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The role of social support on HIV testing and treatment adherence: A qualitative study of HIV-infected refugees in southwestern Uganda

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Abstract

Little is known about the factors that encourage or discourage refugees to test for HIV, or to access and adhere to HIV care. In non-refugee populations, social support has been shown to influence HIV testing and utilization of services. The present study enrolled HIV-infected refugees on anti-retroviral therapy (ART) in Uganda, who participated in qualitative interviews on HIV testing, treatment, and adherence. Interviews were analyzed for themes about four types of social support: emotional, informational, instrumental and appraisal support. A total of 61 interviews were analyzed. Four roles for these types of social support were identified: (1) informational support encouraged refugees to test for HIV; (2) emotional support helped refugees cope with a diagnosis of HIV; (3) instrumental support facilitated adherence to ART and (4) after diagnosis, HIV-infected refugees provided informational and emotional support to encourage other refugees to test for HIV. These results suggest that social support influences HIV testing and treatment among refugees. Future interventions should capitalize on social support within a refugee settlement to facilitate testing and treatment.

Keywords

HIV; AIDS; social support; refugee; Uganda

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Disclosure statement

The authors have no conflicts of interest to disclose

Introduction

In 2012, 25 of the estimated 35.3 million people with HIV worldwide lived in Sub-Saharan Africa (UN Joint programme on HIV/AIDS (UNAIDS), 2013), a region that is also home to a quarter of the world's refugees (United Nations High Commission for Refugees (UNHCR), 2013b). Given the extent of the epidemic, considerable attention has been paid to methods to reduce transmission, increase testing, and promote adherence to HIV anti-retroviral therapy (ART) in this region, including in refugee settings. Although these efforts have resulted in increased access to testing and ART (UNAIDS 2012, 2013), the uptake of services is not well characterized, particularly for refugees. Little is known about the factors that encourage and discourage testing, linkage to care, and adherence in refugee populations.

Previous research targeting social influences on the uptake of HIV testing and treatment in sub-Saharan Africa has emphasized the impacts of social support and stigma on health and health behaviors. Stigma has been associated with social isolation (Takada et al., 2014), serostatus non-disclosure (Tsai et al., 2013), high risk sexual behavior (Siedner et al., 2014), depression (Tsai et al., 2012), and non-adherence to HIV treatment (Katz et al., 2013).

Social support is known to mitigate stigma (Takada et al., 2014) and influence HIV testing and treatment. Individuals are more likely to refuse testing if they live in communities with high refusal rates (Kranzer et al., 2008), while positive social support and social networks beneficially affect HIV testing (Denison, McCauley, Dunnett-Dagg, Lungu, & Sweat, 2008; White et al., 2013). Social support promotes adherence to treatment (Kamau, Olsen, Zipp, & Clark, 2012; Katz et al., 2013; Nachega et al., 2006; Ware et al., 2009), while lack of social support has been linked to late stage HIV presentation and poor adherence (Drain et al., 2013; Katz et al., 2013). A recent systematic review identified both positive and negative social influences on testing: psychosocial and economic support facilitated testing, while fear of stigma, marital mistrust, blame, or loss of social contacts detracted from testing (Musheke et al., 2013).

While there is a relative abundance of data on how social support influences HIV testing in general population samples, less is known about the role of social support among refugee populations. Refugees displaced by conflict are uniquely vulnerable to economic, medical, and social hardships. Normal social networks are disrupted by war and displacement (Muhwezi et al., 2011; Roberts et al., 2009; UNAIDS & UNHCR 2007; Wood, 2008), and can be re-formed and re-broken as multiple traumas and displacements affect a population. Changes in social structure and support increase vulnerability to mental health problems, sexual violence, and sexual exploitation (Muhwezi et al., 2011; Spiegel, 2004; UNHCR 2013a; UNHCR 1999).

The relationship between displacement and HIV risk is complex. Some have suggested that displacement increases vulnerability to HIV as economic pressures result in transactional sex, social norms break down, and refugees move to areas with higher HIV prevalence (Muhwezi et al., 2011; Spiegel, 2004). However, data show that refugees do not have a higher prevalence of HIV (Spiegel et al., 2007) or engage in more high-risk behavior than the surrounding communities (Dahab, Spiegel, Njogu, & Schilperoord, 2013). Treatment

adherence rates among displaced populations are high and mirror those of non-displaced populations (Kiboneka et al., 2009; Mendelsohn, Schilperoord, Spiegel, & Ross, 2012; Mills, Ford, Singh, & Eyawo, 2009). Although limited refugee studies suggest social support facilitates treatment adherence (Mendelsohn et al., 2014; Wilhelm-Solomon, 2009), much remains unknown about how social support influences HIV testing and adherence among refugees. Without better understanding of these influences, it is unclear if social support based interventions used in non-refugee populations should also be implemented in refugee settlements.

This paper explores these questions using qualitative interviews on HIV testing and treatment adherence among refugees on ART. The data are drawn from a broader study of HIV testing, adherence, and perceptions among refugees, conducted at the Nakivale Health Center operated by Deutsche Gesellschaft für Internationale Zusammenarbeit (GIZ) (now operated by Medical Teams International) in Nakivale Refugee Settlement in southwestern Uganda. On initial review of the data, themes of social support repeatedly emerged from the refugees' narratives. The objective of this paper was to use these existing data to evaluate and classify social support and its role in influence testing and adherence among refugees.

Methods

Setting

The study was conducted at the GIZ clinic in Nakivale refugee settlement from March to July 2011. Founded in 1958, Nakivale settlement spans 158 square kilometers in Southwestern Uganda. At the time of the study, approximately 56,000 refugees lived in the settlement, 57% of who were from the Democratic Republic of the Congo, 22% from Rwanda, 13% from Somalia, and 6% from Burundi. The remaining 2% were from Eritrea, Ethiopia, Sudan, Kenya, and Liberia (UNHCR 2009).

The population of Nakivale is served by four health centers, one of which is the Nakivale Health Center, run by GIZ during the study period. At this time, this health center was the primary provider of HIV screening and ART distribution in Nakivale. Patients were tested if they requested an HIV test or presented with signs and symptoms that led a clinician to refer them for a test. Though broader data on the prevalence of HIV/AIDS in the Nakivale settlement during the study period are not available, a subsequent study showed a prevalence of 3.3–4.5% (O'Laughlin et al., 2014). Prevalence rates in the refugees' countries of origin range from 1.1–6.3% (UNAIDS 2010). At the time of the study, 659 patients (83 of who were on ART) were enrolled in HIV care at the Nakivale Health Center clinic.

Sampling and recruitment

Participants were eligible for the study if they were: (1) receiving ART from the GIZ HIV/AIDS Clinic in Nakivale during the study period, (2) 18 years of age or older and (3) willing and able to give informed consent. Participation was voluntary. Patients who came for clinic appointments during the study period were approached to participate.

Study methods were approved by the Partners Human Research Committee (Boston, Massachusetts, United States of America). Consistent with local guidelines we also received

ethics approval from the Ugandan National Council of Science and Technology (Kampala, Uganda) and study approval from the Research Secretariat in the Office of the President (Uganda). All participants gave written informed consent in English, Kiswahili or Kinyarwanda. If there were cultural literacy reasons why a signature was not appropriate, a participant could sign the informed consent document with an 'x' or other non-identifying mark. Participants did not receive any compensation for participation in the study.

Data collection

Data were collected through semi-structured qualitative interviews. Interviews were conducted by a single local research assistant fluent in Kiswahili, Kinyarwanda, and English. The majority of clinic patients and all study participants spoke one of these four languages. The research assistant, himself a refugee from the Democratic Republic of the Congo, had prior public health training and experience with qualitative research methods. He underwent further training in qualitative data collection techniques by experienced researchers prior to the start of the interviews.

Interviews were conducted individually in a private room using an open-ended approach in which an interview guide was used to cover core topics. This method allowed unanticipated topics to surface while providing consistency in the interview process. Interviews covered the patients' experiences accessing HIV testing and care, attending the clinic, and adhering to treatment, as well as their opinions on how testing and care could be improved. Patients were not specifically asked about social support. Interviews were conducted in the language preferred by the interviewee. Interviews were audio taped with permission and later transcribed directly into English by the same research assistant as 'stream-lined' transcripts, which included verbatim accounts of interviewer questions and interviewee responses while eliminating repetition phrases and hesitations. Translations were not independently verified.

Data analysis

Inductive analysis guided by a modified grounded theory approach was used to assess categories of social support and develop a conceptual framework to understand the influence of social support on utilization of HIV-related services (Glaser, 1967; A. Strauss, 1987; A Strauss & Corbin, 1998). The analysis focused on devising a framework to explain the data, but did not aim to offer a final explanatory theory. Interview content related to social support was retrieved from the data and grouped by content similarity by two reviewers. Discrepancies were resolved through discussion. Descriptive categories reflecting examples and themes of social support across multiple respondents were organized to describe the influences of social support on patients accessing HIV testing and treatment in the refugee settlement.

The categories that emerged fit within an existing framework of four commonly acknowledged types of social support: emotional support, informational support, instrumental support, and appraisal support (Cohen & McKay, 1984; House, 1981). As elaborated by this existing framework, emotional support was defined as the conveyance of love, caring, trust and acceptance (Cohen & McKay, 1984; House, 1981). Informational support was information that helped solve problems and explain circumstances, such as

advice and suggestions (Berkman & Glass, 2000; House, 1981). Instrumental support was tangible, and involved the donation of goods and services (House, 1981). Appraisal support involved assistance with self-evaluation (Berkman & Glass, 2000; House, 1981). The responses and descriptive categories from the data were reviewed and reorganized to fit into this framework. The theme of appraisal support did not emerge in the interviews. Finally, the data were classified into conceptual categories of social support that the participant received from others (informational support, emotional support, and instrumental support) versus social support the participant offered to others. Each type of social support identified was described and illustrated with direct quotations from the interviews. The classifications were revisited during multiple returns to the data to identify additional sections of relevant text. Through this process, a conceptual framework depicting the effect of social support on HIV testing and treatment in the Nakivale refugee settlement was developed.

Results

At the start of data collection, 83 patients were receiving ART from the GIZ Clinic. By the conclusion of the study five months later, this number had risen to 215. Seventy-three patients were approached to enter the study; all agreed and were interviewed. Twelve interviews were lost when an encrypted laptop was stolen, resulting in a final data set with interviews from 61 patients. Fifty-nine records consisted of complete transcripts produced from audio recordings, and two consisted of write-ups of notes from interviews where the interviewee declined audio recording. The average interview length was 50 minutes long.

Patient demographics

The majority of patients were female (59%, n=36). The average participant was 40 years old and had lived in Nakivale for nine years. The majority originated from Rwanda (74%, n=45), followed by the Democratic Republic of Congo (18%, n=11) and Burundi (7%, n=4). The majority of participants, 82% (n=50), were Christian, and 16% (n=10) were Muslim. Most participants were married (64%, n=39), with the remainder widowed (23%, n=14), divorced (11%, n=7), or single (<2%, n=1). Most patients (82%, n=50) reported testing for HIV while displaced in Uganda, nine (15%) reported testing in their home country, and the remaining two (3%) in other countries outside of their home country.

Social support, HIV testing, and treatment adherence

During the interviews, four themes emerged demonstrating how social support affected HIV testing and treatment in the refugee setting: 1) informational support encouraged refugees to test for HIV; 2) emotional support helped refugees cope after receiving an HIV diagnosis; 3) instrumental support facilitated adherence to ART; and 4) once diagnosed with HIV, HIV-infected refugees themselves provided informational and emotional support to encourage other refugees to test.

Informational support to guide HIV testing

Informational support facilitated HIV testing through direct and indirect mechanisms. Direct informational support was demonstrated when social contacts provided information on the

refugee's health, the behavior or health of their partner, or on HIV and its treatment. Indirect informational support occurred when a refugee observed others in the community.

Direct informational support often came from family and friends. Some chronically ill patients tested after friends advised them that HIV could be the reason for their illness. 'I used to be sickly and go for malaria treatment but people used to advise me to go for [the] HIV test' [female, age 55], one patient explained. Several refugees changed their perception about the potential causes of their illness after social contacts encouraged them to test: 'I first thought that I was bewitched but later my friend advised me to go for HIV testing, suspecting that I was infected.' [female, age 35]. Although many refugees were ill at the time of their initial diagnosis, illness was not required for friends to encourage testing. A study participant described how an HIV-infected friend 'advised me to also test with an argument that I may wish to marry, so I needed to know my status' [male, age 71].

Some refugees decided to test after knowledge they gained from social contacts changed their beliefs about the implications of a positive test and available treatments. This newly imparted knowledge created a perceived benefit for testing:

A certain lady (a neighbor) whose name is [woman's name] told me that since you are always aborting, it would be better if you went for testing. Then I told her, listen if I go for testing and they tell me that I am sick and yet I am alone with these children of mine, shall I survive? Then she told me, look, you will not be the only one. There are others who tested and found that they were sick. They are taking their drugs, and they are fine [female, age 35].

Knowledge received from social contacts was not limited to medical information. Some refugees tested when they were informed of the behavior or health of their spouses, partners, or prior assailants. One refugee tested after 'people told me that I am sick because there was a man who raped me when I was sick and that man was HIV positive, and he died' [female, age 32]. Another described testing after 'people used to tell me that I married an infected man' [female, age 24].

For some refugees, informational support was indirect in that it did not require a conversation with others. Refugees described how knowing infected individuals or witnessing others test encouraged them to obtain a test. As one described: 'one time when I went to the main hospital...I saw others testing for HIV and thought of testing' [female, age 35]. Another explained that 'because I had friends who were already infected...I thought of going for HIV testing' [male, age 30].

Emotional support to cope with a new diagnosis of HIV

After their initial HIV diagnosis, many refugees spoke of their fear for themselves and their families. Emotional support, particularly acceptance and encouragement, helped refugees overcome these fears to proceed with treatment. Some refugees cited counselors, particularly those who were also HIV-infected, as important people who helped them overcome their fears. Others drew on family support. One refugee stated that, after her diagnosis, 'I thought I was going to die...[but] my husband is an educated person, he had been counseled and... finally got [me] to understand that I was not going to die' [female, age 31]. Another

described how her initial fear was replaced with hope ‘because people who were also sick tried their level best to comfort me, then I discovered I was not alone’ [female, age 47]. For one refugee, the combination of informational and emotional support provided by his friends changed his outlook on the disease:

After [my diagnosis], I got discouraged and whenever I could meet with my friends I could tell them that I was infected. Then they could also encourage me giving me examples of other infected people who are rich, healthy and strong and telling me to continue praying. I started going to those people and asked them if they were really infected. They told me that it was true and that if I could take drugs as directed, I could get no problem [male, age 30].

Not all support was verbal or direct. Sometimes visualizing others living with HIV helped refugees cope. One recounted, ‘I was terrified and thought of how I would live with the virus. But I encouraged myself when I could see all these people getting treatment’ [female, age 45].

Instrumental support to adhere to treatment

Instrumental support in the form of goods or services facilitated adherence by helping patients take or pick up their medications, as well as by alleviating daily tasks to allow patients to attend clinic. Individuals commonly described friends or family who helped them remember to take their medications. One patient described how his wife improved his adherence because ‘when I forget, she always asks me, have you taken your drugs? And so I take them’ [male, age 50].

Refugees on ART at the Nakivale clinic typically have an associated treatment partner who can pick up their medications if they are unable to go to clinic. Many people described this person as serving an important role in supporting their adherence. Sometimes, individuals other than the designated treatment partner also fulfilled this role. One refugee described her child as her treatment partner, but then indicated that ‘Sometimes when I become very sick, my neighbors can also go and take [pick up] them [medications] for me without any problem’ [female, age 39].

Receipt of material goods as instrumental support to facilitate adherence was rarely described. However, indirect support or support of tasks was commonly listed as beneficial. One refugee stated that ‘there were some women who were my neighbors who...would cater for some of my needs’ [female, age 39]. Others described how instrumental support helped assist with necessary tasks so that patients could attend the clinic. As one refugee described: ‘Even my neighbors know [I am] sick. For example, when I am not at home on Thursday my neighbors know that I have gone to pick my drugs and take care of my animals.’ [male, age 47]

Providing informational and emotional support to others

Distinct from the social support they received from others, study participants also described the ways they themselves provided social support to other community members. Participants gave informational support to their social contacts by educating them about HIV. In addition,

participants provided emotional support to their social contacts by encouraging them to test and by accompanying them to the testing site. Participants did not describe offering instrumental support to others.

When asked how they felt other refugees could be encouraged to test, the HIV-infected participants in our study described common themes of encouraging by example and offering social support. While occasional respondents indicated that no one else knew about their diagnosis, most had disclosed their status and embraced their role in encouraging others to test. One refugee explained:

Us who are known to be HIV-positive, we became like HIV signposts. People come to us and ask us what they can do to get tested, and then we could give them directives and even take them to the clinic and they...get tested happily [female, age 35].

Just as many refugees reported they had been encouraged to get tested by friends who had become ill, some reported providing similar informational support to their own social contacts. 'When I meet another person who is sickly like the way I was, I tell him/her to go for testing and get help.' [female, age 54] Another described: 'when we see people with symptoms, we always ask them if they have ever been tested and if they say no, we advise them to go for HIV testing' [female, age 31].

Other participants encouraged testing regardless of a person's health status. One person explained that those 'like me who [have] already been tested, can advise my friends telling them the advantages of being tested and that very many people died because of ignorance' [female, age 35]. One refugee described the obligation to help others in the community by saying:

You see when you have a domestic animal you must check on it every day to see how it is doing. If it is suffering from ticks, you treat it. If it needs fire you make [fire] for [the animal]. That is how you are supposed to care for your own life. So you need to encourage your friends...if he tells you that he has had diarrhea for a week, you should ask him whether he has tested. If not, then you ask him to come with you on Thursday and show him the direction to follow [female, age 47].

Multiple participants explained how improvements in their own health served as an example that encouraged others to access care. 'When they see what we are doing like seeing us digging and doing other things [people who are healthy do], they have started coming willingly' [male, age 55]. Another explained:

When other people come to me, I teach them by narrating my experience with HIV to them. Many people don't even believe that I'm infected even when I tell them because they see me digging and playing football until I show them the records [female, age 35].

Discussion

Displaced from their native land, refugees are sometimes described as having fractured social connections, including disrupted social structures, broken social norms, and isolation

from traditional communities (Muhwezi et al., 2011; Roberts et al., 2009; UNAIDS & UNHCR 2007). Given this context, it was not clear prior to our study whether the benefits of social support observed in non-refugee populations would also be seen among refugees. Our data indicate that, for refugees in Nakivale on ART, social support has a profound influence on HIV testing and adherence to medications. In our study population, informational support encouraged refugees to test for HIV and thus access care. Emotional support helped patients cope with an HIV diagnosis, and instrumental support helped them adhere to HIV treatment. Additionally, patients felt they could encourage testing by providing informational and emotional support to others. Taken together, our findings suggest that, in Nakivale, social support among refugees plays a similar role in determining HIV testing and treatment adherence compared to non-refugee populations. This similarity does not diminish the importance of these findings but rather suggests an opportunity to explore how social support interventions successful in other settings can be modified to the refugee context.

In this study, informational support encouraged patients to test, and the patients in turn offered similar support to encourage others to test. There are similar data from non-refugee communities, where HIV-infected individuals have been shown to engage in high rates of prevention advocacy within their social networks (Ssali, Wagner, Tumwine, Nannungi, & Green, 2012). Similarly, peer-driven educational campaigns have successfully encouraged testing in non-refugee populations (Lau, Tsui, & Lau, 2012) and have identified a higher prevalence of HIV-infected patients compared to general testing strategies (Kimbrough et al., 2009). It has been suggested that when providers can personalize the risks of HIV, uptake of testing is improved (Obermeyer & Osborn, 2007). The results of our study suggest that HIV-infected refugees might also encourage testing uptake by making it more salient and acceptable to their social contacts. Better data on social support among refugees are needed to justify whether interventions similar to those in non-refugee settings can be effectively implemented within refugee settlements to leverage existing social support.

Beyond testing behavior, the observation that emotional support helped refugees cope with their diagnosis is consistent with findings in non-refugee settings that emotional support was one of the drivers for early disclosure (Winchester et al., 2013). This similarity suggests future work should evaluate the utility of social support interventions used in non-refugee populations within the refugee context. Further, interventions capitalizing on social support to promote adherence in non-refugee settings have begun to take hold and should be considered in refugee settings. Treatment partners have been shown to combat stigma, increase hope, and reduce social exclusion (O'Laughlin, Wyatt, Kaaya, Bangsberg, & Ware, 2012). Peer-led treatment groups have been suggested to increase adherence and promote social support (Decroo et al., 2011). Treatment supporters offer social support to promote adherence and have been used in both high and low resource settings, albeit with mixed results (Scanlon & Vreeman, 2013). The social influences observed in our study suggest a possible role for both individual and community supports in the refugee setting. However, unique challenges to these methods in the refugee setting have been described (Mendelsohn et al., 2014), emphasizing the need for further study of how these methods can best be adapted to the refugee context prior to implementation.

Interestingly, little of the instrumental support described in this study was monetary or in the form of goods. This finding contrasts with data from non-refugee settings in which persons with HIV were observed to rely heavily on instrumental support (Cummings et al., 2014), particularly in attempting to successfully adhere to HIV treatment (Ware et al., 2009). This difference may be due to the significant poverty found within the refugee settlement and should be explored in future studies. The instrumental support described in this study frequently involved assistance with tasks, which would have allowed patients to set aside the daily survival burden to proceed with testing or treatment, as has been previously described (O’Laughlin, Rouhani, Faustin, & Ware, 2013). Future work should explore how this assistance interacts with informational and emotional support, to maximize the impact of potential interventions.

It should be considered that the relationship between social support and displacement did not emerge from the interviews in this study. In addition, most participants were from one ethnic group and had lived in Nakivale for nine years, which may have affected both their experiences of displacement and the social support they felt. We cannot draw conclusions on how displacement influenced the social support seen in this population, or how social support may change with duration of displacement. This information will be important to inform future interventions relating to social support and should be explored in future research.

Limitations

The results of this study must be interpreted within the context of the study design. As a qualitative study, the objective of the analysis is to describe findings within the study sample, rather than draw definitive conclusions. Further, interpretation of our findings is subject to seven important limitations. First, this study was conducted in one refugee settlement in Uganda among refugees on ART. Refugees not yet in care or in other stages of care (for example, pre-ART) may be affected differently by social influences. Similarly, there may be differences in social influences depending on duration of treatment, which was not examined in this study. Second, in this study the average duration of residence in the camp was nine years. Although well below the average 17 years of displacement for ‘major refugee situations’ (UNHCR 2004), the social influences seen here may not be generalizable to short-term refugee situations. Third, all interviews were conducted by one male Congolese research assistant fluent in the languages spoken by participants. Given complex cultural considerations and gender dynamics, this may have influenced the degree to which people spoke freely. Fourth, the interviews were not structured to formally examine the roles of social support, so it is possible more details could have emerged had the interviews been designed to probe for information about specific social ties and pathways of informational and material flows. Similarly, this study cannot determine how social support relates to an individual’s experiences of displacement. This should be explored in future studies. Fifth, the majority of respondents in our study were Rwandese, which may have influenced bonding and social ties. The degree to which social influences cross ethnic lines and/or vary by ethnicity could not be determined. Sixth, although the informed consent process specified that a patient’s medical care would not be influenced by their participation and/or responses, responses may have been biased given that the study was conducted at the clinic. Finally, the

social influences noted by the study participants were primarily positive. This could reflect the nature of social support for most refugees, or it could have been a result of the study population, made of patients on ART. It is possible that positive social interactions encourage people to access care, in turn making individuals with positive social support more likely to be on ART and eligible for our study. However, the potential negative aspects of social support are well known (Antonucci, Akiyama, & Lansford, 1998; Coyne & DeLongis, 1986; Rook, 1984) and in some cases can worsen HIV-related stigma (Takada et al., 2014). The distinctions between positive and negative social support among refugees warrant further analysis in future studies.

Conclusion

In conclusion, this study demonstrates the important role of social support on HIV testing, coping after diagnosis, and adherence to treatment among refugees in Nakivale on ART. In addition, it provides evidence that refugees on ART recognize their own influence on the testing behavior of others in the community. Future studies should explore the social networks among refugees, the extent of social influence, and the degree to which social support is influenced by displacement and/or crosses cultural and ethnic lines. Interventions should capitalize on these community interactions to encourage testing and treatment adherence in refugee populations.

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