Survey among survivors of the 1995 Ebola epidemic in Kikwit, Democratic Republic of Congo: their feelings and experiences

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Summary

This study describes experiences of the survivors of the 1995 Ebola epidemic in Kikwit, Democratic Republic of Congo. Most of the survivors in our sample had cared for a sick family member before becoming ill themselves, and most had never heard of Ebola before they developed symptoms and therefore did not suspect that they were infected by the virus. Fear, denial and shame were their principal initial feelings. After release from hospital, survivors were abandoned by family or friends more often than they had expected. Belief in god was an important aid to all of them. Their most negative experiences were witnessing other people dying in the isolation ward of the Kikwit General Hospital, and the reluctance of hospital personnel to treat them. During Ebola outbreaks more attention should be given to the psychosocial implications of such an epidemic. Information campaigns should include antidiscrimination messages and more psychosocial support should be given to patients and their families.

keywords Ebola, survivors, Kikwit, Democratic Republic of Congo

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Introduction

Between January and June 1995 an Ebola epidemic occurred in the city of Kikwit and surrounding villages in the Bandundu province of Democratic Republic of Congo, Central Africa. In January 1995 a charcoal worker in Kikwit died of Ebola, as did several family members 2–3 weeks later who had become infected during the burial rituals. For several months Ebola cases remained undiagnosed. Initially patients with haemorrhagic diarrhoea were considered to have Shigella infection.

In April 1995 the epidemic increased because of a nosocomial Ebola outbreak after surgery on an infected laboratory technician at Kikwit General Hospital (Muyembe & Kipasa 1995). About one week later, several members of the surgical team and other health care personnel involved in the care of the laboratory technician fell ill. Most of them died within two weeks.

News of the health care workers’ death at Kikwit General Hospital spread rapidly among patients, hospital staff and the population of Kikwit. This created great panic and mistrust in the hospital, and almost all patients left. Some sought care at other hospitals, others returned to their villages. Health care staff also left their posts. Only a few very sick patients and some voluntary carers remained in the hospital.

On May 3rd an isolation ward (Pavilion 3) was established at Kikwit General Hospital. Initially there was very little protective equipment for health workers, therefore only very limited care was offered. At first family members were not allowed to visit patients. On May 10th the diagnosis of Ebola infection was confirmed by the Centers for Disease Control in Atlanta.

On May 11th 1995 an international scientific and technical committee was established to help control the Ebola epidemic. One of the first actions of this committee was to clean and disinfect the isolation ward and to improve hospitalization conditions for the Ebola patients. Protective equipment started to arrive slowly and was distributed among health care workers and family members. Only one family member per patient was allowed to enter the isolation ward. At the beginning of the epidemic the priority was to prevent further nosocomial transmission. There was very little contact between health care workers and patients; masks and goggles hampered communication.

Initially, the mortality in the isolation unit was about 80%; it decreased only at the end of the epidemic when patient care improved. Most patients in Pavilion 3 were in a large ward...
with several empty beds between them. They witnessed other
patients dying of Ebola, some of whom were their colleagues.
At the time of the outbreak, Kikwit General Hospital had
neither running water nor electricity.

When their clinical condition improved, patients were
moved from the isolation ward for acutely ill patients to
another isolation ward for convalescent patients where
isolation rules were less strict and more contact with the
outside world was possible.

The Ebola epidemic not only created panic in the city of
Kikwit, but also in surrounding villages, in the Democratic
Republic of Congo and even in the rest of the world.
Extensive, sometimes sensationalizing media attention
probably increased the fear of the general public not only in
Kikwit, but worldwide.

Ebola epidemics research has so far concentrated on
epidemiological aspects (Breman et al. 1997) and clinical
manifestations, while psychosocial aspects received very little
attention. Therefore we tried to study the psychosocial
consequences of the Kikwit epidemic for those who became
infected.

Patients and methods
The study was conducted in July 1995. Based on Ebola
surveillance data, a list of the 60 survivors was drawn up. We
were able to contact 34 (57%). After informed consent was
obtained, they were individually interviewed by another
Ebola survivor using a standardized questionnaire in French.
The questionnaire contained 57 mostly closed questions.
Identical questions were put to all survivors regardless of
hospital experience. Translation into the local language was
done by the interviewer if necessary. Survivors were
questioned about their experiences prior to diagnosis, at the
beginning of the illness, during the acute phase and during
the convalescent period.

Results
Twenty-six (76%) of the survivors enrolled in the study were
women. Reasons for nonparticipation were distance to the
patients’ home (n = 7, 18%), refusal to participate (n = 4,
10%), inability to trace the individual (n = 9, 23%) or failure
to contact the person (n = 6, 16%).

Twelve (35%) participating survivors belonged to the
hospital staff. Sixteen (47%) were married and five (15%)
were children. Twenty-one (63%) were Catholics, while the
other 13 (37%) were Protestants.

Twenty-eight (82%) reported having had close personal
contact with an affected family member. Nine (26%) had
helped in the ritual cleaning of the body of a person who died
of Ebola. None of the survivors reported having received an
injection in the 3 weeks before becoming symptomatic, but
one woman reported that she became infected after taking
blood from a patient. Twenty-six (76%) had been admitted to
Kikwit General Hospital: 15 (58%) to an isolation ward, 8
(31%) to the emergency room, one woman to the maternity
ward because of an abortion and two to another medical
ward. Five (15%) had received medical care at a health centre
and three (9%) had stayed at home.

Experiences prior to diagnosis
Only 11 (32%) immediately suspected an Ebola infection
when symptoms appeared. Their first feelings included fear of
falling seriously ill (50%), denial (47%), fear of being
accused by neighbours (21%) and shame (15%). Twenty-
seven (80%) shared their anxiety with a family member or
another person during the first days of their illness. Twelve
(35%) tried to escape from the family or close
neighbourhood. Nine (26%) took traditional medication, but
none reported having consulted a traditional healer. Three
(9%) had played down their symptoms when seen by medical
staff.

Experiences during the acute phase of the illness
After diagnosis nearly all patients experienced fear: 19 (56%)
feared the suffering, 18 (53%) were afraid of dying, 14 (41%)
feared to be separated from relatives and 8 (23%) feared
abandonment by their family. One person not convinced of
being infected with the Ebola virus was afraid of becoming
contaminated during hospitalization. Seventeen (50%)
believed they had a chance to recover. Twenty-nine (85%)
reported that they received support from the medical staff,
from a family member (70%) or from other patients (24%).
All patients were helped by their belief in god. The most
harrowing experience was the loss of friends and colleagues
who died next to them in the ward and the abandonment by
medical staff at the beginning of the epidemic. Isolation,
including the refusal to admit visitors, was also difficult to
bear for most patients.

Experiences during convalescence
During convalescence, 12 (35%) felt rejected by society,
including family, friends and neighbours. Most of the
psychological support after discharge from the hospital came
from close family members and volunteers from the medical
staff. Twelve (35%) of the survivors accepted that Ebola
infection is a preventable disease, but 11 (32%) saw it as
divine punishment. Eighteen (52%) had no income during
their illness. Nine (39%) survivors reported no psychological
consequences from the disease, but the grief for the family
members who did not survive the epidemic was intense. All survivors felt their experience strengthened their belief in god.

Discussion

Deadly epidemics always have serious implications for society. The epidemic of the disease itself is often accompanied by epidemics of fear, stigmatization, blame and discrimination. People’s reactions to a frightening, intolerable situation may be an attempt to escape, to control, to deny or to displace fear. This was the case when the plague epidemic raged in Europe (Gilmore & Somerville 1994) during the Middle Ages, and it is currently the case for AIDS worldwide (Goudsblom 1986; Goldin 1994). During the Ebola epidemic in Kikwit, discrimination and stigmatization were rampant.

This paper deals with the rarely explored subject of the psychological impact of Ebola outbreaks. Our study findings are important for the management of future haemorrhagic fever epidemics, particularly for the organization of care, for case-tracing and active case-finding. In Kikwit haemorrhagic fever was a very stigmatising disease that created great panic in the community: 35% of the Ebola survivors tried to escape from their family or immediate neighbourhood during their illness, 9% played down their symptoms to health care workers. Stigma and poor health services offered to patients may lead to underreporting of Ebola cases and favour further spread of the infection. More people were rejected by their families than they had feared before and during hospitalization. Not surprisingly, most survivors suffered enormously from witnessing other people die in the isolation ward. But they also very much resented the abandonment by medical staff and the fact that they could not receive visitors. All survivors felt they were strengthened through their belief in god. And although most had lost family members, their religious belief was even greater after the epidemic.

The study participants were not representative of all the Ebola survivors. Only 57% of the convalescent Ebola patients participated in the survey. Distance was one of the most common reasons for nonparticipation; therefore survivors living further away from Kikwit and survivors who were not hospitalised were underrepresented. These individuals may have had different experiences. The proportion of female survivors was greater in the sample than in the overall epidemic (76% vs. 53%, respectively), but the high percentage of medical personnel in the survey corresponds to the overall percentage of infected health care workers (35% and 30%, respectively). Reported use of alternative medicine was rather limited, perhaps due to the high number of medical staff in the sample, or because participants gave socially desirable answers.

In case of a new Ebola outbreak, more attention should be given to the psychosocial implications. Measures to be taken include: Anti-discrimination information campaigns to avoid stigmatization of Ebola patients and their families; better care including psychosocial support for the patients and their families; allowing family members to care for patients provided they are adequately equipped and trained; psychosocial support for carers; provision for dealing with orphans and financial loss due to illness and death.

References