

Oral health from people's living with HIV/Aids perspective: contributions for dentists' continuing education

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People living with HIV/Aids (PLWHA) are vulnerable regarding oral health. Dentists' education, traditionally technical and procedure-centered, may not be sensitive to subjective demands. The objective was to understand how PLWHA deal with their oral health, in order to promote humanized and integral care. A qualitative study was carried out with 12 PLWHA adults analyzing the perception of oral health and care expectations through thematic focus groups and in-depth interviews. The discourses were categorized by the thematic content analysis method. It was observed the need for dentists' training that goes beyond techniques and guidelines, highlighting the importance of listening and dialogic relations - a fundamental action to enhance and deepen care relationships. It is expected that this article based on the Continuing Education in Health, will provide contributions to the educational actions in oral health that may fully contemplate the unique point of view of PLWHA.

Keywords: Oral health. HIV. Acquired immunodeficiency syndrome. Oral health education. Continuing education.



The role of oral health in STD / AIDS and the importance of Permanent Professional Education

One of the interfaces evidenced by the HIV epidemic is the fact that people living with HIV / AIDS (PLWHA) present specific demands for oral health care. According to Damle et al.¹ it is well known that 40 to 50% of PLWHA suffer from oral problems that are usually markers of the disease due to immune system dysfunction. Due to the deep immunosuppression, mainly CD4+ T lymphocytes, HIV infection leads to the appearance of various opportunistic infections and oral manifestations, especially candidiasis, hairy leukoplakia, Kaposi's sarcoma, periodontal diseases associated with HIV and Non-Hodgkin's lymphoma^{2,3}. Therefore, attention to oral health is recognized as one of the pillars for maintaining the general health of the individual and especially of people with a compromised immune system, subject to several opportunistic diseases in the oral cavity⁴. The importance of the role of the dental surgeon in a multidisciplinary team of PLWHA care is emphasized, and considering this context, it is essential to build a specific type of oral health care process for this population.

The survival of PLWHA has increased thanks to early diagnosis, primary / secondary prophylaxis of opportunistic diseases⁵, and especially by the introduction of highly active antiretroviral therapy, freely distributed in the Brazilian Unified Health System (SUS). Care seeks not only survival but quality of life, which has brought new challenges for health services, such as a comprehensive assistance to new demands, extensive to aspects that go beyond biological factors⁶, such as self-care, family approach, community approach and health education⁷. It is also important to highlight the need for oral health care⁶.

Even before the proposals of the National Policy of Humanization of Health (PNH)⁸, it was evident the professionals' lack of preparation to deal with the subjective dimension that every health practice supposes. In this context, it is proposed a change in the ways of caring, as devices with power for the promotion of subjective repositioning that can increase the capacity of people to understand themselves as complex and contradictory phenomena, therefore humans. It opens the possibility for the subjects "to experience what is within and beyond themselves, being able to come out, (re) inventing themselves"⁹ (p. 23). Thus, the PNH seeks a permanent process of reinvention of the subjects, health practices and their world. In problematizing the practices of the SUS worker, the PNH aims to counter the hegemonic discourse in health, potentiating and creating spaces of exchange where people with different values, knowledge, habits, desires, interests and needs find joint solutions to everyday problems⁸.

Ayres¹⁰ presents a perspective of health care stating that taking care of one's health is more than building an object and intervening on it. In order to do so, he proposes that we must consider building projects, we must maintain a certain relationship between matter and spirit - the body and mind - in order to know what is the project of happiness that is being examined, from an ethical-political perspective. Thus, the health professionals must think critically, possess competences with ethical commitments and citizenship, autonomy, ability to solve problems, reflect and transform their practice, because by relying solely on the technical skills they cannot meet the current needs of the human being. The act of caring is consolidated, first and



foremost, through the bond between the caregiver and the one being care for, through a humanistic attitude.

Considering that the present work was build in the context of the elaboration of the dissertation of Master in Education in Health Sciences - Professional Mode, at the Federal University of São Paulo - UNIFESP, a research was constructed with a proposal of intervention in the context of work, aiming at a Permanent Education (PE) process¹¹⁻¹³.

The PE was taken as a reference in order to bring significant contributions to positive changes in the way those involved in the PLWHA oral health care process understand the notion of health care and attention. It should be remembered that the proposal of Permanent Education in Health began in the 1980s, following an initiative of the Pan American Health Organization / World Health Organization (OPAS/OMS) development of human resources in health. In Brazil it was launched in 2003 as a national policy, being important for the implementation of a democratic, equitable and efficient SUS¹¹. The main idea of Permanent Education in Health is the integration between the universe of work and education with actions and collective decisions based on problematizing practices that are based on learning that is accomplished at the service environment. Its main benefit is to promote dialogic conversation, consisting of groups formed by professionals from health institutions, seeking commitment to work, strengthening teaching-service integration and preparing the professional through the development of critical, creative capacity and a proactive stance¹¹⁻¹³. Thus, it is possible to consider that the proposals of Permanent Education in Health can contribute positively to incorporate the principles of care recommended by PNH to oral health practices, especially in the context of PLWHA care.

From the clinical experience as a dentist at the STD / Aids outpatient clinic in the city of Santos, São Paulo, Brazil, a research was carried out regarding the oral health conceptions of service users' as a key issue for PLWHA due to the characteristics of their infection. Another issue observed was the difficulty presented by the dentist practitioners - traditionally known as quite objective, pragmatic and technician. This led to a reflection on the researcher's own training, confronting him with the need to question a reductionist practice of care, in a procedure-centered action that tends to deal with the patient only as a carrier of an organ-focus of care - in this case, the mouth.

In this context, it was also decided to investigate the role and relationship established with the dentist, looking at the health dyad practitioner-user of the service, considering this encounter as a way to promote an experience in which they may reformulate their paradigm by listening to what users have to say and, thus, enabling educational actions that will reverberate in the conceptions and practices of those involved.

Therefore, the objective of the research was to understand how people living with HIV / AIDS, users of a specialized service, deal with oral health in their daily lives, identifying possible contributions to positive changes for activities of permanent education of professionals with a view to increasing effective, humanized and comprehensive care.



Material and methods

A qualitative research was carried out with the purpose of valuing the universe of subjects' meanings, motives, aspirations, beliefs, values and attitudes, which correspond to the opening of a deeper space of relationships, processes and phenomena that cannot be reduced to simple operational variables, as defined by Minayo¹⁴. Several research strategies were articulated: documents' research (dental and multidisciplinary records), broad observation, focus groups, semi-structured interviews and field diary.

The research site was established based on the requirement of the Professional Master's Degree that must be developed where the Master's candidate practices as a professional, in the search for a transforming process of his practices. Therefore, the research was carried out at the Adult Specialized Care Service (SAE-adult) at the city of Santos, São Paulo. The region of Baixada Santista has a historical trajectory regarding the actions of confrontation in STD / Aids. At the end of the 1980s, the city of Santos gained prominence in the national and international press with the title of "Aids capital" because it had the highest incidence of Aids cases per 100,000 inhabitants. ASCS-adult exists since the 1990s, currently serving around 5000 users, including PLWHA and other infections, such as viral hepatitis. The unit has, in addition to the dentistry service, the services of infectious diseases specialist, nursing, psychology, social assistance, pediatrics, nutrition, gynecology, pharmacy, and hospital-day support service. The dental service is composed of three dental surgeons and three oral health aides, with infrastructure that may cover the full exercise of dentistry. The dental service has an average monthly demand of 500 consultations in which general procedures are performed, continuous monitoring of lesions and opportunistic infections of the oral cavity, besides laboratory monitoring (T-CD4 lymphocytes, viral load, blood tests) in procedures that produce bleeding.

The present research encompassed a convenience sample of 12 volunteer adult PLWHA who were invited during scheduled consultation in the dentistry service, of which ten people participated in the strategy of focus groups and two people participated in semi-structured individual interviews. This sample was due to the need for an adequate number of participants in a focus group, which is around five people, considering the conditions of the group. Regarding the criteria for selecting participants, both for the focus groups and for the semi-structured individual interviews, it was used a dental objective criterion to allow a pattern of homogeneity of experiences among the participants. With this, two groups were constructed, each composed by people with similar oral health: Group 1 formed by people with precarious oral health (PPOR); and Group 2 formed by people with adequate oral health (PAOR). This was also necessary in order to make a comparison at the time of analysis, between the two different oral health groups. Table 1 presents a summary of the information regarding age, sex, marital status, education, profession, number of children, time of HIV diagnosis, race / color criteria and type of participation in the research.



Table 1. Main sociodemographic and clinical data of the participants in the research

Participant	Age (years)	Sex	Marital Status	Schooling	Profession	Children	HIV diagnostic time ** (years)	Race/color*	Type of research participation
PPOR1	38	female	single	complete high school	salesperson	0	1	white	Focus group PPOR
PPOR2	48	male	married	incomplete elementary school	educational partner support agent	0	1	black	Focus group PPOR
PPOR3	54	male	single	complete elementary school	granite worker	0	20	brown	Focus group PPOR
PPOR4	59	female	widow	complete elementary school	housewife	4	7	brown	Focus group PPOR
PPOR5	42	female	married	complete elementary school	maid	1	14	brown	Focus group PPOR
PPOR6	66	female	single	incomplete elementary school	housewife	5	23	white	Individual Interview
PAOR1	49	male	married	incomplete higher education	manager	1	1	white	Focus group PAOR
PAOR2	42	male	widower	incomplete elementary school	motorcycle courier	0	5	brown	Focus group PAOR
PAOR3	40	male	single	complete high school	telemarketing operator	0	13	white	Focus group PAOR
PAOR4	44	female	married	complete high school	sales executive	1	19	white	Focus group PAOR
PAOR5	43	female	married	higher education	waitress	0	13	brown	Focus group PAOR
PAOR6	33	female	married	complete high school	student	0	15	white	Individual Interview

*self-reported by the participant.

** All participants are currently using antiretroviral regimen.

The choice of the participants of each group was based on the documents research (medical charts and dental records) examining the objective information regarding the oral health aspects. The criteria for composition of each group were conditions of oral hygiene, periodontal conditions and the quantification of the cavities of the research subjects, as recorded in the medical records. For the assessment of oral hygiene conditions, we used Visible Plate Index (VPI)^{15,16}. As well as the Simplified Periodontal Registry (SPR)¹⁷ to evaluate the periodontal conditions, being also the reference technical index used by the dental service where the research was carried out. Finally, in order to quantify the teeth affected by caries, the criteria of the OMS¹⁸ were applied. Therefore, the coexistence of multiple elements, such as: oral hygiene (satisfactory or not), signs of periodontal disease (presence or absence) and carious lesions (presence or absence) were evaluated for composing the groups.



Focal groups were conducted (group interview)¹⁹, allowing dialogue and interaction between individuals. The composition of the members for each group was: a moderator (responsible researcher); an observer assistant who provided support for the group and who wrote a diary of his observation (dental surgeon); the characteristics assigned by the type of group. Group 1 was composed of five PPORs and Group 2 by five PAORs, and the participants' speeches were identified with a number from one to five along with the group type acronym to facilitate the report. For example: PPOR1 is the number 1 participant of Group 1, composed of people with precarious oral health.

For each type of group, three meetings with different topics were structured, with approximately 40 minutes each, being recorded with the express authorization of the participants. The groups were conducted with thematic issues, and in the first meeting we applied a Free and Informed Consent Term. Table 2 presents the steps and thematic topics that were addressed in each of the focal group meetings.

Table 2. Guiding topics for stages and topics addressed in the focus groups

Focus group	Objectives of the meeting / work focuses	Stages and themes addressed
First meeting	Objective: To explore, with discussions, participants' perceptions, giving voice to the subjects, as well as observing the interaction between participants. Focus: to allow the participants' perceptions and opinions to be explicit about the issue of oral health, especially considering the experience of HIV / Aids seropositivity.	- Explanation about the purpose and procedures of the research. - Application of the Consent Form. - Main theme: "HIV and oral health". - Main guiding questions: conceptions about HIV; conceptions of oral health; influences of oral health on general health and vice versa; oral health and HIV infection; relation to oral health and antiretroviral medication.
Second meeting	Objective: To explore, with discussions, participants' perceptions, giving voice to the subjects, as well as observing the interaction between participants. Focus: to allow the participants' perceptions and opinions to be explicit about the importance of the teeth and gums.	- Main theme: "the importance of teeth and gums". - Main guiding questions: conceptions about teeth and gums (formation, functions, etc); importance of teeth and gums; comparisons between structures of the oral cavity with the rest of the organism; comparisons of materials for personal use with oral hygiene materials.
Third meeting	Objective: To explore, with discussions, participants' perceptions, giving voice to the subjects, as well as observing the interaction between participants. Focus: to allow the participants' perceptions and opinions to be explicit about oral hygiene in daily life.	- Main theme: "oral hygiene in daily life". - Main guiding questions: day-to-day oral hygiene (way of doing, frequency, changes in type of food); conceptions about dental caries and gingivitis; oral hygiene materials (toothbrush, toothpaste, floss, mouthwash / antiseptic); conceptions about fluoride in water.

To analyze the data, a complete transcription of participants' speeches was made by the researcher. Participants' discourses were categorized and analyzed according to Bardin's²⁰ Thematic Content Analysis.

Another research strategy was the semi-structured individual interview²¹, as a way of deepening the issues addressed in the focus groups. Two participants were selected for an individual semi-structured interview - using a convenience sample, on the occasion of their visit to the service for pre-scheduled consultation with the dentist - being one of each condition of oral health, precarious and adequate. Each interview was approximately 40 minutes long using thematic issues. The interviews



were also recorded, transcribed and analyzed according to the thematic content analysis strategy²⁰. Field journals were also composed from a wide observation activity, directly related to the research.

The focus groups and the individual interviews were conducted in the specialized service, in a separate room suitable for the purposes of the research, from December 2015 to May 2016.

All participants signed a Free and Informed Consent Term in accordance with Resolution 466/12 of the National Health Council. The Ethics Committee of UNIFESP under CAAE 49722115.4.0000.5505, technical advice # 1.290.553, approved the research project. It was also analyzed and approved by the Coordination of Training and Continuing Education in Health of the Municipal Health Department of the Municipality of Santos.

Results and discussion

The sociodemographic data of the subjects point to factors that may influence oral health, remarking the notion that emphasizes oral health as an integral and inseparable part of the general health of the individual. It is also being directly related to the conditions of food, housing, work, income, environment, transportation, leisure, freedom, access to land and possession of it, access to health services and information²².

In the present study, we considered only the oral health status of adult PLWHA for the formation of focus groups. However, it should be noted that in our study we observed that the majority of participants with poor oral health are those with lower educational level. Other data such as age, sex, race / color and occupation did not reveal relevant differences between PPOR and PAOR groups.

In this sense, our data concur with other authors such as Buchwald et al.²³ in a study carried out in Germany, which observed that the level of schooling was related to the index of dental loss, showing that low income and low level of education increased twice the risk of dental loss. Another European study analyzed the regional socioeconomic differences and concluded that in places where educational and social inequalities were higher, the tooth loss index was also higher²⁴. In Brazil, a study carried out in Minas Gerais, analyzed the association between the proportion of exodontias, socioeconomic indicators and the offer of dental services. Socioeconomic factors such as income distribution and organization of oral health services are determinants for a large part of dental mutilation in this region²⁵.

Research with thematic similar to that treated in this article are not frequent. A recent work²⁶ carried out in the city of Fortaleza (CE) evaluated variables that dental surgeons established as relevant in PLWHA care. It was observed that solidarity was indicated by two thirds of professionals as a primary factor influencing the quality of oral health care. This finding may help in the process of coping with the HIV / Aids epidemic, indicating a certain overcoming of disease-related bias and stigmatization, still present among health professionals. It remains to be seen how this expression of solidarity actually presents itself and to determine whether this aspect would have the power to interfere in the direct attention to the target subject of oral health.



The realization of the focus groups was a challenge, as there were many absences. However, the focus groups were very rich and allowed to approach the participants' conceptions about the actions taken regarding oral hygiene and self-care. Individual interviews were also a relevant strategy to address in greater depth the participants' conceptions about oral health.

One finding of this research was that, regardless of the state of oral health, several participants made references regarding their life trajectories and the experience of living with HIV / Aids, spontaneously, indicating feelings of apprehension, anguish and fear. They highlighted in emotional reports the anguish of the discovery of the HIV virus, as well as the fear of social rejection, experienced by the difficulty in talking about it with relatives and even health professionals. These elements indicate that the participants' emotional experiences (such as situations of loss, stigma and prejudice) may influence their willingness to take care of themselves and, in addition, dental professionals must be prepared to deal with this emotional context in fact, act in a caring action. We present some speeches by the participants about this:

I had to run to the doctor again because the drugs cocktail is attacking my stomach, right! And my dad did not tell the doctor I got the virus. He just told him that I'm taking it for the joints. That I have an inflammation in my joints, too! But he did not tell him I had the virus. The doctor does not know! Because if he knows! Sheesh! He's my father's acquaintance, you know? (PPOR1)

I hid it from my daughter until she was 18. She's 21 now. She took it well. And I was terrified of what she would think. It's going to be 1 year now that she got married ... I also told her husband. But the only ones who know are she, her husband, my ex-husband, my doctors, my current husband and my parents and siblings, right? I did not tell everyone. Because I'm very afraid; my emotional side is very weak. So I'm afraid of that. Of people rejecting me, understand? (PAOR4)

Comparing the speeches of both groups, Group 2 (PAOR) presented a larger recognition of the importance of oral health and a more complete and more complex notions about the issues involved in the oral health care process. However, it is important to note that Group 1 (PPOR), although it had simpler or primitive notions, seemed to have basic knowledge about oral health and the consequences of lack of care in this area. This observation led us to reflect on the effective impacts of access to information, when it is offered in a purely objective or decontextualized way. This means that patients with precarious oral health had access to information, but did not necessarily adopt practical measures towards such care, indicating that in this act of "informing" there are more complex elements meriting reflection, as seen in the following speech:

I do not know how to floss! I do not use it. I just brush, I have ... I have the mouthwash, that liquid. I just use it. I do not know how to use it! It hurts! I do not know if it's the floss. I have no patience. It's missing! Without the floss. I honestly do not know how to use this thing. I can learn it, from now on, but



I do not think so. I'll learn it ok! (laughs) (...) I'm not going to lie that I do not know how to floss! Every now and then you know what I do? I'll take a sewing thread to see if I can, to see if I learn, right! (PPOR4)

Regarding the general attitude of the participants towards the researcher, we see that they tended to maintain the assumption that it would be up to him (now identified as a dentist) to assume the function of "always": the one which "passes" the necessary objective information. We can also interpret this difficulty of speaking of themselves as an attempt to assume a passive position in relation to the health professional, thus transposing the responsibility of their health to the health professional, as in the lines of PPOR2 and PPOR4:

I really wanted you to explain what a cavity is, ok? (PPOR2)

But will not you satisfy my curiosity?" (...) "Finish, explain! You're here Mr.! not Mr., 'you'. Because you're much younger than me, so it's 'you' "(...)" When are you going to give us the answer? (PPOR4)

In this sense, we can resume the reflections of Ayres¹⁰ proposing that the care process should be a construction involving both parties, in a horizontal, responsible and respectful manner. In traditional health care there is process of strengthening vertical power relations, which has several functions (among them the attempt to preserve the power of the health professional), but which, after all, strip out the possibility of involvement from the subject being cared. In Group 1 (PPOR) there was a general attitude of the participants regarding the dental professional, quite passive and fearful that the professional will evaluate or judge their behavior. On the other hand, the Group 2 participants (PAOR) demonstrated a more active and independent posture, placing themselves in the care action regarding their oral health. The following statements illustrate this question:

Wow, I could not stand it any longer, I bleed too much (gums), I had a headache, I had a stomachache, I had it all! That's when the dentist told me, right! That the laziness was too much, it affects you a lot ... Hardly brushed at all. It really affects this part too. (PPOR4)

I do that gum massage as you said it. (PPOR1)

Then I went to a dentist and I said: Look, I'm ashamed to even open my mouth, it's horrible! Then he said: No, do not talk like that, it's not the first time ... That's when I did the treatment and took out those things that smell horrible, right! Oh, thank God I did it, right? The doctor said, they said that I have to go back every 6 months, I have to do it, or it comes back. (...) If you do not treat it, it comes back. Dependent on cleaning, a lot of hygiene in the mouth, but it comes back, right? He said that to me. (PPOR4)



But that's curious, because I've never sat down with anyone to talk about the importance of tooth brushing. (PAOR3)

Another point to be highlighted in this study was the distinction in the discourses regarding the posture adopted regarding self-care: in Group 1 (PPOR) there was a greater tendency of the participants to detach themselves from the responsibility for oral health, with greater expression of passivity, fear, and shame to be judged in their decisions (as noted above PPOR4). As for the participants in Group 2 (PAOR), there was less tendency to passivity and a greater commitment to self-care and, in addition, a more critical conception about living with HIV / Aids and patients' rights.

Another part of the research that illustrates this difficulty users have in relation to a more involved and responsible attitude in oral health care was observed in the in-depth interviews, when asked "who is responsible for their oral health?" The answers were: for the participant with adequate oral health the response was "Me, of course!" (PAOR6). For the participant with poor oral health the answer was "the dentist!" (PPOR6)

The training of dentist practitioners is a critical point in this discussion. A speech by a participant, PAOR2, points out a serious, but unfortunately still present issue on the prejudiced attitudes of a dentist:

When you go to the emergency room, when you say you have HIV, the dentist does not see you. They tell you to go see your own dentist. This is not the case, but if you are in a situation that you need it, if you say you have HIV (...) No, they do not see you! They tell you to get your dentist to see you. To look for your own dentist! (..) They're sorry but they do not see you. (PAOR2)

We found in this research that there is a stereotyped notion of what is expected of the behavior of dental health practitioners in the patients' perception, in an expectation that they will be always focused on "guiding how to proceed", restricted to oral health, without considering other elements involved in the health care action. On the other hand, given the eminently technical characteristic of the training of the majority of these health professionals (strongly based on the biomedical model), due in particular to the technical nature of dentistry itself - with its materials, procedures, norms, guidelines - act to respond to the demands of guidance, as the only form of care.

Given this scenario, it was becoming clearer that there was a difficulty on the part of the research participants in dealing with the issue of oral health from their own point of view, that is, it seemed that the participants wanted to move away from the possibility of taking responsibility about what is at stake in this area of care. On the other hand, dentists who receive in their training a less complex idea of caregiving, may not realize that this has an influence on the way the subjects listen and understand their orientations, interfering with the way the oral health becomes effective in practice.



Final considerations

The experience of this research, allowed us to observe the occurrence of a personal “opening” of the dentist to the sensitivity of the concrete experience of the subjects (as proposed by Ayres¹⁰), beyond the simple objective guidance typical of procedural-centered actions. This posture allows the construction of educational actions that look at both the subjects (patients who are health care targets) and the dentists (professionals who direct a specific care to the other).

Although the present study has limitations, especially with regard to the qualitative aspect, and its typically restricted sample characteristics, the present work has the potential to point out to the need for training (and transformation) of dental professionals, increasing and deepening the notion of care, of the idea of a supposed “practical objectivity in oral health care”. A proposal that goes beyond the technique stems from this need because, in practice, we all know that there is interference of the dentist and patient subjectivities in the oral health care process, in addition to the current guidelines.

Finally, highlighting what has been known, our findings can provide support for the elaboration of practices of permanent education committed to the type of care sought here, highlighting the importance of listening and dialogic relationships in the care process, something that goes far beyond technical aspects and objectives. In this sense, the proposal underlying this work is a rupture with the process of idealization of oral health care as well as the opening of the possibility of looking at PLWHA beyond the “mouth-organ”. Recognizing that the subjects have this organ that needs a technical intervention, but it is also necessary to allow the mouth to “speak” and, thus, from the subject’s discourse, we can assume a true position of oral health care. In this way, the report of this work intends to promote a reflection of the dental surgeons using a “beyond the mouth” approach - about the subjects and their speech - fundamental actions so that the health professionals of dentistry are able to undertake a true relationship of care.

It is hoped that, based on the proposal of Permanent Education in Health, this work may give inputs for building educational actions in oral health that contemplate what these subjects - targets of care – regarding what they need and make sense for them, considering their experiences and points of view. Finally, it may also serve as an incentive to promote this type of discussion in the professional training of dentists, given the importance and complexity of oral health care.

Authors' contributions

Gustavo Barbosa Parola was responsible for designing and delineating the work, data collection, and discussion of the results, writing of the manuscript and approval of the final version of the manuscript. Karina Franco Zihlmann research project leader, collaborator in the design of the work, analysis and discussion of data, elaboration and approval of the final version of the manuscript.

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