A Staff Dialogue on a Socially Distanced Patient: Psychosocial Issues Faced by Patients, Their Families, and Caregivers

ANNEKATHRYN GOODMAN, RICHARD T. PENSON, ROBERT BLATMAN, JAMES McINTYRE, MARIE ELENA GIOIELLA, BRUCE A. CHABNER, THOMAS J. LYCH, JR.

The Kenneth B. Schwartz Center, Massachusetts General Hospital, Hematology-Oncology Department, Boston, Massachusetts, USA

Key Words. Cervical cancer · Pregnancy · Drug abuse · HIV · Caregivers · Psychosocial · Palliative care

ABSTRACT

Shortly before his death in 1995, Kenneth B. Schwartz, a cancer patient at Massachusetts General Hospital (MGH), founded The Kenneth B. Schwartz Center at MGH. The Schwartz Center is a non-profit organization dedicated to supporting and advancing compassionate health care delivery, which provides hope to the patient, support to caregivers, and encourages the healing process. The center sponsors the Schwartz Center Rounds, a monthly multidisciplinary forum where caregivers reflect on important psychosocial issues faced by patients, their families, and their caregivers, and gain insight and support from fellow staff members.

The following case of an HIV-positive woman who was diagnosed with cervical cancer during a twin pregnancy was discussed at the May, 1999 Schwartz Center Rounds. The patient was in drug rehabilitation having been dependant on crack cocaine, with a past history of syphilis and gonorrhea. She was single and her other children were in foster care. Initially she was suspicious and non-compliant. A plan was negotiated to biopsy the cervical lesion after cesarean section and with confirmation of malignancy she underwent radical surgery and subsequently radiotherapy. Despite the almost insurmountable social and educational distance between her and her caregivers, they managed to bond and facilitate care. Although there were compromises with which staff were uncomfortable, the relationship was maintained and continues. The Oncologist 1999;4:417-424

PRESENTATION OF CASE

A 32-year-old gravida 6 para 5 single woman with a twin pregnancy presented at three months gestation with a Pap smear reading of squamous cell carcinoma. On examination her cervix was replaced by a 2 cm cancer, and a 3 cm pigmented raised lesion, consistent with carcinoma-in-situ, was noted on the posterior vulva. She had a remote history of syphilis and gonorrhea and a recent history of crack cocaine abuse. She had been compliant in detoxification through her pregnancy. She was a smoker, and lived in a residential rehabilitation program. She had five prior deliveries. One child died at age two months with a diagnosis of sudden infant death syndrome. Her four other children were placed into foster care.

Her prenatal course was significant for increased vaginal bleeding and pain. She refused a biopsy of the cervical lesion and after the first evaluation, declined further pelvic examinations. An HIV test drawn at 28 weeks gestation was positive.

Correspondence: Richard T. Penson M.D., MGH Cancer Center and Hematology-Oncology, Cox Building, 100 Blossom Street, Boston, Massachusetts 02114-2617, USA. Telephone: 617-726-5857; Fax: 617-726-6974; e-mail: rpenson@partners.org

Accepted for publication September 27, 1999.©AlphaMed Press 1083-7159/99/$5.00/0

The Oncologist 1999;4:417-424
A plan was negotiated for cervical biopsy immediately post cesarean section, at 35 weeks gestation, with probable radical hysterectomy. The patient took oral zidovudine in the two weeks prior to surgery and received zidovudine i.v. with an i.v. loading dose, for 4 h preoperatively. The twin boys delivered by low transverse segment cesarean section, weighed 320 g (25th percentile) and 270 g (10th percentile) and had APGAR scores of 9 and 9. The placenta was dichorionic. They received zidovudine until three months of age. HIV tests at 48 hours and at three months were both negative.

Immediately after the delivery, examination under anesthesia revealed a much more extensive cancer measuring 5 cm with extension into the upper two-thirds of the vagina consistent with Stage IIa cervical cancer. A radical hysterectomy with upper vaginectomy, bilateral pelvic node dissection, and left salpingo-oophorectomy was performed. Shotty periaortic nodes were not biopsied.

Post-operatively she made an uncomplicated recovery. On day 6 post-operative the CD4 count was noted to be 140 with a viral load of 6,800 (viral particles/mm$^3$). The patient was begun on Bactrim for pneumocystis carinii pneumonia prophylaxis. She was encouraged to use a dilator for her foreshortened vagina. She was discharged and followed by her physicians, Social Services and Visiting Nurses.

Histologically the tumor was a poorly differentiated, large cell, non-keratinizing squamous cell carcinoma with invasion to 2.4 cm and with tumor present at the margins. Twenty two of 27 pelvic lymph nodes were involved with tumor. The high risk of local and systemic recurrence and the benefit of postoperative radiation and chemo-radiation therapy were explained. She received interrupted radiation treatments, the longest of which was an eight-day course. Radiation therapy was associated with severe perineal erythema, dysuria and constipation. This produced anorexia and noncompliance with her medications, and precipitated a short admission for hydration. Culture of ulcerated perianal lesions was positive for herpes simplex II which was treated with acyclovir. The most recent PAP smear revealed mild dysplasia consistent with human papilloma virus infection.

This complex case was presented by staff from the gynecologic-oncology and obstetrical unit. In view of the complexity of the case, and the different disciplines involved, it was presented by a panel consisting of a gynecologic-oncologist, a neonatologist, social worker, perinatologist, and a radiation oncologist.

**Dialogue**

**Gynecologic-oncologist:** Our patient whom we shall call Mary, a 32-year-old woman, was referred from her halfway house when her PAP smear showed cancer cells. When I first met Mary, she spent a long time in the waiting room. She had a hard time coming into the actual office to see me. She was very scared. She declined an examination and we just talked. She had just discovered that she was three months pregnant with twins. She agreed to come back and see me again in a few weeks and did so, at which time I was able to do an examination that confirmed a small completely confined cervical cancer. I recommended aborting her pregnancy and having a hysterectomy as the best option for cure of this cervical cancer. She strongly refused to have a biopsy. She insisted this was a very important pregnancy to her and she was willing to wait on taking care of the cancer of the cervix until after her twins were born. So that is how we started our relationship.

**Perinatologist:** The first time that I tried to meet her, she behaved in the same way. Developing courage to come here was a recurrent theme. Finally I did have the opportunity of meeting her and we were able to develop a nice rapport. She had received prenatal care at an outside institution, which had been very responsible in offering her HIV testing which she had declined and had always declined, in spite of the fact that she was at significant risk with a cervical lesion and a history of drug use. She said she was very motivated to do whatever was best for the children but there were inconsistencies in her actions. In particular, she sometimes wouldn’t show up for appointments and she declined HIV testing, which has an impact on the risk of neonatal development of HIV.

**Social worker:** Shortly after she began meeting with her perinatologist, I was introduced to Mary. I received a telephone call from the Director of the drug treatment...
program in which Mary was participating. The Director expressed concern that Mary was having a particularly hard time dealing with the fact that she had cancer and requested support for her. I initially spoke on the phone a few times with Mary, and then I made a point of trying to find her when she came to her perinatologist’s appointments, because at that time she often did not come to her gyn/onc appointments. She was highly anxious during our initial conversations and would only engage around the topic of her pregnancy. She really did not want to talk about the cancer so I slowly and gently introduced different aspects of that and gave her some basic information to read and just tried to encourage her compliance with appointments.

**Perinatologist:** The initial big question was “how to manage her pregnancy?” Whether to continue the pregnancy and then if we do continue the pregnancy, what should be the route of delivery and what should be the therapy for the cancer and at what gestational age should these things happen. What was clearly the best for the mom was to get delivered right away and to treat the cancer. That was probably not the best thing for the fetuses. The best thing for the fetuses was to stay pregnant as long as possible. Almost all the time, in obstetrics, what’s good for the mom is good for the fetus. This is one of the cases where what’s good for the fetus is clearly not good for the mom. That became clearer when the time came to deliver her. Ultimately what we decided was that we would deliver her and treat her cancer at a gestational age when the babies were likely to do well, when the fetal lungs were mature. So we chose 35 weeks as a time to deliver her.

The other issue was the HIV. She ended up having an HIV test at about 28 weeks for which she gave verbal and written consent and it was not terribly surprising when it came back positive. I think at some level that she had a great deal of suspicion that she was HIV positive. When I told her, she denied that she had ever given her consent for an HIV test. She said “one moment I’m clear and the next, I find out that I’m HIV positive.” She very much separated when she addressed these issues. I tried to frame it in a way that was as positive as you can, which is that we can take advantage of this information. I said that we can take care of you in a way that will decrease the chances the babies will develop HIV. I would say that this clinical interaction was probably the worst one that I have ever had with any patient. This seemed to be a huge fracture in my ability to connect with her and I was a little worried that she might disappear and not receive any further care. But she did come back and we promised not to overemphasize the HIV infection. Ultimately at about 33 weeks she agreed to rediscuss this issue and received a prescription for antiretroviral agents and as best as I could tell maybe even took them. So she got about two weeks of therapy. It’s important to realize that we can dramatically reduce the risk of AIDS transmission from 25% to 8% with these medicines. I felt terrible for these fetuses. This was probably the most frustrating moment in my career.

**Gynecologic-oncologist:** When someone comes in for cancer surgery, it is really important to discuss the risks and consequences of the surgery. A radical hysterectomy is a very body-altering surgery because it involves removing the uterus, cervix, and the upper third of the vagina and the tissues that surround the uterus, through which nerves which supply function to the bladder and rectum run. It is important to understand that there will be a period of time post-operatively, where they have changes in their bladder function and so forth. Now with Mary, it was very hard. First of all she missed all of her appointments with me through her pregnancy until after she had the HIV talk with her perinatologist. With that crisis, she finally came back to talk to me. We talked about the HIV issue and I forced her to talk about the surgery. She was willing to listen to the discussion that we would remove the babies by caesarean section, and finally that I would remove the cancer, and that would involve removing the uterus and the cervix, but to have a more detailed discussion, and then to start teaching her about what she was going to have to do was very hard. In all of our experience with her, there was a limit to what she was able to receive.

**Perinatologist:** She was scheduled for admission the day prior to surgery so that she would be able to get intravenous antiretroviral therapy to have a good blood level at the time of delivery. She was scheduled to come in at 3:00 and at 3:45 she still had not shown up. I had to go out of the hospital to do an errand, and I found her in
front of the hospital looking paralyzed and very little. She was too scared to come in, and she was standing there apparently for 40 to 45 minutes trying to will herself into the building. It was a really impressive moment. She went in and we did her surgery. The first part of the surgery was a cesarean section which is usually not done in the main operating room. The level of enthusiasm of the staff was great. When they take something out of somebody’s abdomen, it very rarely cries. (Laughter) So we have these two little crying babies that were quite vigorous and did very well and went up to the nursery.

Gynecologic-oncologist: Sadly, this cancer which had been a tiny little knob on her cervix back in August, had grown and was actually growing off her cervix, involving part of her vagina by February when we did her C-section and surgery. My dilemma was that usually radiation therapy is more appropriate for larger cervical cancers such as the size her tumor had grown to. I could do a slightly bigger radical hysterectomy but it would be a bigger surgery, the healing time and the consequences and the alterations of the bladder would be greater, or I could set her up for radiation and then maybe do a simpler hysterectomy later on. I decided to go ahead and do the surgery because knowing Mary and knowing how the past months had been, I was really afraid she wasn’t going to show up for her therapy with radiation. Her final pathology reports were devastatingly bad. Most of the lymph nodes had cancer and the cancer was infiltrating into the body of her pregnant uterus and growing around the babies. While the bulk of the tumor was removed, the prognosis is very, very scary and HIV disease seems to accelerate these cancers making her prognosis even worse. The next part of taking care of her was trying to talk to her about these issues while she was also dealing with issues of having to tell her family that she was HIV positive.

Neonatologist: The babies came up to the nursery and within three days they were out of the incubators and taking their feedings by bottle. She wasn’t able to breast-feed because of her HIV status. We had a lot of issues about the family members not knowing and changing the babies’ diapers and they were both getting medication four times a day and the issue with family using gloves and just having a really hard time communicating with anybody. She was also really too ill to even hold the babies or do any of their care for at least the first week.

Social worker: One of the huge moments in her care came when it became clear that she was going to have to tell her family because they were going to participate in the care of the kids which involved giving them AZT. Not only did she have cervical cancer but she had twins, a drug problem, and was also HIV positive. Her perinatologist and I did meet with her and her mom and it was one of the most poignant moments in my career and I think it was in Bob’s also when he really helped Mary find the strength and the words to tell her mother that she, in fact, was HIV positive. They both cried and her mother went over to her and just hugged her and told her that she was sorry that it had taken so long for her to tell her but that she would help her in any way that she could and they hugged and I cried and they cried. It was a very important moment in their lives together.

The question is, should we, as a team, have made a stronger effort at treating the cervical cancer earlier and at getting her HIV Radiation oncologist: I knew that it would be very difficult to have her come over to see me. So I went up to try to see her on the day she came in for her postop visit and by the time I got there she was gone. We finally tracked her down in the rain standing out here smoking a cigarette waiting for a cab. (Laughter) And that’s pretty much where I did my first consult. (Laughter) We were able to explain to her the situation and that she had a very high risk of this cancer coming back if she did not get the radiation treatments. It’s sort of a judgment call when you’re standing out there under this awning and she’s smoking this cigarette. There are people walking by and you wonder if you should actually talk to her there or bring her back in but I was afraid that I was not going to get the opportunity again. She was very afraid of the side effects of radiation such as getting her skin burnt. She did come in for the planning session but she refused to let me examine her. We often need to put these probes in to see where the vaginal apex is and the rectum and she refused to let me do any of that. She came in for her first treatment and then there was a series of excuses for the next five days about why she couldn’t come in. Mainly they revolved around her kids. She had to go out and get them diapers, or she had to go out and get medicine. I explained to her that the treatment doesn’t take that much time and that we needed her to come in. She kept coming up with the same kind of excuses and came pretty much once a week for
about four weeks. We needed CT planning which she kept missing and finally she just said “I don’t want to go through this anymore.” Then three weeks after that, her gynecologic-oncologist spoke with her and convinced her to come back for treatment.

**Gynecologic-oncologist:** This is the point at which we began to suffer the consequences of not being able to talk with her about her surgery in advance. She was having a lot of trouble with her bladder. My nurse had been working with her on that and finally things were better, but she was really angry at me about it. She thought I had done something wrong. She’s a really warm, loving person who is very, very physical and loves to hug people and I think we all really loved her and I think you can reach her through that love despite all the trust issues. I was able to reach her at that point because she came back to see me and brought somebody from the neighborhood health center who had been working with her and her kids. This person sat with us while she finally let me explain to her more about the radical hysterectomy. A few times she closed her eyes and she said “you know I’m only sitting here because I like you so much, because this is really hard to listen to, but now I understand.” She agreed to further radiation. I understand she has been able to come all week. I asked her what made her change her mind and she said “I finally said, I have to come back.”

**Facilitator:** When you keep reaching out to someone, to go where they are, rather than their coming to you, and yet you keep getting rebuffed over and over and over again, the ability to hang in there, to not take it personally, to try and realize where she is coming from, was just extraordinary. Some people just come from a different place so you take it where they start from.

**Gynecologic-oncologist:** We will always wonder whether we could have cured her if she had aborted her twins at three months. How do you deal with that and would it have made a difference? On the other hand I think that she did keep coming back to see us, and continues to, because we let her call the shots. We give advice, but ultimately we respect her autonomy and I think that if we tried a different approach she would never have come back, ever.

**Radiation oncologist:** One of the worries is of course that she may go through all this therapy, and have had this radical hysterectomy, and given the poor prognosis, she is unlikely to do well long-term. That brings back the fetal maternal conflict. The question is, should we, as a team, have made a stronger effort at treating the cervical cancer earlier and at getting her HIV tested. Maybe that would have really influenced us because waiting six months to treat a cervical cancer has a greater negative impact on someone who is HIV positive.

**Gynecologic-oncologist:** This is an opportunity for Mary to do right by her children, and that is her main motivation right now. Yesterday she sat with me in the waiting area before her radiation treatment and she said that she was thinking back on the times where DSS was at the door. She was actively using drugs and she wouldn’t let them in; and what it was like to live that kind of life. She was reflecting on what her life is like now. How she is...

---

**The patient came from a background of loss, deprivation, and drug addiction. Her ability to trust her caregivers was limited.**

Since we talk about patient care relationships here, what do we expect in return when we really reach out, really knock ourselves out for a patient and we get slapped in the face or rejected? Did you all talk among yourselves or with other colleagues and how did you manage to keep going, or did you think “OK that’s it, somebody else can handle this one”?

**Gynecologic-oncologist:** I think some people are harder to take care of but in the case of Mary, despite whatever you want to call it, noncompliance, she is truly a loving, beautiful person and her soul shines out and you try to figure out how in this incredible history, she got to a place where she was. Using drugs and God knows what else happened with her, and losing all her babies, yet you can really feel the beauty in her that shines out and I think that makes it easy, and you don’t take it personally at all. There may be other people who don’t have that shine, where it is a little bit harder to care about them.

**Social worker:** This is an opportunity for Mary to do right by her children, and that is her main motivation right now. Yesterday she sat with me in the waiting area before her radiation treatment and she said that she was thinking back on the times where DSS was at the door. She was actively using drugs and she wouldn’t let them in; and what it was like to live that kind of life. She was reflecting on what her life is like now. How she is...
actively full-time taking care of her healthy sons, and she said how she is at radiation treatments so that she can be a “mom” for them and in the right way; so it’s this huge second chance that she really is committed to following through with, which is an important gift to her.

**Radiation oncologist:** The choices are terrible: do you get to have a meaningful relationship with two children and die or do you choose not to have the children and you get to have a meaningless continued existence and then maybe still die.

**Psychiatrist:** What stands out the most is the stark terror in the work that we are introduced to every day, just to live a life. Mary’s touch with immortality resides in those two robust youngsters, and in her trying to construct a life for her own self-worth. There are certain individuals for whom an abortion is not an issue. It does not seem at all that this is where Mary was, and so her gift and the gift from her caregivers, was that she has two healthy boys that can move forward to a space that maybe Mary can’t even imagine.

**Gynecologic-oncologist:** The way she dealt with anger or not liking something was to withdraw and go away. And perhaps that goes along with drug usage. She was consciously withdrawing to a place where people could not talk to her. The anger that she had with me around the consequences to her body from a radical hysterectomy was real, but it also had to do with fear. It also had to do with not being educated because she very much wanted to not be angry with me.

**Social worker:** The other piece, in terms of my not getting angry, despite how many times I reached out and she wouldn’t cooperate is that I was always aware that each of us was seeing a piece of a very complex whole. She had a total hysterectomy at age 32; if that was her only issue, it would have been big enough. Just as the HIV was enough, but to have newborn twins and a radical hysterectomy and needing cancer treatment and HIV: I kept thinking, “I don’t think I could get out of bed” if I were her. When she left her residential drug treatment program with them about what plans they have made for the care of their children if they reach a point that they cannot care for them. Not to withdraw hope about what they are facing, because sometimes people can survive recurrences, but to realistically discuss risks. With Mary, there are tiny little kind of chinks in the armor that open up and you have to zoom in and do a little task with her before it’s all closed up again and so you can’t really do huge pieces of work with her at one time. Given that she’s coming back, and hopefully that will continue, we will be able to bring up these topics.

**In HIV infected women, cervical cancer is characterized by a more aggressive and fulminant course.**

**DISCUSSION**

This case describes the heart-wrenching complexity that both the patient and her caregivers faced in choosing treatment options. The patient came from a background of loss, deprivation, and drug addiction. Her ability to trust her caregivers was limited. She had difficulty with receiving education, giving informed consent, and complying with recommended therapy. There are many questions about how to optimally care for this patient: What is appropriate management for a woman with cervical cancer in pregnancy? What is the effect of HIV infection on the clinical course of cervical cancer? How do we breach the deep mistrust that divides her from her caregivers and mitigates against giving her the best available care?

**Cervical Cancer in Pregnancy**

Between 0.02% and 0.4% of pregnancies are complicated by invasive cervical cancer [1]. While the standard treatment for an invasive cervical cancer is radical surgery, radiation, or some combination of these modalities with chemotherapy [2, 3], another layer of decision-making is added when a woman is found to be pregnant. The dilemma of whether to abort the pregnancy or wait until fetal viability sparks profound ethical, religious, and emotional considerations. Because of concerns of progression of disease with delay, immediate therapy is offered to women in their first and early second trimester. When the pregnancy is more advanced, therapy is typically delayed until fetal viability [4]. There is controversy about whether survival differs between pregnant
and nonpregnant women with cervical cancer. One study reported an increased frequency of blood vessel invasion and macrometastases in pregnant women [5]. Overall stage for stage, survival appears to be similar [6].

Effect of HIV Infection on Cervical Cancer

In 1993, the Centers for Disease Control expanded the criteria for AIDS-defining illness to include invasive cervical cancer [7]. There are no published studies on pregnant women with both HIV infection and cervical cancer. In nonpregnant HIV-infected women with cervical cancer, the cancer was the AIDS-defining illness in 93% of these women and invasive cervical cancer was the sixth most common initial AIDS-defining illness in women with HIV infection [8]. In HIV infected women, cervical cancer is characterized by a more aggressive and fulminant course. They may present with later-stage disease than HIV negative women. The mean interval from treatment to death in one study was 9.2 months [9]. There are lower reporting rates of cervical cancer in Black and Hispanic HIV-infected women. Many factors may contribute to this underdiagnosis including limited access to health care and fragmentation of health services [10].

Trust and Autonomy

While the imagery around pregnancy and birth is among the most hopeful in our society, cancer and AIDS are associated with death. There is a deeper metaphorical level of blame, stigma, and personal unworthiness in those afflicted with HIV [11]. For those of us who work in oncology and palliative care, a tremendous effort is given to education and empowerment. Mary had lost five children and her twin pregnancy represented a rebirth for herself. The diagnoses of cervical cancer and HIV threatened to shatter her fragile rehabilitation and so she initially chose to ignore these diagnoses. It was only after delivery and her radical hysterectomy that she had to face the consequences of these illnesses. She mistrusted the healthcare providers in part because of the treatment choices they recommended. However, mistrust was also an integral and long-standing part of her lifestyle.

In the traditional patient/doctor relationship, the patient accepts the authority and guidance of their physician with little personal participation in decision-making [12]. An authoritarian approach would have failed and our patient may not have returned for treatment. We found that by being actively available, we were able to bring the patient in for treatment. Meeting each other halfway enriched both the patient and her caregivers. This case illustrates three points about intimacy in medicine, described by Barnard [13]: that intimacy in medicine frequently comes about unexpectedly, that these encounters hold enormous promise, yet, are often accompanied by fear. Because of this intimacy, the patient was able to accept treatment. The multidisciplinary teamwork presented Mary with many avenues of support. Her fears encompassed losing her new children, unacceptable changes to her body, experiencing pain, loss of autonomy, and dying. This universal terror leads to delay in diagnosis and treatment [14]. The caregivers feared making the wrong decision, being rejected by the patient, and the terrible consequences of untreated cancer and HIV. By active and open communication among staff, the team overcame the specter of personal discouragement and frustration.

There is always a delicate balance between patient autonomy and what we, as health care providers, consider to be in the patient’s best interest. However, successful compromises were a key element in this case. By giving the patient choices and accepting her decisions, she was assured that her wishes would be respected. She was able to feel valued and safe. Goals in health care include preventing, curing, caring, and collaboration [15]. Despite many obstacles, the patient delivered two healthy boys, continues to be drug free, and is actively participating in HIV and cancer therapy. The therapy, education, counseling, and support required a multidisciplinary team which shared a uniform philosophy of respect for patient autonomy.

CONCLUSION

The Schwartz Center was founded on an extraordinary relationship between caregivers and a patient, Kenneth Schwartz. Ken was a gifted lawyer and developed a very strong relationship with staff, who were to an extent, similarly privileged. However, Ken argued for the universal importance of a good patient/caregiver relationship. This case illustrates that someone with none of those privileges can still benefit from this important relationship. Trust was developed by respecting this patient’s autonomy and by actively reaching out to her.

ACKNOWLEDGMENTS

This case is a tribute to the dedicated multidisciplinary teamwork. We very much appreciate the excellent work and support of the anesthesia and nursing staff in the operating room, and the nursing staff on the postpartum unit and nursery.
REFERENCES


ADDITIONAL READING