

Kuzel AJ, Woolf SH, Gilchrist VJ, et al. Patient reports of preventable problems and harms in primary health care. *Ann Fam Med*. 2004;2:333-340.

<http://www.annfammed.org/cgi/content/full/2/4/333/DC1>

Appendix 1. Additional Illustrative Quotes Assembled by Steven H. Woolf, MD, MPH

Getting Help

VA10: We're on so many automated systems now that when you call, they ask you to, you know, punch a lot of numbers, and then by the time you get there, and you get to where they supposed to ask if it's either busy, or will be a long wait.

VA17: I think that's okay when you, when you dial a number and you're routed once or twice; when you are routed about 7 or 8 times, it is very, very frustrating ... and then you still don't get a live person on the phone.

VA17: Sometimes you can start dialing that number at 9 o'clock, and then the line is busy, and by the time you actually get to talk to somebody it may be 9:45, 10 o'clock, and then you explain the symptoms, and they say, "Well, yes, can you come in immediately?" And then, had you, you know, known that information, I mean by 9:45 I could have been at the doctor's office.

OH15: So, I'm still getting the voice mail at 10:30 that says the office hours are 9 to 5. Please call back during work hours.... So I called again around 11:30, and I got a busy signal. Then the line was busy for like an hour straight 'cause I kept hitting repeat dialing. So, then I finally got through at 1:00 in the afternoon, and I was put on hold for like 45 minutes.... And I didn't want to hang up because it had been such a difficult time getting through, so I'm just steady holding the phone.

VA15: Getting through to somebody, to a professional health care worker, was almost impossible ... you get non-health-care people answering phone calls, and I don't know if they are trying to screen them, I, I don't know, I don't know if they're busy ... they never called me back that entire day, and I had to call, end up calling them back.

OH7: Line busy, ah, you're put hold for unlimited times. Ah, once you re, once you do get someone, you could be put on hold for an unlimited, unspecified time. Um, it's hard to get a hold of the doctor most of the time. You can't speak with the doctor.... They say the doctor may call you back. It may be the next day sometimes.

OH14: I wanted the doctor to call me back. But, I never received a phone call.

OH13: And they didn't [the doctor], didn't return my call. I figured they would have her return my call. She never called back.

OH7: [Elderly patient] was having shortness of breath, ah, I needed to, I needed to speak with the physician to find out exactly what to do. Ah, I spoke with the nurse. Ah, she said that she would call me back within the half-hour. Ah, she didn't. Ah, I waited something like maybe 90 minutes and ended up, ah, taking my senior to the emergency room.

OH3: [The receptionist] was upset 'cause I wasn't paying our bill the way she wanted me to, so she didn't allow me to speak to the doctor.

OH12: My father was trying to get some medicine because he was in pain. And they were acting like they couldn't do anything for him.

OH13: They acted like they were not really interested in my problems.

OH7: I could barely move, I needed to see a doctor right away, and I couldn't get in.... I was told that the doctor was filled up, um, and that I would have to possibly go to emergency, which would entail for me seeing someone that didn't know my history, didn't know my problem, didn't know my meds.... Someone could have talked to the doctor.... I probably could have been prescribed a stronger medication. Something to at least relieve the pain until such time as I could have been seen.

OH13: I have made several phone calls to my doctor to try to get an appointment, and they make me wait almost a month to get it.

OH11: I was very sick, and this particular doctor, her staff actually told me that I couldn't get an appointment until 6 months later.

OH1: I made an appointment in October to see my OB/GYN because I was having problems at that time, and he gave me an appointment for February.... So, I made the appointment over the phone, okay, and the Monday before, the appointment was to be on a Thursday, they called me and told me the doctor would be in surgery that day and my new appointment was made in April.

OH15: I was sick for like 3 days, so I finally called the doctor's office and told them that I needed to come in, and when I called I explained to them that I was really weak, and you know I did not want to be there for an extensive period of time. So she told me to come in like 10:30. So I went there at 10:30. I sat in the waiting room until 1:00 and you know, it's just like I was already weak, and I had a temperature, and they ended up admitting me into the hospital.

Checking In

OH7: You go to the window, you knock on the window and you stand there, and you wait and there's someone sitting at the window. You knock again, no answer. When you finally do get an answer from this person that's sitting there at the window, they've got attitude. They don't use a professional manner ... talking down to you like you're a nobody. Like you're taking up their time. Like you're not a paying customer. Like you're disturbing them.

VA15: When you go in, you have somebody sitting in a glass enclosed room, and you're on the outside, and there is usually a patient next to them that they are registering, and you're supposed to stand there, in front of that patient, and in front of that receptionist, and tell them what your medical problem is. And they get very snippy if you don't tell them, just out, I'd like to see the doctor, I'm not going to discuss it with you.... So when you walk in you basically broadcast what your problems are.

VA8: Sometimes I went in there before, and there wasn't nobody sittin' at the desk; you had to wait around for somebody to come, sit down, to sign in. You sign in, but nobody, it take 'em forever to read the sign-in sheet ... I've waited anywhere from 5 to probably 15, 20 minutes.

VA25: The people who work at the front desk there are very unprofessional.

OH2: [The receptionist] was very nasty, and she didn't listen to things that you were saying.

OH5: It was just her attitude, like she didn't want to be bothered.

VA11: She is a crotchety old receptionist you have to go through, and, and she doesn't care.... I get a bad impression every time I go in there, because she is the first thing you see, and the first thing you have to deal with, and there is nothing helpful about her, nothing.

VA17: They shove a form in front of your face and ask you has anything changed, and then, or please go through it again like, you know, your dumb and stupid and you don't really understand, you know, what they mean by changes.

OH1: They treat everybody like a new patient, and that is not necessary. It's like a waste of time because they ask too many questions, but if they pull my folder, they can see everything that I have just said, everything that they have just asked me about.

OH11: I called my family doctor to set up an appointment. Then I went in that day, they didn't even have my appointment down in their book.

VA25: I would sign in and sit down, and about 5 minutes later they would call me up to the receptionist's desk and tell me I didn't have an appointment.

OH1: The appointment was made for the following day. When I got there the following day, they told me I had an appointment the day before.

The Wait

OH5: You got to wait so long just, just to get in to get your, ah, get your appointment. After you get there, ah, if you have an appointment at 12 o'clock, you might not get in there until 1:30 or 2:00.

VA10: Usually if you go first thing in the morning, there's a long line waiting just to get in, so that just about tells you what your day is gonna be like.

OH3: I guess the doctor seem like she forget about you ... so where my appointment might have been at 9:45, I might not get seen until 11:00.

VA15: I said how I saw the waiting room was full, about how long will I have to wait? Probably 45 minutes. All right, I'll do the 45 minutes. I waited 3 hours before I got back there.

VA25: When I took my son in for a visit, I stayed in the doctor's office for at least 2 to 3 hours regardless of what service he was having done.

OH6: I go see my doctor, my appointment is at 1:00, and gradually I know people are coming in, and I know people are sick, next thing you know it's 2:30 and I am still sitting next to the same people that was there before I was.

VA15: I went in, and 15 minutes after my appointment I said, "What's going on?" "The doctors are running a little late." That's obvious to me, "Could you tell me how long it's going to be?" "It'll just be a few more minutes" You know, they might have well have just patted me on the head, and you need to go sit down, you know, and I waited another 10 minutes, 15 minutes, then they brought me back to the waiting room, and at this point I've, you know, got 2 very little children, they start deteriorating for lack of a better word, you know. They were, they were getting very restless, very aggravated. I was getting very agitated so I left.

OH7: I asked the receptionist, um, how long would it be before the doctor came in? I've been sitting here quite awhile and really starting to hurt, and her reply, something I won't forget, was "either you wait or you leave..." It's like she's doing you a favor letting you sit in the doctor's office.... I'm quite sure that schooling and the doctor would have wanted her to act in her professional manner ... it would have been just so simple to be nice.

VA14: I sat in the waiting room, and, ah, 45 minutes later I hadn't been called back ..., so I went up and asked what the problem was, you know, did you forget I'm out here? And they said, no, no, we will be with you as soon as we can, the doctor's just busy today ... so finally the nurse comes out and calls my name. I go back in the room, I get all undressed, get on a gown, and I'm sitting up here on the table, and an hour goes by, and a doctor hasn't come in yet. So, at that point, I get up, I put my clothes back on, and I walk out. When I first started going there, they had a little sign hanging up in the, in the waiting room that say. "If we have not called you in 15 minutes, please come to the desk," and, you know, question it. The sign's gone now.

OH7: Then it was, wait for the doctor, they call you in, the nurse gets blood pressure, that's what she has to do, sit you in waiting room, the exam room, I'm sorry, and you wait still. You spend on average 4, 5 and a half hours seeing the doctor ... which is, which is atrocious.... You've got people sitting and waiting with scheduled appointments and a doctor not there, and a staff that won't try to explain to you what's holding him up, holding, holding him up or where he is.

VA3: And then you left sittin', in the examin' room you left sittin' there.... Oh, I've sat there for 30, 45 minutes. I've sat there longer.

VA6: I stayed in there so long, when he come in there, I was putting my clothes so I could go home.... I would have an appointment at 10 o'clock, it'd be 2 o'clock before I get out of there ... 1 o'clock.

The Visit

VA1: I felt that I was being just, uh, just a number, instead of, uh, treating me as a patient.

VA24: I just felt rushed, like everything was done quickly.

OH11: My doctor came in again, and he sat down, asked me what was wrong with me, wrote me a prescription, and left

VA2: When I go ... when I go there ... I mean it's this quick, boom boom boom. You know they've got so many people. They're running you in, they're running you out. And, you know, so, you've got to try to remember everything you need to say before your time is up.

OH6: Sometimes you don't have enough time, because he comes in there boom, and he's out, out the door ... I have to second guess myself, I have to make sure, did I have enough time to say everything that is going on with my child? He should at least take the time to find out everything instead of me, second guessing, try to think did I tell him this or did I tell him that.

VA17: Sometimes I do feel that it is a rush, you know, situation, um, you know, they walk in, or he walks in and says, "Okay, tell me what's going on." But you can just sort of sense that he's got 50 million things going on, you know ... so, um, sometimes I do feel that the, ah, you know, it is an assembly line.

VA8: Sometimes I feel like the doctor, when you finally do get into the little room where you wait on the doctor, and it, ah, I, sometimes I just think the doctor comes in and just rushes right on through it because he's got so many people waiting on him he's trying to get 'em out just as fast as possible.... I feel like he needs to take more time, to listen to him better, look at his ears better, it just seems like he's, everything goes so fast, and it's over and done with.

VA16: You hear a knock and then he comes in, he do the same thing, and he say, "Well, everything all right." And I say, "Well, how was my blood, how was my sugar that last time I was in here? Or blood?" "Oh, yeah, that's right, go get blood work before you leave today." I shouldn't have to be askin' all these things ... he cutting corners, you know, as the people say. He is not doing everything that he possibly supposed to do, or should do, he is doing just stuff to get by.

OH2: They just stay in a hurry, and they just knock it off or disregard what you are saying and just tell you give them 1 or 2 things, and that's it.... I tried to talk to the doctor, but she just flagged me off as like just give her that and that, and she was on and off on her way.

VA14: So I'm putting on a gown, he's over here helping somebody else, and I can hear them tell him, tell them the same thing: "Okay, you put on the gown, I'll be right back with you," and then he's back in my room, and in 2 minutes he has listened, that quick, to what I'm trying to tell him, and he gives me a solution.... Then he goes over there and gives them a solution to their problem....

OH1: I put [my feet] in the stirrups, and the nurse or someone tapped on the door and said, "We need you to come here for a minute," and 40 minutes later they came back.

OH2: They forgot me and they were getting ready to close up and go to lunch.

VA25: The doctor said he would go get me some samples of cream and come back, and I waited in the exam room for 20 minutes, and I went out to the front desk, and the receptionist told me that the doctor had went to lunch and he would be back in 30 minutes.

Listening

OH3: [The doctor] would just talk real fast. Sometimes I couldn't understand. Give me some medicine and send me on my way.... I said, "I don't know what you're talking about. You have to break these down for me. I don't know what's going on."

VA19: I don't have rapport with this, uh, doctor. He doesn't know me, and I don't know him. He doesn't know my family, uh, and he doesn't know my medical history.

VA22: I think a person like me who doesn't understand medical terminology or exactly what you're saying, I think for somebody, for like a doctor who is talking to a parent who doesn't know the right questions to ask, they could just be more specific, I don't know, something more close to the truth.

OH12: The doctor really wasn't listening to what I was saying, and it was like, I kinda told him what happened and he already had his mind made up about what happened, and I was trying to tell him that I didn't think that was it. I mean, I'm not a doctor or anything, but you kinda know what's going with your body.... If he had just listened more to what I had to say....

VA14: I really don't feel like he's heard what I've tried to tell him. Cause like I say, he interrupts while I'm talking to him, and he's just, you know, he says, "Oh yeah, well that's, that's normal," or he, you know, instead of just sitting and listen to me, and tell me what I've got to say, then you tell me what you think. But while I'm talking to him he's constantly interrupting me. "Oh yeah, uh huh, uh huh, I know what your talking about. And what else?" And he's kind of rushing me through to get, get me to finish what I'm trying to tell him.... I would feel more comfortable I think if I knew that he was taking enough time to hear what I'm trying to tell him.

OH14: He could have asked me more questions regarding the pain that I was having. If he didn't understand what I was saying, he could maybe gave symptoms of something else regarding chest pain and narrow down to a certain diagnosis for the chest pain, instead of saying it was indigestion, and I was telling him that it wasn't indigestion.

OH5: And I said, and I, and I, I'm thirsty and thirsty and thirsty. I mean that's all I want to do is drink and drink, and I look back at it, like, like he took to long to diagnose what was, what was wrong with me ... I mean he didn't really explain, I mean, heh, he didn't really explain what the consequences were of, I mean, of the disease that I did have ... and [the Internet] helped me more than the doctor did.

OH6: He then said, "Oh no, you are overdosing him." Well this is what you told us to do. You know, this is what, this is the exact same thing, this is the exact words you told us to give him, this amount, this amount of medicine.

OH2: The medicine do say that you should expect to gain 8 to 10 pounds once you start taking the medicine, but I had exceeded 8 to 10 pounds and was going forth more. My clothes were getting tight and everything, and I told her, and she told me it was just the clothes that I had on.

OH7: I asked another question as to, ah, the myelogram, and his reply was "This is what I just told you"; um, but it wasn't what I had asked him. Here again I'm, I'm saying he wasn't listening to what I was asking him.... He was telling me what he wanted to know, what he wanted me to know, but he wasn't answering my questions. He wasn't telling me what I wanted to know.... He feels that what he says should have been understood fully without someone asking.

VA12: I finally was at my wits' end a couple of months ago when I went in to the doctor, and [my daughter] is on the floor coughing and vomiting, and I look at him with tears in my eyes and said, "This is ridiculous. Either you're going to tell me what's wrong with her, and tell me that you can not cure it," ... and I feel like I've been a little rude to him, and I don't mean to be, and he looked at me and says, "Well Ms. [last name], I really thank you for your frankness, and I want to let you know we will continue working on this until we get it down to a diagnosis,"... but it amazed me that I had to be all but rude to the man for him to treat me like a human and look at me and do something other than, "Yeah, she's got a virus," you know. I hate that I had to go that far, and I hate that she had to be sick for 18 months before he took it seriously.

VA24: I do feel like she could have investigated it a little bit more, um, instead of just telling me to give him an enema or get him to drink more water, eat vegetables, or whatever.

OH1: I said, "Okay, but if you look in my file, it will tell you that you have to draw it from my right arm, been like that all my life." So 6 times, about 6 times she poked me in my left arm.

Referrals and Follow-Up

OH5: I said I want to see a specialist, and I said I would feel much more comfortable if I go to a specialist myself just to see me to see what the problems are, and he reluctantly done it but acted like its a, he told me

I really didn't, you know, need to, and I don't think he should never tell me what I need to do VA22: It took them about a week or 2 to call me back [to obtain a referral]. There was a certain person I had to talk to in order to get an appointment with a specialist.

VA15: So on the 8th or 9th day I called them back and I said, "Look, this is not getting better. I need to find out if you guys will get me a referral." "No, you have to come in." "But I've already been seen, and your printout says that I can get a referral, and the last time I was there I had to wait 3 hours, and I really don't think it's appropriate for me to have to wait 3 more hours, or potentially wait that long, just for somebody to say your right, we can't handle this, we'll just send you to a specialist." As a result, I said forget it. I did not go back in and have not been treated.

VA14: He, uh, had sent me, a while back, to an orthopedic doctor, and I had to get a referral to go see the doctor. So I called his office, and I said, you know, I need a referral, he wants me to go see this other doctor, and she, she said, "Okay, we'll get, we'll take care of it." Well I made the appointment, went to see the other doctor, and there was no referral there. And so they won't see me without a referral, so I have ended up sitting in their office trying to call my doctor's office to get the referral to find out the referral clerk is not there today. And I said, "Well, you know, you've known about this appointment for weeks now, you know, I should have had a referral."

VA13: The patient's are doing a lot of the leg work, you know, they are not giving you directions on how to get there, or where to go.... I don't know what, what I'm doing, or I'm not familiar with the area.

OH8: We were given the numbers to contact them, and we were never contacted from the outside,... we had to research the, you know, the facilities for ourselves

OH5: I know if I need some medicine, like if I run out, and I still have to go to the office ... bet they are after that 15 buck co-pay

OH6: The lady at the desk, she told me that, you know, I'll call [the prescription] in later today, so I went in and I went to [name of pharmacy chain] to go get it, and they said they didn't have it, and at this time it was like 8:30 ... 8:30 at night, and I called at 12.... The pharmacy closed at 9:00!

OH2: When I go back, I have to remind them for a lot of things she gave me, things to do they forgot, and I have to remind them, and they will tell me, "Let's wait till next time," and it will still never get done.

VA19: They always tell ya if there's anything of great concern, they'll get in touch with you, but I, I, it's exceedingly rare, in my experience, uh, particularly for a checkup or your annual thing, that, that they'll ever call you for anything unless you call.

VA24: I have never had anybody call to check back up on the kids.

OH11: I think that's his responsibility to call me, not me calling him to ask about my test results.... I could have been waiting for weeks

VA24: She was the one that found out that I was pregnant and did not call to let me know that I was pregnant.

OH8: I'm giving it at least maybe 2 to 3 months or so, and they still couldn't tell us what it was or what was going on.

Expressions of Emotional Injuries

VA4: You want to stay with someone that you could have some confidence in.

VA2: I don't always feel very secure about my care ... I don't have as much faith in him.

VA7: You just don't know whether that nurse is telling that doctor everything you told her.

VA7: Sometimes they look at you, or they make you feel like, um, they don't have time for you; that's the impression you get, is they don't have time for ya.

VA13: Another feeling of, you don't know what you're talking about, and let me do my job, you know, and you just accept what, you know, what we give you.

VA10: It leaves me feeling ... that I'm not cared for, that, that they don't care for me when I can't get a human voice or when I can't get someone to answer the phone, and if I try several times and I still get the same response, it just makes you feel like, you know, no one really cares.

VA14: Well, it, it sometimes it makes me feel like my problem is not really important to them ... and emotionally it just kind of makes me feel like, well, you know, we've got people that are worse than you, we'll take care of them first.... I feel like sometimes that, that patients don't really matter to them, you know. It, it's kind of like your herded through, okay I can't help you, let's send you over to this doctor.... But I didn't feel like he really cared how I felt.

VA12: That doctor's office makes you feel, I mean, almost violated. To the point where they are in all control, and, and there's nothing you can do ... you literally feel like cattle being put through the maze of the slaughter because you don't know what's at the end of the thing.... It's a frightening thing to be in the doctor's office or a hospital and not know what is going to happen to you.

OH1: It was just stressful to have to be violated by sitting in the office with kids crying, and you don't feel good already.

OH5: It was a very big disappointment to me.... For the office, it took a little bit of away from the professionalism I think that they had before ... I mean it's like your nothing ... it also hurt because, I mean, you put trust in your, in your medical, you know, provider, I mean, and then that happened.... I thought, I don't have to put up with this.

OH7: Actually I felt frustration, I felt betrayal on their part.

VA2: I started to cry.... I had fears emotionally about psychologically how I would deal with it.

VA6: The first thing you think is cancer. And you worry about that! And that was somebody's dumbness, not to take that electrode off.

OH7: Well it makes you very angry, very perturbed, ah, not knowing what to do next.... Oh, oh, both emotionally, emotionally you're very upset, ah, you become angry, irritated. Physically with me, ah, it runs my blood pressure up ... it made me blow up.... And it made me, ah, come out of character.... I said some things to her that really made her day a little worse

OH15: I wanted to make somebody feel as bad as I was feeling.

VA12: I have had the doctor make me lay down because I'm so frustrated when I get in there.

VA7: When I got home I was still mad about it.

Perceived Racism

VA13: When I called in to make an appointment with the doctor, I think that could have maybe had something to do with my race, and maybe she picked it up over the phone.

VA4: I would sit all day, and they would take all the white people first and let you be the last ones to take.... If you have appointment you got to sit there 2 hours when you get your appointment.

VA10: I don't feel that who I am should have anything to do with me being seen by a doctor, but I have seen people come in that are white, and they go right in to their doctor, and I've seen the lobby, be sittin there, and there be a whole bunch of black people sitting there, and they just be sittin there longer, and longer, and longer.

VA1: Where I came from, they didn't believe in serving us, so, uh, we had to do the best we can. And so by being here now, the time we living in now, and they don't do what they have to do, uh, I, I, I can look back at my life and things are much better than they used to be, but still there's room for improvement.

VA12: I think that might have been in terms of race, 'cause I believe that other people would have been able to get care or get more care in terms of pain.... I just didn't think that they cared about his pain because I felt like he was black. I really thought that was the reason why they did not care about how much pain he was in.... 'Cause I've heard other people, I have had other friends of other races, you know how you compare stories, and they tell me that they can get medicine regarding their problems.

VA9: When I ask him that question about tryin' to get me some kind of help in my condition, he ain't gonna do it for me, but I think he would did it for a white person.

OH5: I mean people have dignity ... and it looks like when they are trying to ask [about health insurance], like they are trying to take it away from you.

VA20: I think that they looked at him as, you know, just another little old black man, you know, that got hit in the car and doesn't have insurance ... they got so many people that are indigent or whatever that they just herd them through like cattle, and cut, to cut down on their cost or the time, then, you know, they just don't give them the care that they charge them for ... out there, going fishing, he was probably drinking beer along with the rest of the guys and everything, so they're just looking at him, you know, like a bum on the street.... I really think, you know, they looked at, you know, the person and what they thought he represented, and that, you know, really caused them not to, you know, do the type of exam that they should have to find the problem and to give him the treatment that he needed. I think if he had been of another race, maybe even another sex that he would have gotten better treatment.