SOCIAL CONSEQUENCES OF AGENT ORANGE IN VIETNAM

'Under the dark cloud of not knowing'

PHAM HUONG THAO,
ANNIKA JOHANSSON,
TRAN MINH HANG

Introduction

What happened to the people who were exposed to Agent Orange during the war? How has the chemical warfare affected social and family life many years later? We have interviewed families where the husband and/or wife were exposed to Agent Orange, as soldiers or civilians, and who later got disabled children. Using qualitative interview techniques we have asked about their lives since the war ended, their own health problems and those of their children, their perceptions and fears related to Agent Orange and their worries and wishes for the future of their children.

The selection of families for the interviews was done by the local Red Cross among those identified as 'suspected victim of Agent Orange'[1] in three areas: the district of Y Yen, Nam Dinh province in the North, the district of Hiep Duc, Quang Nam Province in the Centre and the district of Ham Tan, Binh Thuan coastal province in the South. The local Red Cross official contacted the families in advance to explain the purpose of the study and ask if they were willing to take part. It was made clear that this was a research study about people's health after the war and not linked to the Red Cross activities[2]. We had asked that no mention be made initially about our interest in Agent Orange. They were assured that they were free to decline to be interviewed and that this would have no repercussions on their allowances or other things. According to our Red Cross hosts, no family declined. Averages of 20 families in each district were interviewed.

The interviews were conducted in the homes of the families, with husbands and/or wives, depending on who was present, sometimes also other relatives. Some of the interviewees' disabled child/ren were young, others were grown up and if they were at home they were always present during the interview. An interview normally took between one and two hours. They were tape recorded and transcribed by the researcher who did the interview and then translated from Vietnamese into English by a professional translator. The quotations in the text are taken *verbatim* from the translated

[1] Following a Government Decision (Article 2: Decision 120/2004 QD-TTg of the Prime Minister's Office), the Vietnam Red Cross (VRC) defines a 'suspected victim of Agent Orange' as someone who was exposed to the chemical spraying during the war, either as soldier or civilian, and who has developed certain diseases. The children whose fathers or mothers were exposed to the chemicals, and who were born with congenital malformations or have developed other specified conditions, are also defined as suspected Agent Orange victims.

[2] The VRC has been charged by the Government to establish lists of suspected Agent Orange victims in each province. Based on these lists, the VRC is distributing special Agent Orange allowances as a complement to other allowances granted to poor families with disabled children. Currently (2005) the amounts vary between 85.000 VND and 300.000 VND (Article 2: Decision 120/2004)

transcriptions. They are shortened and sometimes the order between sentences has been changed in order to make the reading easier, without changing the interviewee's meaning. Here we present some examples from our encounters with families in the three areas.

Health and family life

When peace was restored in 1975, the first wish of the young men and women who had spent years as soldiers, guerrilla fighters or volunteers, was to establish a normal life - continue education, start working, getting married and building a family. But for many, the happiness of being home and enjoying peace was gradually turned into a long struggle against their own health problems and into sadness and grief of experiencing their children's severe illness or death.

The interview was introduced by a general question about the health conditions of those who had experienced the war. Some considered themselves to be in normal health while others described themselves as weak and handicapped in their daily lives. Their symptoms were varied and complex and obviously their health problems could be due to a variety of causes, incurred during or after the war. Some had been demobilised already before the war ended due to poor health, others had developed their different symptoms after coming home. However, they all shared the experience of having been heavily exposed to Agent Orange during the war, as these three men:

I went to the south in 1967. After some years of fighting there, I was wounded, my health became weak and in 1972 the unit decided to send me to the north for convalesce. After a period of rest in the convalescent centre, I was still not fit to return to the front line so I was demobilized. Now I get allowance as a victim of Agent Orange. I have pustules all over my body and limbs that no medicament can cure [showed his pustules on arms and legs]. Inside the body is the same... The itching is unendurable, sometimes it moves inside the body… Sometimes I cannot sleep for night on end, I have pustules all over the body.

I'm not well. Sometime I feel I carry no weight at all, sometimes I feel everything goes round and round. My body seems not mine. I have pain in all organs, pain in the liver... It is difficult to breath, sometimes I cannot breath. When I stand up, everything swirls and I can't stand, then I collapse. When I was hospitalised, the doctors said my blood was black. My blood pressure goes up and down. Sometimes I lose balance. I don't know how long I will live but I feel very weak. After medical check-up in hospital, the doctor said that my heart, my kidney and my lung were all affected by Agent Orange.

My health has weakened since I was in Khe Sanh. They said it was because we drank water poisoned by Agent Orange. When I was there I was very strong … I could drive the lorry for 30 nights running without sleeping along the Truong Son trail. The roads were very rough and very difficult to drive on. I could throw up a 20 litres of gasoline onto the lorry with one hand…But now I have heart and liver diseases, I have to bear the consequences of war.

One of these men had been diagnosed as suspected victim of Agent Orange already in the 1980s while the others had received the diagnosis in the mid 1990s when the information about the suspected consequences of Agent Orange was widely diffused in Vietnam. In the

narratives of these men, Agent Orange was perceived of as having invaded the body and affected vital organs, causing them weakness and constant pain - 'it moves inside the body', ' I have pain in all organs'. As we had no medical scientists in the team, we were not asking details about physical and psychological health of individuals, but rather of the consequences of ill health and disablement of a family member for the rest of the family. This was a recurrent theme in most of the interviews and gave rise to rich and detailed descriptions. Apart from daily caring for the disabled and diseased, which was often an extremely heavy task, the psychological well being of the individuals and family interaction were profoundly affected.

The loss of a son and a husband

We met Mrs.Dau, a wrinkled old lady with lively speech and gestures. She spoke at length of her son Chinh's life and death, laughing at humorous episodes and shedding tears as the memories of her deceased son became too painful. Chinh was recruited to the army when he was only 19 years old and fought for many years at the front, mainly in the Central Highlands. When he came back home in 1975 he took a university degree as an agricultural engineer, got a job in the district, married in 1977 and got four children. But Chinh was in poor health ever since the time he came home and his health deteriorated steadily:

He was weak and sickly since coming back from the front, we didn't know why. He had a pain in his spinal cord and later developed lung cancer… He was treated at hospital for one month but it was too late, he was sent home to die. In Hanoi they said his death was due to the

An area of A Luoi district- where was sprayed Agent Orange/Dioxin

Photo: Source of CGFED

war, they said it was Agent Orange. Everybody in the district mourned him…he was only 47 when he died. Had he lived today he would have been 55… Sometimes I think of other families with many children, many sons. I only have one son and he died before me… When I think about this I cannot sleep…the more I think the more miserable I feel …'

As Chinh had been fighting for several years in the central Highlands in areas where the chemical warfare had been intense, he was diagnosed as a suspected victim of Agent Orange by doctors in Hanoi, based on his own disease pattern and also on the pregnancy history of his wife and the health of his children. At the time of his death, one of his small children had already died and two others were suffering from neurological problems.

Chinh's widower Ca described the family's history:

We married in 1977 but I had several miscarriages and had my first child only seven years later. Our son Toan Anh was born in 1983, he was weak since birth. At the age of seven we took him to the Vietnam-Sweden Children's Hospital in Hanoi where they told us that he had a disease of the blood. We were told that he had been affected by Agent Orange. When he was seven, Agent Orange took his life. One year after Toan Anh birth I got pregnant again but I lost the child in the fourth month. In 1985 I gave birth to Son, who was also very weak since birth and was taken to hospital several times…he had a kidney disease. The third son, Truong, was born in 1989. He has epilepsy and needs medicines all the time. My daughter Nga was born three years later. She is weak and her mental health is not stable…I myself I almost got mad when my husband died and the children were so weak and sick…I was taken to mental hospital for three months. Now all three of us take 'mental medicine'.

Ca described herself as 'brave' to have married a man who had been at the front for so long, as she had heard from people in the district that such men could develop diseases and get children with malformations and diseases. Despite this fear she had agreed to marry as they loved each other. Today she is convinced that her husband's death and the death of her children are consequences of the 'poisonous Agent Orange' her husband was exposed to during the war. 'The problems came from him, not from me' she said quietly, consoling herself that at least she cannot be blamed for the family's tragedies which had driven her to 'madness' as she described her condition.

When Chinh died, his Agent Orange allowance was stopped while his children continued to get half allowance (45.000 Dong/month) as they are also classified as suspected victims of Agent Orange. Chinh's mother and wife now live in a delicate balance where Dau still can contribute by cooking and looking after the children when they come home from school, and Ca brings some cash earnings from selling farm products. Most of the farm work on the small family plot is done by Ca, sometimes with the help of a neighbour but Ca has never asked the children to help on the farm. She feels that they are too weak and need all their energies for school. But what will happen the day when Dau is too old to work, and when the two children leave school and should find jobs, both with 'weak nerves' and one epileptic? This day is not far ahead and the two women are deeply worried about their own and their children's future.

A father and his daughter

As in the case of the family of Dau and Ca, in many families the interactions between family members and the well being of the individuals were profoundly marked by the ill health of one of the parents, often the father, and by the severe

disablement and sometimes death of children. Our interviews with Mr Phong and his daughter provided a poignant and sad illustration of this.

Phong had a complex disease pattern and had been examined many times for his health problems which started already when he came back from the front in Cambodia in 1982. As a patient of the late Dr.Le Cao Dai[3], he was one of the earliest established cases of suspected Agent Orange poisoning. The combined evidences of his exposure history, which was extraordinary (see 'Narrative of War and Spraying' in this volume), his own serious health problems and the fate of his children all seemed to point in this direction. Two sons had died at the age of two, the third had lived until he was eight and had died only some months prior to the interview. Apparently the three boys had all suffered from severe cerebral palsy and mental retardation. Phong described the cramping, their twisted limbs and how they were always crying, never smiling:

Phong described his third son like this: *His body cramped, he cried and his legs and arms stretched out and became stiff. I decided to take him to the Vietnam-Swedish Paediatric Hospital. They studied his case…and said that it could not be cured… so we took him home and helped him to take medicine when he cramped. The three of us took turn to look after him [himself, his wife and his young sister]*.

The strain on the family of caring for the sick boys at home, altogether for a period of over 12 years, was evident in their speech and in the emotions displayed. When we met the family they was still in grief after the death of the last son, the wife cried softly and Phong reproached himself:

It is me who brought unhappiness to my wife and children. I often told my wife 'if I had not married you, you wouldn't be so unhappy. Now that we are married, we must live together and encourage each other to live'. But there were times when my wife was very distressed with her husband and sick children. After getting married with me, she had to shoulder a heavy burden. I'm always ill and angry because of the injury in my skull. She is very sad. I sometimes console her but when I get angry, I loose self-control. I know that it is wrong but I can't help it. Sometimes I reproach my wife and daughter, I throw things or I just leave home and wondered around … At times, I feel that I cannot live any longer… Whenever I think of my daughter's future, I'm very sad. But I have to accept our fate.

Phong's second child is a girl, Phuong, born in 1983. She was not home at our first interview but we had the chance to come back a meet her later. She is asthmatic and suffers from arthritis, but her health is improving and with medication she says she feels 'normal'. Phuong is studying nursing at a school some hours away and comes home over the weekends. In her narration the fate of her three brothers is closely interwoven with her own life:

Phuong: *You know well my family situation… I come home every week, especially since my youngest brother's death, to please my parents. My youngest brother lived eight years…. After his death, my sadness decreased but sometimes I miss him (crying). I do not want to think about this; you know that there were three similar cases in my family…but my youngest brother lived the longest, for almost eight years… One*

[3] The late Dr Le Cao Dai was a medical doctor and researcher who had himself been a witness to the chemical spraying during the war and seen the consequences among his patients. He worked for many years with the 10-80 Committee, and participated in many national and international research projects on the health consequences of the toxic chemicals He is the author of the book Agent Orange in the Vietnam War: History and Consequences, 2000.

month before he died, he was totally exhausted, my aunt and my grandmother had to carry him in their arms all day. His face was quite nice but he became emaciated due to long diarrhoea. I read books and knew that his digestion system was damaged, so I anticipated the situation and informed my family that he could not live much longer; we tried our best to save him .... In the past, everybody felt sad because of my sick brother, we had to take care of him every day, so we felt psychologically oppressed. We loved each other but we kept it within our hearts and extended our love to my youngest brother. Everybody had their own thought, we could not share. After his death, we pay more attention to each other... It was my dream since I was a child (to study medicine) considering my family situation… I felt sad because I could not save my brothers…but after studying in Medical College I felt even more disappointed as I did nothing for my brothers.

Interviewer: *Do you have boyfriend?*

Phuong: *No, frankly speaking I do not have a boyfriend now. My situation does not allow me to think about that. It is difficult for me to get married, I am afraid of being affected by my father. My brothers were seriously affected by my father, who knows about my case? So I have not decided yet. There are several men who love me but I do not dare to think about that now…*

Like Phuong and her father, many people feared the genetic effects of Agent Orange and that the consequences of Agent Orange would come back in the second and third generations. There was also the worry that healthy siblings of disabled children, born to Agent Orange victims, might carry the damaged genes, thus compromising their chances for getting married. These worries and concerns permeated many of the interviews, especially those from Nam Dinh in the North.

Worries about a daughter's marriages

In our meeting with a couple in Y Yen we realised their gnawing anxiety about this, not so much from what they said but from the way talked. They were both in their early 60s and had married in 1975 when the husband came back from the front in the South. The wife's first pregnancy had ended in a late miscarriage, and a year later she gave birth to a son who died soon after birth. A daughter was born in 1980; she was healthy and is today working as a teacher. The second son, born in 1982, was paralysed since birth and died at the age of six. The last child, a daughter, was healthy like her sister and was going to get married in a few months. When we asked what had been the problem of the two sons who had died, the wife said that she had heard about Agent Orange but was very uncertain about what to think:

After the death of our son I didn't think of it [Agent Orange]. Then I was told by people who watched television [about Agent Orange]. But I though that this could not be our case, as my two daughters are both well. The oldest daughter passed entrance exam to Teacher's Training College… the second daughter is very strong, she has no disease….I don't know what to think…there is a possibility that they were affected but only a little. I think it is fate.

The husband supported her disbelief in Agent Orange as cause of death of his sons:

I found that some men who didn't go to the front had the same problems as our family…My wife was not young when she gave birth, this may have been the reason….None of my friends have the same problem as me. It is my fate.

This couple reasoned logically about the death of the sons and would not subscribe to the common opinion that Agent Orange was the cause. If the daughters were healthy, why should only the sons have been affected? If the husband's friends had no disabled children, although they had also been exposed to Agent Orange during the war, why should his sons

have been affected by it? It was their fate, they concluded. But when talking about their daughter's forthcoming marriage, their worry about possible associations with the brothers' problems was apparent:

One of my daughters is going to get married in November. Her fiancé is a doctor from here... We are worried... if there is any problem... I don't know how it will be in the next generation…

We realised after the interview that our visit had been troublesome for them. They were focussed on the marriage of their daughter and didn't want the neighbours to notice that we had paid them a visit. Although we had expressed a wish not to be introduced as an 'Agent Orange team', this was apparently difficult to avoid. The couple wanted by no means to draw attention to the sad fate of their two sons and the possible association with Agent Orange, which might cause the future groom to change his mind about the marriage with the daughter. Had we known this we would not have visited the family in the first place.

Recalling past misery

In another interview in Y Yen, the couple had a similar history of having both disabled and healthy children, but their healthy daughters were already married and had got normal children. The parents were therefore no longer worried about the daughters' marriages and they talked at ease and length about the problems they had experienced. Of six children born between 1973 and 1989, three were healthy and three had died severely disabled between the ages of eight and ten in what they described as 'brain disease':

They couldn't walk. They didn't understand anything, they were only lying in bed. Recalling those days is terrible; they didn't speak, didn't hear…while eating, sometimes they got choked and sneezed, throwing all the food onto our face... Many times my wife and I quarrelled with each other, it was very miserable… They were lying in bed jerking, groaning, and we had to use tranquillisers to help them sleep. Sometimes during the night my elder daughters took them to their uncle's house because my wife and I needed to have some rest… During the 16 years that we took care of them the family was very poor. It is only in recent years that we could build our house.

When one of the daughters was to marry in 1996, two of her disabled brothers had already died but the youngest little sister, six years at the time, was still alive (she died at the age of ten). The husband explained that the family of the future groom hesitated before accepting her for their son's marriage:

My brothers advised me that when the boy's family came to visit us, we shouldn't let them see Hoa [the disabled daughter]. They [the boy's family] had asked the doctor if my family had any problems and the doctor said no. Nowadays in the press and on TV they say that the consequences of war might affect the second and third generations. They [the boy's family] had some hesitations but finally they decided to accept my daughter for marrying their son. Now she has two daughters and they are both normal.

The husband explained that rumours and gossip about the family with its three disabled children were rampant in the community before the information about Agent Orange was diffused through the press and TV:

They [the neighbours*] first thought that this was the punishment because we had behaved badly or because we didn't worship. I didn't agree with them, in fact we had been many times to the pagoda for worshipping, we had consulted fortune tellers and got herbal medicine, but all in vain…. After I got a certificate for having been affected by Agent Orange, the neighbours didn't dare to say so any more…But now the*

problem is that …people around say that this family is affected by Agent Orange and if marrying the daughters, the offspring may get cerebral palsy… This is what they say, but not that we have behaved badly or anything.

The gossip of neighbours had faded that the family was being punished for past sins of ancestors for their disabled children, but instead another fear and rumour was darkening the reputation of the family – that of being 'affected by Agent Orange'. This family had succeeded in overcoming the hesitations surrounding the marriage of their daughter and they were not really worrying about their young son's future marriage – 'boys can chose' as they said. But for the many girls and young women with disabled sibling, the fear of genetic effects of Agent Orange in the third and fourth generation throws a shadow on their lives and future child bearing.

Epilogue

The narratives have deepened our understanding of how sensitive and complex the issue of Agent Orange is in the Vietnamese society today. Many families we have met who already have a very hard life, have an added burden of feeling guilt and worry that the chemical that made them sick has also afflicted their children, and that the third and fourth generation may also be affected. Some appear to feel relief that their sufferings and misfortunes can be explained as caused by Agent Orange and the war, and not by the immoral behaviour of ancestors or other personalised cause. For others, on the contrary, it is felt as a threat to their families to be associated with Agent Orange, which is suspected to cause genetic damage. This was very pronounced in families where healthy siblings of the disabled were planning to get married and the families tried hard not to draw attention to this possible connection. Some young women had themselves made the decision not to marry as they feared that they might carry 'damaged genes' inherited from their father or mother and also get disabled children.

Failing the kind of scientific research that could shed light on the real consequences of Agent Orange in Vietnam, the worries and rumours about its potential damage continue to spread. The uncertainty and fear about the long-term effects of Agent Orange creates a feeling of 'living under a dark cloud of not knowing'[4]. Conclusive scientific evidences of this will be late, if they will ever come. Given this situation of uncertainty, it is important to for the Vietnamese authorities and mass media to consider carefully what information is disseminated to the public and how it is received. Experiences from other countries have shown that the effect of information on health hazards may sometimes be more harmful than beneficial for the people concerned, unless concrete preventive measures can be suggested or remedies offered. An example is the 'hot spots' of dioxin contamination where people can be advised how to minimize the potential health hazards.

Above all, like other families in similar difficult conditions, the people we have met in this study have the right to support, material and psychological, to rehabilitate and alleviate sufferings of the disabled and sick, and to build better lives for themselves and their children.

[4] An expression coined by Dr Nguyen Viet Nhan from Hue University, who has worked for many years with these problems.