

Humanities: Art, Language, and Spirituality in Health Care

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Creatively Caring: Effects of Arts-Based Encounters on Hospice Caregivers in South Africa

Patricia Ann Repar, DMA, and Steve Reid, MD, PhD

Departments of Music and Internal Medicine (P.A.R.), University of New Mexico, Albuquerque, New Mexico, USA; and Primary Health Care Directorate (S.R.), Faculty of Health Sciences, University of Cape Town, Cape Town, South Africa

Abstract

International literature and experience suggest that arts-based encounters can be effective in reducing stress and burnout in health care workers. Are these principles universal? Are they as applicable and effective in resource-constrained situations in Africa as in other parts of the world? We describe the impact of creative and arts-based encounters on a group of hospice caregivers at South Coast Hospice in KwaZulu Natal. An experienced facilitator built a caring and trusting relationship with the participants over a three month period through a variety of means, including a singing and songwriting intervention specifically designed to empower and give voice to the hospice caregivers, most of whom were Zulu women. We documented the process through several rounds of interviews, extensive field notes, and audio recordings. This article is a reflection on the experience and draws from the interviews, correspondence among researchers, field notes, and a performance piece written by the facilitator one year after completion of the study. We found that the songwriting and other creative activities of the engagement provided affirmation and acknowledgment of the caregivers as well as an opportunity to release stress, grief, and pain. They experienced changes in terms of hope and freedom both for themselves and their patients. The conceptual themes that emerged from the interviews with the caregivers were interpreted in terms of their inherent cultural assets, a release of agency, a sense of revelation, and transformation. The expressive arts can have a significantly beneficial effect on hospice workers and their patients, and clinical engagement can be enhanced through creative encounters, even in resource-constrained situations. If such creative processes were to be promoted among a wider group of health workers, daily routine work in health care could be not just a repetition of well-rehearsed utilitarian rituals but rather a series of creative and transformative encounters. J Pain Symptom Manage 2014;47:946–954. © 2014 U.S. Cancer Pain Relief Committee. Published by Elsevier Inc. All rights reserved.

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Address correspondence to: Patricia Ann Repar, DMA, Music Department, The University of New Mexico, Center for the Arts, MSC04 2570,

Albuquerque, NM 87131-0001, USA. E-mail: repar@unm.edu

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Prelude

From field notes: March 18, 2011

One of the community health care workers pulled me aside and wanted to talk about the death of her 32-year-old daughter from AIDS, the fact that her 12-year-old granddaughter (the same daughter's daughter) is HIV positive and taking antiretrovirals but does not know why, that financially every month is a terrible struggle, and that she is trying to save R500 (ca. \$50) per month so she can buy an inexpensive car to drive her very overweight mother to doctors' appointments and so on. She thanked me over and over again for the support saying that no one asks her how she feels and certainly never asks how she feels about her daughter who will have been dead two years ago this coming October.

South African hospice workers face enormous challenge and stress particularly in rural areas where health care resources are limited and where the prevalence of HIV infection can be up to 50% in the reproductive age group. Many of these providers suffer from profound and cumulative grief having worked with the dying through the early years of the AIDS pandemic, when they often experienced multiple deaths on a daily basis.

From field notes: February 21, 2011

The nurses' stress was compounded, not only by the continuing high rate of HIV infection but also by the poverty and lack of food. Many of their patients could not take the antiretrovirals that would keep them alive simply because they did not have as much as a bowl of cereal to take them with. Nonetheless, every morning they carried on and sang their hymns before heading out into the rural areas—and they sang beautifully, with great passion and in multiple harmonies. I wondered what would happen when they started singing their “inner voices.”

This article is a reflection arising from a study that aimed to assess the impact of creative and arts-based encounters on the morale, motivation, and productivity of nurses and community health care workers at a hospice in South Africa.¹ Developed by the University of New Mexico's

Arts-in-Medicine Program and adapted from Rollo May's *The Courage to Create*, the creative encounter proposes that in “meeting and joining an other without judgment or expectation, something new can be born, in body, mind, or spirit”.^{1, p39} May speaks of artists and creative persons as “the ones who express being itself...their creativity is the basic manifestation of a man or woman fulfilling his or her own being in the world”.^{1, p39} He contrasts the difference between “art as decoration” or “making life prettier,” and “giving birth to some new reality.”^{1, p39}

In this study, we hoped to establish a creative, caring, and trusting relationship between the facilitator and participants through which a new or different way of being might become possible. Based on the results from existing research²⁻⁵ and the success of the Arts-in-Medicine Program at the University of New Mexico Hospitals (<http://artsinmedicine.unm.edu>), we knew it was possible, but we had no idea whether “creating a new or different way of being” was feasible and beneficial in an African context where resources are far fewer and an HIV/AIDS epidemic continues to rage. We also knew that Zulu women loved to sing.⁶

From field notes: March 19, 2011

Regardless of what songs get written (or not), my relationship with the nurses and community health care workers has become increasingly close and what they see as “supportive.” When they are called into a meeting with bosses (other than Fanny who is Zulu and their immediate supervisor), they completely shut down and a profound disconnect happens (within themselves and between themselves and management). So the songs, the photos, the massages, and the recordings have all contributed to allowing them, just for moments here and there, to be who they are—not who they are supposed to be. This disconnect, I think, is reflected in their malaise, their fatigue, their immediate and chronic illnesses, their deadpan faces much of the time, and their constant complaint about low salaries.

Theme and Variations

It was suggested that we approach South Coast Hospice (SCH) as a site for the study

given their established reputation in providing excellent care and their interest in supporting research. They enthusiastically agreed. Established in 1983, SCH offers palliative and hospice care for the people of Port Shepstone and surrounding rural areas. Located on the south coast of KwaZulu Natal, SCH provides an eight-bed inpatient unit and seven mobile teams of professional nurses and community health care workers who travel into urban and rural communities every day delivering medicines and care. Of the 35 clinical staff members, 22 agreed and were available to participate in the study, which was to be conducted in February through April 2011.

From field notes: March 25, 2011

As we are driving into one of the surrounding rural areas, I describe the study and the upcoming songwriting workshop to Zee. She does not realize that I am an academic who must talk about things at length before actually doing them (if I do them at all). So she just starts making up words and melodies right then and there. She is singing about how much she loves her two sons and how they make her “happy happy” while I am still climbing out of my disbelief. But she carries on—revising and trying the verse again and again and I find myself becoming happy happy.

Originally, the research team assumed that the facilitator would spend most of her time writing songs with the participants. In fact, the facilitator, who has been a composer, educator, and artist-in-medicine for some 20 years, spent most of her time building rapport with the participants through a variety of means, such as designing unique portrait cards for the SCH staff; setting up a community bulletin board where new photos of staff, families, and patients were continually posted; providing early morning, 10 minute chair massages; recording morning prayers, hymns, and original songs; conversing about a wide range of topics including health issues, family concerns, problems at work, and national issues of poverty and unemployment; and contributing to patient care by singing, playing instruments, or providing comfort touch.

From the performance piece “Who Cares”:
October 2011

So, every morning at 7AM there I was, a girl from the land of snow and art and academia—face to face with them—women from the land of sun and sea and the mighty Zulu tradition. It was like Little Miss Perky meets Zena the Zulu warrior. About six weeks into the study and hundreds of photos, homemade cards, songs, poems, massages, recordings, donations, and conversations later—I am still wondering if anyone from the 22 who signed up for the study will write a single song or single poem.

All of these activities paved the way for the first songwriting workshop three weeks into the study, during which they wrote short poems, improvised melodies, and performed one of the participants’ songs in multiple harmonies.

From field notes: March 11, 2011

It’s the same thing everywhere...everyone fights the reflective process because it hurts. I do not care if they ever write in the journals I gave them. But I do want them to remember their songs and live their songs...not just sing a little line they made up and then forget about it.

The second workshop, eight weeks into the study, was equally productive as participants took it upon themselves to produce a community concert featuring their newly composed songs and some traditional hymns. They chose to have the concert off hospice grounds and on a public holiday when friends and families might be more available to attend.

From invitation to colleagues and community members: April 19, 2011



ANGELS SING ON!

A Free Concert by South Coast Hospice Caregivers

on

Wednesday, April 27th 12:30 p.m.

at

Walton's Stationery

Post Office Entrance on Aiken Street

Celebrate the holiday and the creativity of South Coast Hospice staff -
with newly-composed songs, hymns, poetry, and dancing!

From field notes: March 11, 2011

The most memorable moments in the first workshop were:

1) At the beginning, when I started to thank them for their openness and for sharing their lives with me, I welled up with tears (I was overtired and it was such a point of culmination after many months of preparation). They empathized with me (there were little “ahs” and moans all over the room!) and two people including Evy went to get me tissues. 2) At the end, after practicing the verse several times, they really heard themselves and were both delighted and surprised by the beauty of what they had just created. 3) When they heard from me how talented and capable they were of making their own songs. 4) When Mandy chose #4 of only three choices—we all giggled like little children. It was so much fun to laugh together in the middle of a work day! 5) When I realized later on in the evening that it took enormous courage for them to make something new (and more so for the younger and more timid)! Is that what it takes to empower a life?

In the first few weeks of the study, the facilitator interviewed every participant individually, asking them to speak freely about themselves, their home life, and their work. At the end of the study, members of the research team other than the facilitator interviewed participants and hospice management. Three months after the study, yet a different member of the research team returned to interview participants and management again. They were asked to describe the arts-based encounters in retrospect, whether or not they had made a difference in their lives and their work, and how song and poetry writing could be sustained at SCH and replicated at other sites.

From the performance piece “Who Cares”: January 2013

On the long ride back to the hospice, we drove alongside about 20 high school boys singing and dancing their long walk home in their very formal uniforms in the hot African sun. I bring out my stash of rusks for the day and we celebrate. Then, we randomly choose a few words, string them

together, and sing for about 30 minutes while heading home. By the time we rolled into hospice, we were high as kites. Then, Zee in her quiet way turns to me and says “It’s like you can make a song about anything at all that’s in your head Patrice—is that right?” And that was the first time that I knew I was in the right place at the right time—and I stopped caring about what happened with the study and I just wanted to care about Zee and Bonggi, the music and the love we had shared that very hot day in rural KwaZulu Natal.

The interviews conducted at the end of the study were surprising, almost shocking, to both the facilitator and the research team. Although some of the participants did write songs and poetry throughout the three month period, there was no obvious evidence to show that the study had any lasting effect on the morale, motivation, or productivity of the participants.

From pre-compositional notes on “Who Cares”: October 2012

I remember feeling doubtful about the success of the study right up until the day of the concert. I had been working on a blues tune with the following lyrics: I’m talkin’ about songs and they’re talkin’ about food. I’m talkin’ bout singing and they’re talkin’ bout starvin’. I’m talkin’ bout the power of creating and they’re talkin’ bout the power of God. I’m talkin’ bout SELF-expression and they’re talkin’ bout the husbands and the boyfriends, the sons and the daughters, the mothers and the fathers, the aunts and the uncles and the cousins and the grandmothers (I do not know where the hell all the grandfathers got to.) Next verse yet to come.

After careful analysis of all the interviews, however, it became clear that participants’ ways of seeing the world and being in the work environment had been changing. We summarized the content of the interviews in terms of four main themes (Fig. 1), namely stress, affirmation, love and laughter, and the effects of the creative encounters.

The main causes of stress as identified by the participants were the constant exposure to death and dying, including patients, family, and community members; high unemployment,

poverty, starvation, and homeless children in surrounding rural communities; not having enough resources to help patients; living with a life-threatening illness themselves; and poor wages and lack of support from hospice management.

From facilitator's e-mail to collaborator:
March 3, 2011

I am feeling sad today but still happy to be feeling at all. I am not sure where it is coming from. Possibly I am taking in some of the nurses' pain and their patients' pain, not because of all the illness but because of the conditions more than anything else. This sadness has been very prevalent in the initial interviews with participants.

In terms of affirmation, there were specific comments about the acknowledgment of self as someone capable of creating:

I'm thank[ing] Patrice to open my mind that there is something I can do [about the AIDS crisis]... I wasn't think[ing] that one day I can create my song.

But the time when you come and do, open my eyes, say, "I know, that time when I do things I'm creating."

So because the song it's my own thing so I can make my own things because we have to prove ourself that we got talents.

With regard to the theme of love and laughter, participants connected the act of singing to spiritual and cultural expression and values. One of the inpatient community health care workers told us that "when you sing a song...you feel like you going in heaven." There were comments about "how music is the best way of talking to people." One put it this way: "Sometime if you talk people, they start crying...If you sing, he will try to contact God about their sickness and then he will see he is important even in the world and even in the community...No one neglect him or her." One of the elderly nurses thought carefully and explained that "when the music is sung, the patient relaxes—feels that he is loved. And he is being cared for." Ultimately, she summarized by saying "music is love."

The effects of the encounters were described in terms of the caregivers themselves and their patients. Participants mentioned that the engagement as a whole brought people together, as one described: "here we have four departments. It's admin department, inpatient department, training center and

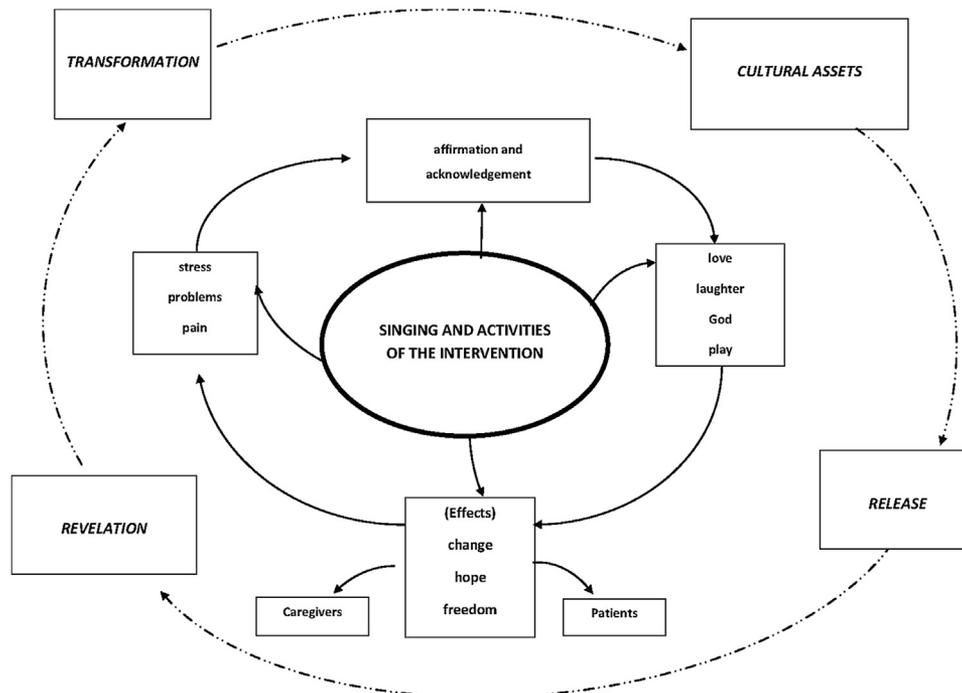


Fig. 1. A diagrammatic representation of the major themes.

the team that goes out [homecare]. So by her music, makes us come together.” They acknowledged the relationship between music and stress relief as one of the nurses said, “You cannot help someone if you are stuck, you cannot help the outsider if you got the stress but Patrice try everyday to make us free of stress before we go. With music and therapy.” And one of the senior nurses referred to burnout, “[we] got very stimulated. Uh, we were very uplifted...there are times when you, uhm, you get the burn out. You just do not want to work. You are fed up. She had to cheer us up and we had to compose some songs, which we enjoyed very much, uh, and in that we got very inspired.”

Several of the participants chose to actively grieve through the writing and performing of their songs and poems. People spoke often of their personal losses and how the engagement helped them to acknowledge their grief and “feel better.” One spoke about her mother:

Especially I get a time to remind myself about my, uh, my last day with my mum. So when Patrice give us the chance to sing any song that you made yourself, but I was remember my song that I was, I was sing [ing] the last few days before my mom pass away... And it just help a lot to me because I was crying a lot...It was very nice because I was forming the dance, how I will I like to dance my song.”

Other people spoke about the stress of regularly losing patients and how the music provided a welcome diversion: “I think it was a good idea for us because we are working with patient and we are working very hard so we, I think, we took our minds from the patients so that we cannot be thinking about patients all the time.”

Caregivers commented on how they had learned to make songs particularly as an expression of their personal feelings. “She taught us that you can write a sad story or a happy story or whatever, then you can, out of that story, make four lines. That four lines can make a song.” Another participant commented that “with singing you can express the feelings of how you feel and you can even get energy to work with patient.” They spoke of how “the song gives hope, that

maybe that patient will get better and ehh even to us, if you got a problem then if you come here and sing, that problem will go away.”

The creative encounters addressed other personal problems as well, including the pain of past trauma, unwanted teenage pregnancy in the family, and living with HIV. One wrote a song about a car accident in which her best friend at the age of six was killed. Afterward she said the following: “I think that I am feeling better. As from when I was six I did not talk about it...now I sing for me, because now I talk about it, and at home we just sing the song I wrote. I think it makes me feel better.” One of the other caregivers who is living with HIV was very happy that her daughter had been included in the poetry writing and the concert. She was relieved that the young girl, through the writing and performance of her poems, would now have a way to remember her mother should HIV cut her life short.

Although the engagement did not directly include work with patients, the final interviews showed that throughout the study participants had been thinking about and exploring the use of music with their patients. One nurse said, “I think it has empowered me because, you know, this is another door to deal with my patients.” And a few of them spoke about how singing could help the patient focus on something other than pain and illness. “If you sometimes think...everything is pain. But if you say, ‘Can I sing for you?’ you see the smile, you just see the smile.” One told the story of encountering one of her young HIV-infected patients suffering from headache and stomachache.

I visited, staying outside of the house and then I start to create with the song about trees. [sings] there is a trees, there is a trees, we look very nice...thula, thula, thula 'twana (translation: quiet, quiet, quiet child). The time when I'm doing these things, when I'm sing, I tell the children there's a something you look, and she knows and he knows the trees. But when I create a little song, the child was start to smile, “Oh, aunty, is a song;” say, “Yes my girl, is a song ...” Ey, that time when I'm going, the whole families, family were very, very happy...

She concluded the story by saying that she helped relieve the pain a little bit “without go to the clinic, without go to pharmacy to buy something, but just create little bit things.” Her close colleague spoke of how they not only wrote songs for the patients but encouraged patients to write songs themselves. She would tell children, “You are very important in life. You can do things on your own...even the song...you can create the song...maybe you speak out or thanks [for] things they do for you.”

Postlude

From field notes: April 29, 2011

Will they remember, I wondered? Perhaps when they feel free enough to laugh and sing anywhere at any time about anything; or when they cry in a way that “contacts God” as Carol said. Nomfundo remembered when she sang to the trees with her young patient dying of AIDS and DeeDee when she sang for Africa; and there was Cindy who remembered more and more as she changed from always looking down and speaking inaudibly to greeting me with a big smile and writing a song and singing it in a ferocious voice in a flaming red dress with long hair trailing down her back — looking regal and powerful.

Three months after the study, we found that the effects of the encounters were not only being sustained but also were being further developed by the caregivers themselves.

And so, we want to really, to teach even the others, yes, because they not or they'd like to but no one to, to give encourage like us. Patrice give it to us, encourage. So now in us, we do not have a jealous, even to encourage others. [All laugh] Especially work with the children and even the adults as well...There are a lot of children finished at school, they didn't do nothing...So now I will teach them even to sing because they...not all the children know to play the ball so I also put another group to create and sing a song while they sitting, rather than to go to the road and do the funny things, ja.

Fig. 1 portrays a holistic view of the major themes of the study and the sense that we made of the implications of the creative and arts-based encounters. The concrete components of the encounters are represented at the center of the diagram, with the results of the encounters in the first ring of subthemes. Based on these results, we were convinced that it is possible to acknowledge the innate creative potential of a group of health workers who feel constrained by stereotypical professional roles in the workplace, and move with them through a process of discovering a new set of possibilities. This in turn can lead to an experience of personal transformation as represented by the themes in the outermost circle in Fig. 1.

From field notes: March 25, 2011

The lunch break comes and we find a shady spot. I am not prepared for what comes next. One of the community health care workers Zee, tells me she is HIV positive—and then she looks straight into my eyes and tells me that she can look at people and see whether or not she should trust them—the way she was trusting me now.

It would appear that the engagement was successful in terms of its original intent, to develop a creative, caring, and trusting relationship through which a new or different way of being could be created. The process not only involved caregivers in singing while at work but also stimulated them to write their own songs about their own experiences. This is the unique feature of the study that went beyond the therapeutic effect of helping health workers to feel better; to what May describes as the fulfillment of being. The capacity and the joy with which the Zulu caregivers engaged in the process of singing and songwriting illustrate the potential of integrating cultural strengths into care for self and others. As the study unfolded, it became clearer to us that the caregivers' responses were not so much the result of any one particular arts-based intervention as much as the fact that they had been given permission to express their own innate capacity to care creatively.

The ongoing release of stress, grief, and other emotions over the three months also stimulated a revelation or a change in self-perception. Participants realized their capacity

for creating new and alternative approaches to caring for themselves and their patients. We realized that the project, rather than imposing a solution, had in effect “taken the lid off” their inherent talents. It appears that this process was transformational not only in a cognitive sense but also at an affective level that would influence behavior. The impact of the songwriting and the public concert directs our thinking beyond music as comfort or therapy, toward music as a potential means of becoming more fully alive, both in the workplace and outside it. This led to much deeper changes than we had anticipated, which will ultimately impact on their caring for patients.

From the performance piece “Who Cares”:
January 2013

I got sick from seeing and feeling the repression and suffocation brought on in the name of professionalism, in the name of Zulus politely accommodating white and corporate culture. So, I pranced around and stood up on tables and chairs, and wiggled and giggled like a little girl. I wanted to let myself become their clown—to sing in the midst of their sadness and dance through their despair—to write poems and songs with them that dared to speak the unspeakable. Their well-being became my business.

And as I became the clown, I discovered more of who I am and have always been—the little girl in first grade who loved to wind her way home after school giggling with her friends, stopping in the corner store to buy candy and to make Tony laugh, singing little ditties to herself all the way home. The Zulu nurses gave me all of that back—they reminded me of who I really am at the core — a simpler, softer self, and one whom I can love. It seems that I became their business as much as they became mine.

By its very nature, the creative encounter is a shared experience of “birthing something new.” Both the participants and the research team were led into new ways of being. Based on the positive experiences of all concerned, we were convinced that clinical engagement can be significantly enhanced through creative process in an African setting. If such creative process were to be promoted among a wider group of health workers, daily routine work

in health care could be not just a repetition of well-rehearsed utilitarian rituals but rather a series of creative and transformative encounters, ultimately fostering hope, inspiration, and rejuvenation.

Developing a creative approach in health care could help us to see patients not as “clinical problems,” but rather as unique and complex individuals vulnerable to a stunning variety of challenges and capable of extraordinary solutions. Patient care, after all, is essentially a creative process—finding out what the actual problem is, and then imagining and creating, or co-creating with a patient, a better alternative outcome. Even in life and death situations, creativity is an essential component in deconstructing and reconstructing lives in crisis.

The creative and expressive arts have a lot to offer us in health care. Operating within a largely biomedical positivist paradigm, the human aspect of medicine is often lost. The arts and the creative processes by which they are made can offer fresh perspectives on our work not only in clinical practice but also in medical education, management, and research.

We have led workshops in creativity for health care professionals in a variety of settings, and participants agree that it can be learned and taught, and can address intractable and complex problems. Everyone has the innate capacity for intuitive thinking, the desire for a sense of possibility, and some degree of childlike curiosity. The arts give us different ways of seeing and being in complex situations, which allow new things to happen that may not initially have been considered. Theories on creative process and artwork itself can help us find new ways of working, new perspectives on and solutions to old problems, and the inspiration to move forward regardless of how difficult things may seem. This study has demonstrated that this approach is just as effective in resource-limited situations in Africa as it is in other parts of the world.

From collaborator’s e-mail to facilitator: May 2011

Taking it from chaos to music. Not perfect orderliness but music—fluidity, harmony, shifting of roles and textures, beauty, unity, support, movement, dynamics, and so on. I see and feel the notion of music continue to expand and deepen and fill in with detail.

Remembering the spirit of joy, camaraderie, support, ambition, energy, enthusiasm, empowerment, fun, freedom, and sense of achievement in that room and wanting that every day for them—for me—for us all.

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