, and during this year I will revisit my booklets and work on increasing their distribution.

In addition to the time constraints of my project, I must admit that I had quite a hard time at first dealing with the deaths of my pediatric patients. Fortunately, Dr. Tamara Vesel, the PACT team Attending Physician, was quite perceptive to my emotions surrounding these deaths, and she went out of her way to discuss these events with me and normalize my feelings. I am not sure how other Ghiso Fellows have dealt with the initial deaths during their fellowship, but some organized preparation for these events might be a useful session to hold prior to the Fellowships, possibly mediated by Dr. Buxbaum. On the other hand, perhaps past Ghiso Fellows could meet with new Fellows to discuss such situations and how they dealt with them. I would have benefited from such a session and would be happy to organize/participate in one for next year's Fellows.

V. Self-Reflection on Experience

Reading my personal statement from my Ghiso application is both heartening and frustrating at the same time. While I was able to accomplish many of my personal goals in terms of those experiences I wished to have, I simply did not have the time to produce as much for others as I would have liked. In this way, I feel somewhat selfish, having given back only a fraction of what I feel I have gained from the experience. I take comfort in the fact that these experiences have prepared me to be able to give back more to every patient I will see in the future.

In general, I feel as if I accomplished my two broad goals of being exposed to the pediatric palliative care field and beginning to introduce magic into patient care. The experiences detailed above forced me to confront and answer many questions related to both goals, some of which I had predicted I would encounter and others which I had not foreseen.

In terms of my time with the PACT team, the two most significant issues I faced were the death of my patients as well as the inability to separate my personal life from my professional life. Over the course of the summer, twelve children who I had met personally or whose families I had met passed away. This included three deaths within my first 2 weeks with the PACT team. Although I had thought about how I would deal with such events, I was not prepared for the reality of this situation. In addition, as noted above, I was not at the hospital when Devon died, and I felt extraordinary feelings of guilt about having taken the day off for personal reasons and missing this event. As such, I approached Dr. Vesel to discuss such feelings, and we had three long conversations about how to deal with such events as well as how to allow yourself time off when you need it. Specifically, she reassured me that the PACT team, myself included, had done everything it could for Devon and her family. In addition, she stressed the importance of being completely and totally “there” when you are around patients. If you can establish such a presence with families, she noted, you will be able to allow yourself the time off when you need it, as you will have done everything you could for such families. Finally, she encouraged me to think about the happy times that Devon had had, particularly those that had been a result of my and other’s presence close to the end of her life. As the summer progressed, the deaths of children did not become easier. Rather, I was better able to reframe my understanding and attitude towards such events, primarily as a result of my conversations with Dr. Vesel. Perhaps the most important lesson I received from this summer was the knowledge that I can personally handle this specialty both mentally and emotionally, which has solidified my desire to pursue a career in pediatric palliative care.

In terms of my desire to incorporate magic into pediatric patient care, I had success on the individual level but not on the more global level I had wished. The time constraints of the summer and the second year of medical school did not allow me to distribute my magic booklets as well as I would have liked, and I hope to remedy this lack of time by returning to this project later in medical school. On a more personal level of development, however, my ability to adapt my magic to different children has never been tested as much as it was this summer. Over the course of the fellowship, I performed and taught magic to children who were blind, unable to use both arms, in pain, and unable to communicate back to me. In each case, I was able to adapt my magic to bring enjoyment to the child. In addition, as noted above, I learned that children in the hospital are often mistrustful of magic at first, and that a quick way to relieve this mistrust is to perform the trick on an adult whom they trust. These lessons about trust and adaptation, although seemingly simple, will be incredibly useful as I continue to perform magic for children of all ages and illnesses in the years to come.

Thus, the Ghiso Fellowship served as an unparalleled period of personal development and learning through which I have confirmed my desire to pursue a career in pediatric palliative care. My newfound ability to bring magic into any hospital room, coupled with the confidence that I can handle the emotional tolls of this field, will undoubtedly have a positive impact on countless future patients and their families.

VI. Interactions with Faculty Mentors

Although my official mentor was Dr. Joanne Wolfe, I only worked with her intermittently, as she was not on service for the PACT team during my fellowship aside from a few days. Dr. Wolfe and I did meet approximately every 2 weeks during my fellowship, however, where we discussed the work I was doing with the PACT team in addition to other aspects of pediatric palliative care. For the most part, however, I had two separate mentors, Dr. Tamara Vesel and Janet Duncan (NP), who were on service for the PACT team during my 6.5 weeks. I cannot stress how integral both of these people were to the success of my experience. Dr. Vesel went above and beyond to not only teach me about the field, but also to help me process the emotions that inevitably accompany the work we were doing. I received numerous phone calls from Dr. Vesel after children I had been particularly close to passed away, simply to see how I was doing. In addition, Dr. Vesel and I met one-on-one on numerous occasions to discuss both specific patients as well as general topics in palliative care. Janet Duncan was also a wonderful resource for me, as she essentially took me under her wing for the first week I was there. She helped me write my first few patient histories and then let me do them on my own, and she was always ready to explain something to me or tell me about a patient. In addition, she played a big role in identifying particular patients she thought would benefit from my visits, and she continues to email me when the PACT team has a patient she would like me to meet.

VII. Suggestions for Improvement

A. ***Help applicants set reasonable goals***. My greatest source of frustration was my inability to complete everything I wanted to within the time I had. It might be helpful to remind applicants to set reachable goals for the time they have allotted for the fellowship.

B. ***Prepare applicants for patient deaths***. Since most applicants will experience the death of a patient during their fellowship, the program could benefit by having a physician or fellow-run session prior to the start of the fellowship describing how to deal with such events.

C. ***Scheduled Ghiso Fellow Meetings***. Although our group met three times with Dr. Buxbaum, these meetings would have been more organized and more frequent if they had been scheduled prior to the start of the fellowships.

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