

De-shaming for believability: A Grounded Theory of physicians' communication with patients about adherence to HIV medication in San Francisco and Copenhagen¹

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Abstract

To be "adherent" to a medication means to take the medicine as agreed upon. Poor adherence is the main barrier to the effectiveness of HIV medication. Communication between patient and physicians is a major factor in adherence. We found that this communication is very often awkward and superficial, if not completely lacking. According to the proposed theory, it is a core determinant of adherence communication whether or not physicians use a "de-shaming" communication strategy. When physicians do not, they receive answers with low believability, and may even abstain from exploring the possibility of non-adherence. Furthermore, physicians have difficulty in handling low believability of patient statements, and their more or less beneficial strategies may have negative consequences for the relation between patient and physician, and for the patient's adherence. The here proposed theory "de-shaming for believability" suggests that communication with patients about adherence can be understood as four steps governed mainly by three factors. The four steps are: deciding whether to ask about adherence or not, pre-questioning preparations, phrasing the question, and responding to the patient's answer. The three factors/determinants are: the communicator's perceptions of adherence, awkwardness, and believability.

Introduction

Background: HIV Treatment and Adherence

When patients take their medication as agreed upon, they are said to "have good adherence" (Osterberg & Blaschke, 2005). However, patients often have poor adherence (Osterberg & Blaschke, 2005), and especially in HIV treatment, it is one of the main causes of treatment failure (Osterberg & Blaschke, 2005; Wood, et. al, 2004; Dybul et.al., 2002). HIV treatment requires good adherence in order to maintain maximum treatment efficacy and avoid that the HIV virus mutates and becomes resistant to treatment (Osterberg & Blaschke, 2005; Wood, et. al, 2004; Dybul et.al., 2002). Still, around one fourth of patients have poor adherence to HAART (Wood et. al., 2004; Barfod et.al., 2005). Several factors are related to poor adherence, especially patient-related factors such as depression, abuse, and weak social support, but also regimen complexity, patient's lack of trust in the treatment, and poor patient-physician relations (Barfod et.al., 2005; Fogarty et. al., 2002). When looking at physician fac-

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tors, we find that experienced physicians achieve better patient adherence (Delgado et.al., 2003), and that trusting patient-physician relations (Heckman et.al., 2004; Mostashari et. al., 1998) and open communication (Schneider et. al., 2004) are associated with better adherence to HAART. In interviews, patients also stress that communication with physicians is important in maintaining adherence to HAART (Roberts, 2002) as well as other diseases (Osterberg & Blaschke, 2005; Cox et. al., 2004). Accordingly, guidelines for treating patients with HAART recommend that adherence be addressed at all follow-up visits to prevent treatment failure (Dybul et.al., 2002; Poppa et. al., 2004). The majority of physicians dealing with HIV also report that they do so (Roberts & Volberding, 1999; Gerbert et.al., 2000; Roberts, 2000; Golin et.al., 2004).

Physicians' communication with patients about adherence to HAART can, however, be problematic. In descriptive questionnaire and interview studies physicians have identified lack of time and resources, as well as their own lack of training as the main barriers to their communication with HIV-positive patients about adherence (Gerbert et.al., 2000; Roberts, 2000; Golin et.al., 2004). Furthermore, a recent systematic review has concluded that two-way discussions and partnership in treatment decisions regarding medicine-taking in general most likely seldom take place (Cox et. al., 2004). To our knowledge, no observational study exploring physicians' communication with patients about adherence to HAART has been done and no analytical theory of adherence communication has been developed.

The overall aim of this study was to observe and explore physicians' work with patients' adherence. During the study, communication emerged as a main issue. The aim of the present analysis therefore is to conceptualize and interpret the communication patterns of physicians when they discuss with patients about treatment adherence, and the difficulties physicians face during this communication and the ways they handle them. During this process we developed a proposed theory of four basic steps and three main factors/determinants of physicians' adherence communication. Since most HAART adherence studies have been done in the U.S. (Sherr, 2000), we wanted to explore the possible role of contextual factors and included a U.S. setting as well as a setting outside the U.S.

Theory

Overview of Findings and Core Category

To "de-shame for believability" means to communicate in a way that reduces the shame surrounding a subject, so that more believable responses are received. This theory claims that the degree to which physicians "de-shame for believability", and the way they do so, is crucial for the communication between patient and physician about medication adherence.

However, physicians "de-shame" not only for believability of patient responses, but also to build up a relation with the patient, who may then be more likely to comply. And the way physicians handle low believability in the communication about adherence is not only important to the "de-shaming" process, but also as general determinant of the subsequent relation between patient and physician and the personal relation between these to roles.

The theory conceptualizes the communication process as a four-step process governed by three areas of physician perceptions: adherence, awkwardness and believability. The theory

holds that physicians' individual communication patterns are not only determined by their perceptions about patients' adherence, but also by their perceptions about the awkwardness of discussing adherence with patients and by their perceptions about the believability of patients' statements on adherence. These three aspects of physician perceptions depend on the general attitudes of the physicians as well as the specific circumstances with a specific patient (e.g., when a physician suspect that a patient is non-adherent, it is a function of his or her general suspicion of non-adherence as well as the observation of specific clues in this specific patient).

This theory claims that physicians' perceptions of these three factors (adherence, awkwardness, and believability) shape their behavior through four basic steps in the adherence communication process: the decision to ask about adherence, the possible pre-questioning preparations, the phrasing of the question, and the response to the patient's answer.

The theory is further explored in the body of this paper. I first present the three perception factors and their main determinants (or "subcategories"). Then I describe the main ways that physicians act during the four steps in the communication process and how the three perception factors influence these actions. In turn, I briefly look at the consequences of these actions for the awkwardness, believability, and adherence information content of patient responses as perceived by physician and researcher.

Factor A: Adherence Perceptions

Physicians' communication with patients about adherence is – not surprisingly - strongly influenced by their perceptions about the patients' degree of adherence and the perceived importance of adherence.

Physicians determine the degree of adherence both from the treatment effect (viral load) as well as from situational factors. If the patient has a *rising* viral load, physicians will virtually uniformly be suspicious that the patient might have low adherence, especially if the viral load is rising from very low (i.e., "undetectable") levels. However, physicians' interpretations of a *stable, undetectable* viral load vary considerably, since some physicians considers this proof that the patient is sufficiently adherent, whereas others will still be very alert for poor adherence. Physicians' interpretations of the patients' situational factors also vary considerably. However, all physicians generally make an overall assessment based on the patient's lifestyle, abuse patterns, perceived personality, and timing of medication refills, and they listen to patients' statements regarding adherence.

Most physicians have the general perception that adherence is very important: "It's the most important limiting factor in treatment," (SF3) or "I do a lot, I think, around adherence issues 'cause the stakes are so high" (SF11). A few physicians, however, feel that there is no need to worry much about adherence, as long as the viral load is undetectable, and others do not worry if the patient already have multi-drug resistance and a high viral load. For example, one part of an interview went like this:

INT: Can you say more about to what degree [patients] are sufficiently adherent when they are undetectable?

DR: Well, I mean what is the goal of anti-viral therapy? I guess it's to drive the virus to undetectable ...

INT: So you don't think they could be missing enough to be at risk of developing resistance?

DR: I don't care. That's not a big worry to me – I'm not a big resistance-phobic person (SF13).

According to this theory, physicians who do not consider adherence to be an important issue tend to communicate less with patients on the subject, whereas physicians who consider it to be very important tend to communicate more about it.

Factor B: Perceived Awkwardness of Exploring Adherence

According to this theory, it is a main determinant of adherence communication, whether or not physicians perceive it to be an awkward issue. We found, that many actually feel it is an awkward subject. During interviews, physicians seldom spontaneously declared that exploring adherence was an awkward thing to do. But when physicians were asked why they had touched on the subject the way they did, perhaps only superficially or not at all, they often explained that further explorations were unnecessary and also would have been too awkward:

*Some patients can get a bit offended if you ask [about adherence]... They may feel that the trusting relationship is challenged... I remember one patient who got very defensive and said, *But you know that I have always taken the medicine, why do you now suddenly start sitting there saying things like that*" (Cph8).*

Physicians mainly perceive explorations into adherence to be too awkward if the patient has stated good adherence on previous visits:

It's the awkwardness of the repetition of the series of questions (SF7).

Physicians also perceive explorations to be awkward when there are no objective signs of non-adherence, when there are other pressing issues in the consultation, or if the physician perceives the relation with the particular patient to be difficult and fragile.

Explorations are also often considered awkward if the physician generally focus very much on showing patients respect and on avoiding creating feelings of guilt:

I think [the physician] being in loco parentis too much is not what adult [patients] are going to really be thrilled about. You're more apt to get positive results if you're trusting and a little lenient (SF13).

or

I'll rather praise people than make them feel guilty by insisting on exploring something that may not be working ideally, but which works okay (Cph15).

Exploring adherence is not perceived as awkward if the physician has a “de-shaming” communication style (see below), do not worry about the patients’ possible feelings of shame and the believability of the answer, or do not perceive the patient relation to need special nurturing.

Factor C: Believability Perceptions

Believability issues are also important during all four steps of physicians’ communication process and are determined by the specific situation as well as the physician’s general perceptions.

In the specific situation, the believability of a patient’s claims of good adherence is evaluated by physicians from their independent assessment of the patient’s degree of adherence (based on viral load and situational factors as described above), coupled with the patient’s perceived general trustworthiness and the phrasing and tone of the patient’s adherence statements. If the patient is very firm in his intonation or detailed in his description of medication intake, the patient’s answer will more often be believed. If patients disclose non-adherence, physicians usually believe this, although they may feel that the degree of non-adherence is understated.

Physicians differ in their general perceptions regarding believability. Some physicians feel that patient statements on adherence are generally believable:

I actually believe what patients tell me” (Cph1)

and physicians can even seem torn between their suspicion of poor adherence and an almost moral obligation to trust patients. Others accept low believability with ease:

It’s ... in my opinion, one of the hardest things to get a truthful answer for (SF9).

Physicians in various ways explain the underlying reasons for low believability. Low believability can be explained by the patient’s politeness or sympathy with the doctor:

Clients are very aware of what their doctors want to hear, particularly if they like their doctor (SF9),

or by the patient’s shame:

[Admitting having missed doses] is an admission of failure. And then they think the doctor finds them stupid or not serious about it” (Cph13).

Low believability of patients’ answers can also be attributed to “craziness” or unacceptable manipulation and arrogance:

I just don’t want to sit there and be ridiculed ... that they just sit and decide they know better than me” (Cph14).

Naturally, poor believability of patients' statements on adherence can also be attributed to actual lack of knowledge, i.e. poor memory or mental repression. However, these explanations seldom observed in this study.

In the following, we will explore how physicians' perceptions of adherence, awkwardness, and believability influence the way physicians handle the four steps in the communication process.

Step 1: Deciding Whether to Ask About Adherence or Not

Some physicians rarely ask about adherence, others ask only superficially, and in this study we found that only very few ask most of their patients in depth. Physicians' decision to ask or not is largely determined by their perceptions of adherence, awkwardness, and believability. In this study, patients hardly ever brought up the subject themselves.

According to this theory, physicians tend to ask about adherence if they perceive a patient's adherence to be low and they perceive adherence to be an important issue. However, in several situations, the physician will not ask at all: If physicians perceive the specific patient's adherence to be good, or if they generally do not consider it a very important issue, they often feel it is not necessary to ask, and also that it would have been awkward to do so:

The reason that I do not ask more [... about adherence] could be that it feels unnecessary. And it could perhaps seem like a silly question, sometimes (Cph1).

If the physician has very low trust in the believability of patients' statements on adherence, this may also keep him from asking:

To ask 'Do you sometimes forget to take your medication' can be used for nothing ... There are these studies we have seen, showing it is useless. It's fifty-fifty whether they answer yes or no – no matter what situation they have been in (Cph7).

On the other hand, physicians can also be led to abstain from asking about adherence if they trust the patients so much that they expect them to spontaneously tell about possible adherence problems:

I will not ask ... everybody whether they have ... forgotten a dose on a single occasion ... this of course has to do with that I generally believe ... patients' bring up their problems to surface (Cph1).

Step 2: Pre-Questioning Preparations

According to this theory, "pre-questioning communicative preparations" is of central importance to the subsequent explicit adherence communication. In general, physicians usually try to create a trusting, informal, and friendly atmosphere in the consultation room. This can be considered as a general pre-questioning communicative preparation, as one reason to do so, is to receive more believable answers from patients. Physicians often feel this "de-shame" patients and make it easier for patients to be honest, e.g., about non-adherence. In this study, many physicians were also observed to have an informal body language, to use slang and

jokes, and to chat with patients about private things, like how the patient had spent his vacation.

However, more explicit pre-questioning preparations can also be used. (Actually, this was only seldom observed in our study, as physicians usually popped adherence questions abruptly without explicit warning). According to this theory, it is only when physicians are very aware of awkwardness and the need to promote believability that they prepare patients for the question with a "warning shot," e.g. by referring to prior discussions or the results of recent blood tests. Physicians may also "de-shame" patients by generalizing adherence problems prior to asking about adherence, e.g. by saying: "Most people find it hard to remember taking the medication" (Cph8). According to this theory, pre-questioning preparations facilitate believable answers.

Step 3: Phrasing The Question

When physicians individualize questions and pick from a broad palette of question styles and question content, it facilitates elaborate answers according to this theory. However, in this study we observed that most physicians use a favorite phrase with most patients.

Question Styles. The main properties of question styles are whether the questions are broad and open or specific, and whether or not they are suggestive, and whether or not the physician is conscious about the toning of questions.

Examples of broad and open questions are "How are you doing with the medication?" (SF11) or "How is it going with taking the medication?" (SF15). In this setting of shame of awkwardness, patients' first answers to open questions are often only superficial or not about adherence. Only when physicians give very much priority to adherence, do they follow-up with questions that are more specific. Physicians focusing on adherence may also open the adherence discussion with a more specific question, e.g. about number of missed doses within a given time frame, although this question style seem more interrogative.

Questions can also contain implicit suggestions about the patients' degree of adherence. A suggestive question implying that some doses might have been missed can be, "How many doses have you missed in the last 14 days" (SF14). Such questions are mainly asked when physicians are very focused on the need to promote believability. Physicians feel such phrasing makes it less awkward for people to admit having missed doses, because "this means everybody is missing" (SF14). On the other hand, suggestive questions implying good adherence can be, "You don't have any problems taking your medication, do you?" (Cph11). This kind of phrasing is mainly used when physicians are less focused on the need to promote believability and more focused on maintaining a respectful, non-awkward communication in general. Such phrases function mainly as a reminder to the patient of the importance of adherence and less as a facilitator of in-depth dialogue on the subject.

The tone of questions is also an important aspect of the question-style. The toning influences the patient's answer, and physicians are conscious about it under circumstances where they pay attention to awkwardness and believability:

I always ask to what degree they're taking their pills and I try to do it in a low-key manner – kind of like offhand – so that my patients have an absolute sense that they can tell me everything (SF1).

Content of Questions

The main difference in the content of adherence questions is whether or not they address the quantity or the quality of the patients' adherence. Questions regarding the qualitative aspects of medication intake elicit more elaborate responses from patients.

Questions about the quantity of missed doses are common when physicians perceive adherence to be important, but are less focused on awkwardness and believability. These questions are used both to assess adherence and to remind the patient of its importance. Different degrees of specificity in number and time range are addressed, though a time range of two weeks is often used. Answers to these questions are often vague and their believability not convincing both to the physician and the observer.

Questions about the qualitative adherence-related aspects of medication intake are mainly asked when adherence is perceived to be an important but potentially awkward issue. These questions are less awkward to ask than questions about the quantity, and the answers seem more believable. Three main topics are addressed:

- Knowledge of the regime: Whether patients can describe the regime is routinely checked by some: "I want to know what they are really taking, because... so many times they are not taking what is [written] on the bottle" (SF7). These questions do bring about some discussion, although they have some aspect of interrogation, and they underscore the asymmetrical relation between physician and patient.
- Motivation for treatment and adherence: Motivation is mainly asked about by checking for side effects. Doctors very often perceive side effects to be the main motivational barrier to treatment. The patients' perceptions of positive treatment effects or their motivation for adherence is very seldom asked about.
- Behavioral patterns. Only when physicians give adherence very high priority and they are very aware of the awkwardness of the subject do they ask about the routines patients have or could develop for taking and remembering the medication, and how they handle difficult adherence situations. Patients do, however, talk more freely about these practical problems than about knowledge and quantity of missed doses. Furthermore, during their description to doctors, they do themselves become aware of new solutions.

Step 4: Responding to Patients' Answers – Handling Varying Degrees of Believability

Responses to Patients Stating Good Adherence with High Believability

When physicians perceive the believability of a statement on good adherence to be high, they briefly acknowledge the answer, perhaps with praise, a warning about the possible consequences of non-adherence, or a question about side effects. Physicians feel that a further

exploration of the patient's adherence strategies would be awkward and unnecessary in this situation.

Responses to Patients Stating Good Adherence with Low Believability

Physicians respond to patients' statements of good adherence with low believability in three ways: *Okaying*, *circumventive dialoguing*, and *confronting*.

Okaying the answer despite its low believability is mainly done when physicians think that adherence is not that important, or that further explorations would be awkward, mainly because the relation to the patient is fragile. Also, if the physicians more generally focus more on reducing awkwardness than on achieving believability they tend to be "okaying" patient statements even when they have low believability:

It was the message I wanted to send – that they can answer me whatever they want (Cph15).

Circumventive dialoguing is here defined as continuing the communication on adherence without drawing attention to the possible low believability of patient statements. One important way to do circumventive dialoguing is to address the qualitative adherence-related aspects of medication intake instead of the quantity of missed doses, e.g., by asking what time of the day the medicine was taken, whether it was taken with food, etc. Another kind of circumventive dialogue is to re-ask closed questions about occurrence of missed doses, but with altered specificity regarding the time frame or number of missed doses. This was several times observed to elicit otherwise hidden non-adherence. For example, one dialogue went like this (SF2):

Any problems with the medicine?

No.

You take them all?

Yes, the 3TC, the Viramune... and the eeh, Epivir.

Any problems taking them?

No.

You took them this morning?

No man! I did not take them this morning!

Confronting low believability covers a range of reactions from subtle signals of doubt to clear expressions of anger. For example, physicians confront patients without being aggressive by stating that the patient's rising viral load without mutations was most easily explained by low adherence. Sometimes physicians explicitly ask for honesty.

When physicians perceive low believability as unacceptable, and are less focused on the awkwardness of the subject, they may shame the patient for lying or get upset and angry, i.e., by displaying a raised voice and flushing skin.

Responses to Patients Stating Poor Adherence

Physicians virtually always believe in statements of poor adherence. Such statements make all physicians focus on adherence. However, some physicians will focus on reducing the awkwardness of topic. They tend also to talk about the qualitative aspects of medicine taking, e.g. they explore the underlying reasons for missed doses and attempt to assist with behavioral advice, and they try to strengthen motivation for adherence through neutral information. Other physicians will focus differently, instead of de-shaming the topic and the patient they will try to strengthen motivation for adherence through condemnation or shaming of the patient. The first strategy leads to more dialogue than the second, and we believe it also leads to better adherence.

Discussion

We propose a simple four-step theory of physicians' communication with patients about adherence, where the content of each step depends on the physician's perception of three things: adherence, awkwardness, and believability. The four steps involve the decision to ask, preparations for asking, the question and the response to patient's answer. To "de-shame" patients regarding poor adherence is an important, but underused strategy for facilitating communication on the subject. Therefore, physicians' communication with patients about adherence is often awkward and superficial, even when physicians try to create a friendly atmosphere. Physicians' interpretation of the believability of patients' statements on adherence is another major factor in the communication process.

The main communication patterns were similar in San Francisco and Copenhagen, although a question style implying poor adherence was mainly observed in San Francisco and the adherence discussions in San Francisco were slightly more comprehensive than in Copenhagen. To our knowledge, this is the first observational study to provide a theory of physicians' communication with patients about adherence to HAART. The main weaknesses of this kind of study are that the theory cannot be interpreted as validated fact (Glaser, 1998; Malterud, 2001; Kvale, 1996) and that the descriptive aspects cannot be generalized to other settings. San Francisco and Copenhagen are not typical HIV treatment sites, e.g., because of their high research priorities. However, the conceptual products of Grounded Theory methodology should have good a "fit" within context and can also sensitize physicians and researchers in other settings to the basic social processes discovered, although the specified processes may be less prevalent elsewhere (Glaser 1999). Thus, the findings may be relevant in non-HIV settings as well.

It is a possible source of bias that the observation itself may have made physicians focus more than usual on adherence, despite their explicit statements to the contrary (Smith & Mertens, 2004), and the observation may also have made the consultations more awkward. However, even though observations only lasted half a day to one day, there were very few indicators that the observed consultations were not "typical." Another limitation is the non-inclusion of patient's viewpoints, although our findings regarding the importance and the diffi-

culty of communication between patients and physicians are supported by many others who have interviewed patients about adherence to HAART (Roberts, 2000; Meystre-Agustoni et.al., 2000; Laws et. al., 2000; Murphy et. al., 2003; Hill et. al., 2003; Remien et. al., 2003; Goliln et. al., 2002; Westerfelt, 2004).

The aforementioned minor differences in communication patterns between physicians in San Francisco and Copenhagen may be tentatively explained by some differences in context. As compared to Copenhagen, the clinics in San Francisco had longer consultations, much less follow-up by nurses, and a patient population with more homelessness and drug abuse. San Francisco, moreover, traditionally has a strong gay grass-roots HIV movement and a political HIV commitment among physicians, possibly linking physicians there closer to their patients. There may also be a general American tendency to openly sharing feelings (Dillon, 2002). Furthermore, some eligible physicians in San Francisco did not participate, leaving a selected sample to be studied. All this may contribute to the slightly more comprehensive adherence discussions and more consciously developed communication strategies observed in San Francisco than in Copenhagen.

Previous interview studies have highlighted lack of time, resources, education, and experience as the barriers to physicians' work with patients' adherence to HAART (Roberts & Volberding, 1999; Gerbert et. al., 2000; Roberts, 2000; Golin et. al., 2004). Our study highlights communication and the crucial role of adherence perceptions, awkwardness, and believability. These aspects of social interaction are often not given much attention in standard theories about health behavior (Glanz et. al., 1997), patient communication (Silverman et. al., 1998), and adherence support (Dybul et. al., 2002; Poppa et. al., 2003).

Recent studies find that HIV+ patients seldom tell physicians about adherence problems (Meystre-Agustoni et. al., 2000; Laws et. al., 2000; Enriquesz et. al., 2004). Our study points out physicians' difficulties of doing interviewing and counseling when patients are reluctant to tell about their problems. This is supported by a study of hypertension that points to the role of physicians' question styles in receiving believable information on adherence (Steele et. al., 2004). Our findings are also in line with an interesting study, which finds that when general practitioners meet a non-adherent diabetes patients, they tend to get frustrated and adopt a paternalistic attitude and try to threaten and pressurize patients into becoming adherent (Wens et. al., 2005). A Grounded Theory study have explored how people "vague out" on issues they do not want wish to discuss with interrogators (Rizzo, 1993).

The existing theory of motivational interviewing holds that assistance in behavior change should not primarily be done by giving advice and information, but rather by assisting patients in exploring their own priorities and in developing their own strategies for solving problems (Britt et. al., 2004). In line with this, recent guidelines for counseling about adherence to HAART (Poppa et. al., 2001) and other medications (Osterberg & Blaschke, 2005) stress that physicians should develop a partnership with patients and communicate in a non-judgmental way.

These recommendations for clinical practice are supported by our findings. However, the theory of "De-shaming for Believability" also suggest these recommendations be supplemented with an enhanced focus on "de-shaming" techniques, the provision of a broadened palette of question styles, and some conscious strategies for sensibly handling low believability

of patient statements on adherence. We believe this would make physicians better equipped for supporting patients' adherence.

Future research needs to challenge or verify our findings in other settings. Patients' perceptions of the awkwardness of discussing adherence and the background for low believability also need to be further explored.

In conclusion, communication is a main difficulty in physicians' work with patients' adherence to HAART. The here proposed theory of adherence communication identifies three factors that influence how communication may proceed through four steps. This theory – and the identification of awkwardness and believability as key issues in patient-physician communication on this subject – may aid analytical thinking on adherence communication for use in clinical practice and future research.

Methodological Notes

We followed the methodology as described by Glaser (1979, 1998), but also found some practical advice in the second edition of the book by Strauss and Corbin (1998). A medical approach to qualitative research methods was honored (Malterud, 2001). Inspired by comparative anthropology (Lambert & McKeivitt, 2002; Spradley, 1980), both a U.S. and European setting was included to explore the role of contextual factors.

The author, who is a bilingual physician with training in qualitative research, did all the observations and interviews as well as the primary data analysis. Data collection and analysis were continuously checked with the co-researchers and supervisors (two physicians and one anthropologist – see acknowledgements section) and with external physicians and methodologists to validate findings and broaden the analysis by incorporating viewpoints from multiple disciplines (Malterud, 2001). The Institutional Review Board at UCSF approved the study.

Prior to the interviews, the author was familiar with the classical health behavior models (Glanz et. al., 1997), some main adherence theories (Wilson et. al., 2002; Fisher & Fisher, 1992), the basics of physician-patient communication (Silverman et. al., 1998; Britt et. al., 2004), and with guidelines for HAART adherence counseling (Dybul et. al., 2002; Stone, 2001). However, in Grounded Theory pre-formulated concepts and theories are only used to "sensitize" the researcher, as all concepts must earn their relevance through constant comparison with data (Glaser, 1998; Strauss & Corbin, 1998).

Data Sources: Settings and Physicians

We chose San Francisco and Copenhagen, as both cities may be expected to provide "state of the art" services. We included five large outpatient clinics, three in San Francisco: University of California, San Francisco (UCSF), San Francisco General Hospital (SFGH), Mission Neighborhood Health Center (MNHC); and both of the two existing clinics in Copenhagen: Rigshospitalet (RH) and Hvidovre Hospital (HH).

In San Francisco 16 out of 23 eligible physicians participated, in Copenhagen 18 out of 19. Of the seven non-participants in San Francisco, three never responded to our e-mail, three consented but were not included due to illness or time constraints, and one declined without

explanation. The non-participating physician in Copenhagen was excluded because of time constraints.

Data Collection

Interviews were used to explore how physicians understand and make sense of their own situation and behavior (Kvale, 1996), and direct observation was used to transcend physicians' own understanding (Glaser, 1998; Lambert & McKeivitt, 2002). Data were collected from December 2001 to August 2003. All physicians employed at the clinics were invited by e-mail or posted letter, and participants signed a consent form. Patients were given an information sheet, and all participating patients gave explicit verbal consent. The author observed each physician's consultations during one workday and simultaneously took notes on the physician's verbal and some non-verbal communication. To minimize intrusion and ensure confidentiality, and to facilitate participation of all physicians, we did not tape-record or film the consultations. Subsequently, a qualitative, semi-structured interview (Kvale, 1996) with the physician was done about how he or she had perceived and worked with patients' adherence that day (interview guide enclosed as Additional file 2). Physicians were asked how they had assessed and enhanced each patient's adherence, how they would explain each patient's degree of adherence, and how they recalled and interpreted their own communication with the patient about adherence. For validation, physicians were invited to comment on the researcher's noted observations and immediate interpretations, as recommended by Kvale (1996). These comments were included as further data to verify, correct, and broaden the observations and interpretations of the researcher. Interviews with physicians lasted about one hour, were audio-recorded and transcribed verbatim. The handwritten notes on observations were typed into a word-processing program within one day of the interview.

At the end of interviews, physicians were asked if they felt they had changed behavior due to the presence of the observer. Generally, physicians stated that they were used to having students observe their work and that the observer's behavior was easy-going and non-intrusive. Fourteen of the physicians stated that there was no influence from the observer, 13 stated that they had been conscious of the presence of the observer, especially at the beginning of the day, although it did not change their adherence communication, and 6 said they had probably focused a little more on adherence than they usually would. One physician's answer to this question was not recorded.

Patients and Consultations Observed

In total, 183 consultations were observed. In San Francisco, 49 consultations with patients receiving HAART were observed as well as 11 consultations with patients not currently on treatment. In Copenhagen, the corresponding numbers were 95 and 28. In San Francisco, we observed consultations with 42 men, 6 women and 1 transgender currently on HAART. In Copenhagen, the corresponding numbers were 78, 17 and 0. In San Francisco, 27 were of Caucasian origin, 22 were not. In Copenhagen, there were 77 and 18, respectively. We prioritized highly to minimize patient dropout and to allow an undisturbed interaction between patient and physician. Therefore, we only collected the directly observable data on patients, and did not ask about patients' age, mode of transmission, housing situation or drug use habits.

However, we roughly estimate that in San Francisco 60% of the included patients had been infected through homosexual practices, 15% heterosexually, and 20% through intravenous drug abuse, whereas the corresponding estimates in Copenhagen are 50%, 40% and 5%, respectively. We further estimate that roughly 20% of included patients in San Francisco were regular users of illegal drugs other than marijuana and that 10% were homeless, whereas the corresponding numbers in Copenhagen are 10% and <1%, respectively. Approximately 10% of consultations were not observed, as requested by patient or physician. Patients and physicians most often explained that this was because sexual issues were to be discussed. Only very few patients gave other explanations or no explanation.

Analysis

In the analysis, all interviews were replayed on audio and all data were re-read several times. The transcribed interviews, as well as the notes on observations, were used as data. First, a brief summary of the observations and interview with each physician was written within one day of the interview. Then, during open coding, all notes on observations and the transcribed interviews were fragmented into meaning units (a few sentences or a paragraph), which were labeled with one or more concepts or statements. Concepts were developed both from the interviewed physicians' own statements and the researcher's interpretations. During the entire coding process, analytical memos on concepts were written, concepts were re-named, units of text were recoded, and recurring themes were noted (Glaser, 1998; Strauss & Corbin, 1998). After the open coding, we narrowed our focus to the communication process and related concepts to each other during selective coding. Theoretical relations between concepts (e.g., that XX leads to YY) were developed from analysis of observations as well as from interviews. During this process, several alternative theories were developed and explored, and finally we ended up with a simple four-stage three-factor theory. For practical handling of the large amounts of conceptualized text, NVivo software was used (Version 2.0, by QSR International Pty).

Sampling was done at five different clinics in two different cities to allow for the role of contextual factors to emerge. However, as the similarities of communication patterns at the different sites were much larger than the differences, contextual factors came to play only a minor role in the final analysis.

San Francisco vs Copenhagen

We observed only very little difference between San Francisco and Copenhagen in terms of adherence communication. Average consultations were longer in San Francisco than in Copenhagen (26 vs. 16 minutes) (Table 1) and the subject of adherence was mentioned in 36 of 49 (73%) consultations in San Francisco compared to 58 of 95 (61%) in Copenhagen. Adherence discussions were slightly more comprehensive in San Francisco, where a question style implying that the patient had missed some doses of medication was mainly observed, whereas a question style implying good adherence was mainly observed in Copenhagen (described in more detail later). The atmosphere seemed less formal in San Francisco than in Copenhagen, e.g., some physicians gave patients a hug or told them about incidents from the physicians' own private lives. Since the similarities between communication patterns in San Francisco and Copenhagen were so much larger than the differences, in this paper we will not further dwell on the differences. In a similar way, physicians' age, gender, experience, and

education did not emerge as independent determinants of their communication with patients about adherence to HAART and was not a primary concern from the outset of the study.

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Competing interests

The author declares that he has no competing interests.