Impact of Chemical Warfare with Agent Orange on Women’s Reproductive Lives in Vietnam: A Pilot Study

Le Thi Nham Tuyet, Annika Johansson

During the American war in Vietnam, huge quantities of the highly toxic herbicide dioxin (‘Agent Orange’), were sprayed over large areas of central and south Vietnam. In addition to polluting the environment and causing cancers and other diseases in those directly exposed to it, dioxin has caused high rates of pregnancy loss, congenital birth defects and other health problems in their children. This paper reports the findings of a pilot study in the year 2000 among 30 Vietnamese women whose husbands and/or who themselves were exposed to Agent Orange. The aim was to develop research in order to explore the impact of chemical warfare on people’s lives. Using the reproductive lifeline and semi-structured interviews, information was gathered on both partners’ periods of exposure to Agent Orange, pregnancy outcomes, perceived health problems of children and experiences of living with handicapped children. The women had had a high number of miscarriages and premature births. About two-thirds of their children had congenital malformations or developed disabilities within the first years of life. Most of the families were poor, aggravated by impaired health in the men, the burden of caring for disabled children, and feelings of guilt and inferiority. The plight of ‘Agent Orange families’ is special and should be placed in its historical and political context.

Keywords: dioxin, reproductive history, pregnancy loss, congenital birth defects, disability, stigma, Vietnam

The American war in Vietnam ended a quarter of a century ago. Between 1962 and 1971, 72 million litres of herbicides were sprayed from aircraft, trucks and by hand on more than 3.6 million hectares of forest and villages in Central and Southern Vietnam, with the aim of killing all the vegetation. The herbicide was named ‘Agent Orange’ after the orange bands painted on the drums it was shipped in. In the early 1970s it was discovered that one of the components of Agent Orange (known by the shorthand notation 2,3,7,8-tetrachlorodibenzo-p-dioxin, also called TCDD or dioxin) caused birth defects in animals, and it was banned in the USA and several other countries. In 1971 the defoliant operation in Vietnam was halted by the US military, four years before the end of the war in 1975. It is estimated that about 17 million people living in South Vietnam during the war and about one million from the North were directly exposed to dioxin. Exact how many died or suffered from the consequences of dioxin is not known. According to Vietnamese estimates, the numbers are in the hundreds of thousands.

Dioxin is described as the most toxic substance discovered by mankind to date. It is very persistent in human tissues and the environment. Dioxin infiltrated the country’s water and soil, entering the food chain and accumulating in people’s tissues, passing from mother to child through breast milk. Samples of fish, shrimp and breast milk collected from southern Vietnamese women in the early 1970s showed very high
levels of dioxin, while decreasing levels were demonstrated in the late 1970s and 1980s.2,3

More recent studies, however, have shown elevated levels of dioxin in human blood samples from different localities in Vietnam, the highest being near former US bases with Agent Orange storage facilities and loading areas. An example is Bien Hoa, one of the largest US bases in former South Vietnam, where a spill of Agent Orange occurred during the war. Thirty years later blood samples from Bien Hoa showed extremely elevated dioxin levels - up to 271 parts per trillion (ppt), compared to levels of 2 ppt in blood samples from Hanoi, where Agent Orange was not used.4 The authors suggest that the high dioxin levels in the blood samples is due mainly to contaminated fish, a typical food in the Vietnamese diet. In a 1994 study, Schecter5 compared dioxin levels in pooled breastmilk samples from various countries. Highest of all was the city of Da Nang, a former US base in central Vietnam (34 ng/kg, lipid), compared to Thailand and Cambodia with levels of 3 ng/kg. Thus, many years after the end of the war in Vietnam, severe environmental contamination remains, potentially exposing people to serious health risks, including during pregnancy.

**Adverse effects of dioxin on reproductive health**

Research on American ex-servicemen from the Vietnam war has shown significant associations between dioxin exposure and certain kinds of cancer, including soft tissue sarcoma, non-Hodgkin's lymphoma, Hodgkin's disease, respiratory cancers, prostate cancer and multiple myeloma.7

Effects on the reproductive system and the ability to bear healthy children are more long-term and therefore more difficult to establish. It is known that dioxin is an endocrine-disrupting chemical with a highly toxic effect on the reproductive system. Even at very low concentrations, it may seriously disrupt normal reproduction in humans, e.g. lowering fertility, increasing antenatal mortality and the risk of endometriosis, and causing birth defects. Though the mechanisms by which dioxin acts are not clear, it interferes with the production and function of many different hormones, growth factors and enzymes. Its effects and toxicity are much more consistent and severe in the early stages of human development than in adults. Erickson6 reported higher incidence of spina bifida, cleft lip, hydrocephalus and childhood cancers among children of war veterans than in controls. Stellman9 demonstrated significantly higher incidence of miscarriages in women whose husbands were war veterans compared to controls, though no increased risk was detected by Wolfe10 in a similar study. However, data from US war veterans are limited by the lack of information on dioxin level in the blood at the time of conception. The power of the study for detecting an increase in the rate of a specific birth defect is also limited because of the relatively small numbers in the exposure groups.11

Dioxin accumulates in breastmilk. During nursing, it is transferred from mother to baby, who may absorb as much as 95 per cent of dioxin in the milk. Evaluations of the impact of elevated dioxin levels in mothers' blood and breastmilk show that the most adverse associations are found with in utero exposure through the umbilical cord, including neurological effects, low birthweight and intrauterine growth retardation. Reviewing the scientific literature on the potential health hazards of dioxin-contaminated breastmilk for the infant, however, the TSD12 concluded that the adverse effects of dioxin seemed to be compensated for by the beneficial effects of breastfeeding.7,12

Case reports and health research from Vietnam suggest higher incidences of miscarriages and premature births, birth defects, low birthweight and childhood cancer in offspring among women who themselves or whose husbands were exposed to Agent Orange during the war.13,14 Le Cao Dai15 demonstrated that over five per cent of the children of Vietnamese ex-soldiers exposed to Agent Orange were born with defects, compared to only one per cent among soldiers who remained in the North Vietnam and avoided exposure. The congenital malformations associated with Agent Orange range from anencephalus and conjoined twins, to cleft lip and cleft palate, and limb, facial and auricular anomalies, varying from mild to severe. Harada16 noted: 'There is no one definite feature of the congenital malformations observed in Vietnam; if anything, diversity is their characteristic.'
The official bodies in Vietnam dealing with Agent Orange investigations are the ‘Committee 10-80’, established in 1980, and the newly set-up Department for the Consequences of the War at the Ministry of Labour, War Invalid and Social Affairs (MOLISA). The leading NGO is the ‘Agent Orange Victims Fund’ set up in 1998 under the Vietnam Red Cross, which is recording data on Agent Orange victims province by province, organising rehabilitation centres and mobilising support from local to international levels for Agent Orange victims and other disabled people.

Research on Agent Orange in Vietnam consists mainly of epidemiological or clinical studies dealing with the effects of dioxin contamination on human health and the environment. To understand the social and human dimensions, however, medical information needs to be supplemented with qualitative data. For this purpose, a project was initiated in 2000 by the Research Centre for Gender, Family and Environment in Development (CGFED), a Vietnamese NGO. Its aim is to describe the reproductive lives of women whose husbands and/or themselves were exposed to Agent Orange during the war and who have given birth to disabled children, and to explore the social and family consequences of Agent Orange contamination.

This article reports the findings of a pilot study among 30 Vietnamese women identified as mothers of ‘Agent Orange children’. Its purpose was to gain experience with the reproductive lifeline as a tool to map the reproductive histories of the women and generate more specific research questions.

Subjects and methods
Four different areas were chosen for the pilot study: Quang Ngai in the South of Vietnam (9 cases), Hoa Binh in the North (8 cases), Ha Nam in the North (7 cases) and Hanoi, the capital in the North (6 cases). Quang Ngai province, with Da Nang as provincial capital, was one of the areas most heavily sprayed with Agent Orange. Many soldiers lost their lives in Quang Ngai and an even larger number returned home as invalids. Some areas in Quang Ngai are still heavily polluted with Agent Orange, affecting drinking water and farming soil. Throughout the North, there are a large number of ex-soldiers who used to fight in the most heavily polluted central and southern highlands. The three provinces in the North selected for the study – Hoa Binh, Ha Nam and the capital Hanoi – represent mountainous, lowland, rural and urban areas.

With the help of the Red Cross Agent Orange Victims Fund and the Women’s Union in the four provinces, we made a purposive selection of 30 women who had given birth to at least one disabled child and who were known to have a history of Agent Orange exposure in the family. Usually it was the husband who had been exposed, sometimes both husband and wife. All families selected were recognised as victims of Agent Orange by the Red Cross, by the local authorities and by the families themselves. The women were informed about the aims of the study and told that they were free to decline. All 30 agreed to be interviewed.

The women were interviewed in their homes by two Vietnamese social scientists, one male and one female. The instruments used were the reproductive lifeline and a semi-structured questionnaire. The reproductive lifeline is a tool, often used in retrospective demographic studies to minimise recall errors. It is a graphic representation of reproductive events along a time axis, to which we added questions about military service during the war. The interviews started by recording the woman’s year of birth and marriage, first and all consecutive pregnancies and their outcomes (miscarriage, abortion, stillbirth, live birth) on a lifeline. To rule out obvious hereditary cases, we asked if the woman knew of any birth defects or other disabilities among her husband’s and her own siblings or their children. In a qualitative interview, the woman was then asked to describe the disabilities of her own children, how the child/ren coped with daily life, the experience of managing a family with disabled children and any support she got from relatives, neighbours and the local authorities.

If her husband was present during the interview, which happened in several cases, the male interviewer interviewed him, especially regarding the health of the children and how he was exposed to Agent Orange. Although the families all knew they were being interviewed as ‘Agent Orange families’, we did not emphasise this aspect in the interview. The only question directly related to Agent Orange was about
whether they had been exposed during wartime spraying and, if so, where and for how long. If the husband was not present at the time of the interview, the wife was asked this question.

The women mostly answered freely, but some questions related to the disabilities of their children were very painful and they were hesitant to say much. However, reproductive lifelines were recorded for all women. Most interviews lasted for about an hour; some were shorter, around half an hour. A medical doctor from the Agent Orange Victim Fund accompanied the team and interviewed the families further, asking for more detail about health problems and the need for rehabilitation and care for the children.

**Findings**

Most of the families in the study were poor farmers with a bare minimum of existence and meagre nutritional levels. A few families in Hanoi had a somewhat higher standard of living. In all cases, the husbands had been soldiers in Agent Orange sprayed areas, for periods from three to eight years. Some of the women had either grown up in areas where chemical spraying took place or had worked as youth volunteers in such areas.

The majority of the women had passed reproductive age and were living with one or several disabled children who at the time of interview were in their teens or older. The mean age of the women was 50. The oldest was born in 1938 and the youngest in 1965. The mean age at marriage for the women was 23 (range 20-34). One third of the women had married after age 25, which is considered late for women in rural areas, but this was common during the war years due to men's long absences.

The 30 women had had a total of 148 pregnancies, of which 9 per cent had ended in miscarriage and 14 per cent in stillbirths or premature births. Of the 108 children born alive, 14 had died before the age of five and four had died at older ages.

Sixty children (66 per cent of all children born alive) were described by their parents as disabled in some way. Most had been born with some visible malformation or disability (37 per cent) while others had developed a disability during the first years of life (27 per cent). Of the 60 disabled children, 40 were described by their parents as unable to attend school, but able to help with agricultural work and domestic chores. Twenty children were very severely disabled physically and mentally, and had to be attended by their parents for every daily need. Some never left their beds and were unable to utter a meaningful word.

There were no cases of congenital malformation or other disabilities among siblings of the husbands and wives respectively, nor among the children of their siblings.

**Case histories**

**Be**

Be is from Ha Nam province, the oldest of the 30 women. The family is very poor and food is short several months per year before harvest. Be was born in 1938 and married Huan in 1959. They had two healthy boys in 1964 and 1966; both sons are now married and have children. In 1968 Huan joined the army and spent three years in Quang Nam-Da Nang. He got sick and was demobilised in 1971. Since then his health has been very bad; he has skin rashes, gets frequent headaches, pain in the joints and feels very weak.

In 1971 they had their third child, a daughter. She is 'slow' and unable to learn, still unmarried (at 29 she is considered too old to find a husband) but she is now the main labourer in the family. In 1974 Be had her fourth child, Thu. This girl was 'unnatural' at birth, she cried a lot and did not grow normally. She was taken to hospital several times but the doctors gave no hope. At 26, Thu is unable to take care of herself, she is always angry and cannot be left alone. A fifth daughter, born in 1976, has developed normally and is now married.

At first, Be felt 'inferior' because of her disabled daughters. She and her husband did not know the reason for Thu's problems. But they have heard that several of her husband's friends who had been in Agent Orange areas during the war have also had disabled children. The neighbours show sympathy and her husband is also very supportive. But he is weak and no longer able to work, so Be has to work very hard although she is quite old. Their greatest worry is who will take care of their disabled children when they get old and pass away.
Normally in rural Vietnamese families, husband and wife share in agricultural work. In many of these families, the impaired health of the husband due to Agent Orange contamination and other war injuries means that the wives, like Be, have had to carry major responsibility both for farming and the children.

**Dieu**

Dieu, aged 54, is from Hoa Binh; she was married at age 30 to Bieu, who was the same age. They had fallen in love when they were young, but as he was in the army from 1966 to 1975, they had to postpone marriage. Bieu fought in Quang Nam-Da Nang for the whole period and was contaminated by Agent Orange. He was wounded and came back a war invalid. One year after marriage they had a son but he was weak and died at seven months of age. In 1978 their first daughter was born, a healthy child who is now married and has a son. The third child is deaf and dumb but can work tending the cattle and doing heavy farm work. The next child, who died at two months of age, was weak in ways similar to the first child. The two following children are mentally normal but have skin rashes all over their bodies, strange stomach pains and feel itchy and get swollen arms and legs in winter. Dieu took them to the doctor but never got any help for their problems, and now they cannot afford doctors. Her husband, who had been in poor health since he was demobilised, died in 1997. Now she is alone with three handicapped children. Her brothers and neighbours often visit and help the family with clothes, and the local authorities pay for books and pens for the children. She feels unable to care for her family; instead, her children have to take care of her.

**Tam**

Tam and Quy are from Quang Ngai province, where both grew up. Quang Ngai is known as one of the most fierce battlegrounds of the war and was heavily sprayed with defoliants for many years. Tam was born in 1953 and joined the youth volunteer force in the mountainous areas between 1963 to 1967. She married Quy in 1975 when the war was over. Quy was in Agent Orange sprayed areas between 1963 and 1972. He is now a war invalid, with frequent headaches and pain from his war injuries. They had their first child in 1977, a son. He was very small at birth and remained weak, with deformed arms and legs, and died in 1998. Three consecutive pregnancies resulted in two premature births and one baby who died soon after birth. In 1983 a boy was born, who grew up normally. After two more premature births where the babies died. Tam gave birth in 1987 to another daughter who is severely disabled. She cannot sit, her body and brain did not develop and although she is 13, she looks as if she is 6.

**Lan**

Lan is a retired teacher, living in relatively good material conditions in Hanoi. Lan was the third of 11 siblings. Born in 1941, she went into teacher training and married at 22. Lan's husband, Duong, was born in 1935 and was trained as a doctor. Between 1963 and 1969 he was a military doctor at the battle fields in Quang Tri. During the spraying in Quang Tri, Duong reported, all vegetation was completely burnt, and he and his friends had to dig hide-outs under the bamboo trees and cover their faces with damp cloths to avoid inhaling the terrible smoke. Their first child was born in 1965 and died at birth. The second son, Lam, seemed normal at birth but gradually it became evident that something was wrong. At 31, the boy only weighs 35 kilos, he cannot control his movements, eat by himself or utter a meaningful word. He needs constant help from his parents. They consulted many doctors, but in vain. Longing for a normal child, Lan gave birth again in 1971. The daughter seemed healthy at birth, but sadly, her neck was too soft and she died when she was three months old. The same thing happened to a baby boy, born two years later: 'How painful it was, the baby had curved arms and was very weak. He also left us forever at three months. What a tearful time it was for me, there was nothing left... As a wife and mother, I always feel tormented and lost... My husband, too, suffers great pain and blames himself for bringing us despair.' They gave up the idea of having another child, and are helped by the encouragement and support of neighbours and relatives. Among Duong's friends from the army, several have suffered a similar fate to Duong.

It was evident from the interviews that the women had been under heavy physical and
mental strain for many years from pregnancy loss and bearing and caring for handicapped children, some of whom had died at early ages. Their burden of work was often extremely heavy, especially in cases where the husband was wholly or partly a war invalid. Sons and daughters who were physically fit often had to shoulder the responsibilities of caring for disabled siblings, farming and household chores. Both parents felt deeply worried about the fate of their disabled children when they themselves would get old and pass away. Some husbands expressed feelings of guilt that their misfortunes were self-inflicted and that they had brought unhappiness to their wives and children. Many women said that they felt inferior for not being able to give birth to normal children. One family had had seven children in the hopes of having a normal son, only to have more miscarriages and disabled children. Some of the women interviewed had as a last-resort ‘asked for a child’ from another man. These cases were described discretely to the interviewers by neighbours or the Women’s Union leaders. Some families had received help from the local authorities and from the Red Cross in the form of disability aid and financial support to enable their disabled children to be trained and rehabilitated. Neighbours were often cited as helpful, but the women often felt ‘ashamed’ to ask neighbours for help. Most families were caring for their disabled children at home themselves.

Using the reproductive lifeline
One aim of the pilot study was to gain experience of using the reproductive lifeline as a tool to minimise recall errors and to give a ‘backbone’ to the interview. Recall errors are common in retrospective studies. The idea of the reproductive lifeline is that by giving a sense of inter-relatedness and coherence to events, the likelihood that relevant events are omitted will be reduced.\(^\text{19}\) Our impression from the pilot interviews was that the visual presentation of the lifeline helped the women to recall the timing and sequence of pregnancy-related events, including pregnancy losses. Together with the interviewer the women would try to recall these events by relating them to other events, such as the end of the war or their own marriage, the year the family moved to a new house, etc. In this way, they contextualised their pregnancies and births, and also had the chance to describe their experiences and feelings. We believe that this method was well-suited for interviewing this group of women, who had had many pregnancy losses and generally troubled reproductive lives.

Caspì et al\(^\text{19}\) also point to the advantages of event history data (as collected with the help of reproductive lifelines) over longitudinal data collected at fixed points in time. They point out, however, that retrospective event history reports have only been validated against earlier self-reports and that there is no real proof of their greater accuracy. Although our impressions were that the reproductive lifeline data reported by the women were accurate, we have no test of validity or accuracy for the data. In future research, several measures can be taken to enhance the accuracy of data.

Belli\(^\text{20}\) points out two particular methods to enhance the accuracy of retrospective recall. One is the use of ‘landmarks’ to aid the dating of events. By connecting to easily remembered event, the less-easily remembered events may be more reliably recalled. As mentioned above, the ‘landmark’ method was frequently used in our study, both spontaneously by the women and sometimes prompted by the interviewers. The reference to the end of the war was the most common and, for our study, appropriate landmark. However, the use of landmarks was not fully developed in the pilot study. A more systematic use of locally specific landmarks will be important for further research with Agent Orange families to enhance the accuracy of data.

The effectiveness of using landmarks depends, according to Belli,\(^\text{20}\) on their effectiveness in conjuring up associated information regarding other events, both in terms of what happened and when. This, again, was done spontaneously by the women in our study but on an ad hoc basis. Structuring the interviewing to encourage the use of parallel retrieval more systematically will be important in further research. A related component lies in the training of interviewers. Researchers have noted that training interviewers to use the life-history calendar is more time-consuming than for an ordinary survey. It requires, for example, spe-
Dieu: reproductive lifeline

-cial skills in being able to encourage ‘parallel retrieval’ through proper probing techniques. For the pilot study, we spent relatively little time on interviewer training as we were not so aware of the special skills required. This will be an important aspect in further research.

A second aim of the pilot study was to identify more specific research questions. Two main themes for research related to stigma and agency emerged from the interviews. It is known in Vietnamese culture that parents with disabled children may hide them for fear of being blamed or not being able to marry off their healthy children. Feelings of stigma associated with having disabled children were not uncommon among both the women and men in this study. Mixed with this was a sense of inferiority at not being able to have healthy children. The failure to give birth to a healthy son was felt as particularly heavy, as Vietnamese culture strongly emphasises the need for a son to continue the lineage and to care for elderly parents. Whether the stigma associated with having ‘Agent Orange children’ differs from the stigma that parents of other handicapped children may feel is an important issue to explore further.

The question of whether there is also social discrimination against ‘Agent Orange families’ and their disabled children is also an important topic for further research. We found no indications of discrimination against the 30 families, but we did not ask specifically about this. It is likely to be a highly sensitive issue, however, that will require delicate probing by skilled interviewers and possibly combining interviews with focus group discussions, where community attitudes and values may be more easily discerned.

‘Agency’ is based on the notion that ‘individuals are active creators of social life’. Linked to agency is the notion of ‘entitlement’, which can be described as the subjective component of rights – what a person feels entitled to rather than what formal rights they claim. Based on research in different cultures, Petchesky hypotheses that most women, however poor and uneducated, act consciously to negotiate their reproductive rights and needs, based on a sense of entitlement.

An interesting lead for further research would be to explore whether this finding from multi-centre research in seven countries in the 1990s applies also to ‘Agent Orange families’. Preliminary findings from the pilot study seem to indicate that many of the women had reached the limit of physical and mental exhaustion where there was little space for agency beyond mere survival. Stigma appeared to interfere to some extent in this struggle. Although we did not ask what they thought the cause of their misfortunes was, the women themselves usually mentioned Agent Orange as the cause. There was a time element in this; many said that ‘before’ they did not know the reason why they were having disabled children, but more recently they had become aware of others with a history of Agent Orange exposure who, like themselves, had had disabled children. However, none of the women expressed a sense of entitlement to assistance or compensation; rather they expressed a sense of resignation to their fate.

What is special about ‘Agent Orange families’
The families in our study were recognised by the local authorities, the Red Cross and them-
selves to be 'Agent Orange families', i.e. with records of Agent Orange exposure of the husband and/or wife, and with disabled children. It is difficult and very costly to establish a genetic association between parental dioxin exposure and disabilities in children in individual cases. This was not the aim of our study; rather the aim was to explore the situation of families who are socially recognised as victims of Agent Orange. At the individual level these families' problems are similar to those of other families with handicapped children – all are equally in need of support. Myths and stigma associated with handicaps in children can be dispelled through public education, based on sound knowledge of social perceptions of and attitudes to handicaps.

However, at the societal level the plight of 'Agent Orange families' is special and should be placed in its historical and political context. The impact over time of the largest chemical warfare in history on families and individuals in Vietnam should be highlighted, described and given a human face. This pilot study has been valuable for further research to this end.

'Vietnam is now a country at peace, extending hands to former enemies, but the victims of Agent Orange will never live in peace.' (Lan, a woman in the study)

Acknowledgements
We are thankful to all the women and their husbands who opened their homes for us and shared their often very painful experiences and memories, the local Women's Union and Red Cross who were helpful in identifying the families, Dr Le Cao Dai of the Agent Orange Victims Fund, Vietnam Red Cross, who has been a source of inspiration and information for the whole study, and Dr Pius Okong for valuable comments on the draft.

Correspondence
Prof Le Thi Nham Tuyet, Research Centre for Gender, Family and Environment in Development, 19 A 26 Nghia San, Cau Giay, 347 Lane, Hoang Quoc Viet Street, Hanoi, Vietnam. Email: cgfed@hn.vnn.vn. Dr Annika Johansson, Karolinska Institutet, 17116 Stockholm, Sweden. Email: annika.johansson@phs.ki.se

References and Notes
6. Most data presented here are taken from a review of the latest research on the health effects of dioxin, found in [7]. The TSD is an update of the US Environmental Protection Agency's assessment of dioxin's health effects (USEPA 1994). The TSD is found on: www.chej.org/report.html
11. Over 20,000 American ex-servicemen have received compensation from the US government for diseases caused by Agent Orange. Spina bifida is so far the only birth defect accepted as grounds for compensation to war veterans' children. No compensation has been paid by the US government to the Vietnamese people for the damage caused by Agent Orange.
12. The organisation Birth Defects in Children has information on effects of dioxin at: www.birthdefects.org
17. The lifeline may include reproductive history data and other events, e.g. education and work, depending on the research

18. These were first generation, post-war children born with disabilities. Cases of second generation children born with disabilities have been reported, but are as yet unverified. Verbal communication, Le Cao Dai, April 2001.


Résumé