

# Perceptions of herpes zoster and attitudes towards zoster vaccination among 50-65-year-old Danes

Gitte Lee Mortensen

## ABSTRACT

**INTRODUCTION:** Herpes zoster (HZ or shingles) and its complication post-herpetic neuralgia (PHN) are common in persons above 50 years of age. A vaccine that decreases the incidence and morbidity associated with HZ was licensed for use in 2006 and will be marketed in Denmark as from 2013. This study aimed to explore the relations between illness perceptions of shingles and attitudes towards zoster vaccination.

**MATERIAL AND METHODS:** Three qualitative focus group interviews were conducted with 22 patients, relatives and individuals with no personal experiences with HZ. Semi-structured interview guides were applied including questions identified in a literature study. The data were analysed using a medical anthropological approach.

**RESULTS:** The study showed that HZ and PHN, in particular, have severe impacts on patients' quality of life (QoL) and often affect their relatives' daily lives as well. Nevertheless, people who have no experience with HZ underrate both its prevalence and its QoL impacts. Such misperceptions often result in delayed treatment and may lead to a low uptake of zoster vaccination.

**CONCLUSION:** Individual attitudes towards zoster vaccination are closely related to subjective perceptions of HZ and views on vaccination in general. Vaccination recommendations to target groups are necessary, but individual choice is determined by knowledge about the disease, personal risk assessment and the recommendations of the general practitioner.

**FUNDING:** The study was funded by a research grant from Sanofi Pasteur MSD.

**TRIAL REGISTRATION:** not relevant.

Herpes zoster (HZ or shingles) is a reactivation in the sensory nerve ganglia of latent varicella zoster virus (VZV or chicken pox) caused by a decline in the cell-mediated immunity to VZV. As such decline is usually age-related, HZ incidence rises at the age of 50 years [1, 2]. HZ is characterized by a vesicular skin rash usually accompanied by acute pain or itching. The most common and severe complication of HZ is post-herpetic neuralgia (PHN) which is mostly defined as pain persisting for a minimum of three months after the resolution of the HZ rash. PHN resolves in the majority of cases, but may persist for years [1, 3-6].

The estimated incidence of acute HZ in the general population in Western countries ranges from three to five per 1,000 person-years [3, 5]. The lifetime risk of HZ is approx. 25%, but rises to 50% in those aged > 85 years [1, 3]. The risk of developing PHN also increases with age. Thus, 10-20% of patients with HZ aged  $\geq$  50 years develop PHN [4, 5, 7]. HZ is more common in women than in men, and also in immunosuppressed individuals [1, 2, 5]. With growing elderly populations in Europe, the rising incidence rates are expected to continue and management of HZ and PHN is therefore expected to constitute an increasing burden on national health care systems in the future [8].

Though quantitative studies revealed that HZ and particularly PHN are associated with a considerable reduction in health-related quality of life (HRQoL), their impact is commonly underrated. A review demonstrated that PHN-related pain can cause chronic fatigue, sleep disorders, difficulty concentrating, depression, loss of bodyweight and social isolation [1]. PHN often interferes with basic daily activities, such as bathing, mobility and housework [1, 3, 9-11].

Delayed presentation of HZ often prevents timely treatment, which should begin within three days from infection to be effective. Antiviral agents are used to treat the VZV infection and corticosteroids can alleviate the acute pain, but it is unclear to which extent these drugs prevent PHN [1]. PHN is highly resistant to treatment as management is limited to antiviral treatment and analgesics. Some tricyclic antidepressants, opioids and anticonvulsants may be effective against neuropathic pain. Acupuncture, chilli-based cream and psychological support for depression and pain-management have also been used with positive effects [1, 6, 9, 11].

A prophylactic vaccine that increases VZV-specific T-cell immunity was licensed for use in 2006 and can decrease the incidence and morbidity associated with HZ and PHN [2]. The vaccine has been shown to reduce the HZ illness burden by 61% in vaccine recipients (individuals aged  $\geq$  60 years); furthermore, its efficacy against HZ was 51%, while PHN incidence was reduced by 67%. The vaccine was most effective in preventing HZ in 60-69-year-olds, but more effective in reducing disease severity in individuals aged  $\geq$  70 years [4]. The vaccine is not indicated for the treatment of acute HZ or

## ORIGINAL ARTICLE

AnthroConsult

Dan Med Bul  
2011;58(12):A4345

**! TEXT BOX**

I sat on a chair all night with tears running down my cheeks. It's that dreadful, this disease, it's horrible. I was off work for a week which I usually never am, but I just couldn't go. I just sat there... It completely exhausted me at the end. Then on top of it, because I was in so much pain, I got this drug, a painkiller, and then I started throwing up all the time, I got a cold and my stomach constipated... You're totally labile, you can't take anything and you cry all the time. Nobody can say anything to you without you starting to weep. I think it's such an awful disease. I've never experienced anything like it. If you could invent some sort of bandage to wrap around your back so you could sleep, just a little bit. You can't lie down at all. I was desperate at the end. I got no sleep and I lost several pounds. You get no rest anywhere. At some point, I had to go back to see the doctor, because it's so dreadful and my belly had this protrusion. He said: "Well, why do you think it's called 'helvedesild'? It is absolutely like being in hell".

*Female patient with shingles for two months.*

ongoing PHN or to prevent the development of PHN in patients with acute HZ. In the USA, zoster vaccination is recommended to all persons aged  $\geq 60$  years [2, 12, 13]. In Denmark, the vaccine is expected to be marketed in 2013.

The present study aimed to examine the ways in which patients, their relatives and persons eligible for zoster vaccination perceive HZ and PHN and how this related to their attitudes towards zoster vaccination. HRQoL was defined as the patient's subjective physical, psychological and social well-being [14].

#### MATERIAL AND METHODS

The study was based on three qualitative focus group interviews with a total of 22 patients, relatives and individuals with no personal experiences with HZ ("baseline") (Table 1). The method aimed to create confidential settings in which participants with comparable experiences could openly discuss their views on HZ and vaccination issues. While individual interviews are apt to analyse personal disease narratives, focus groups are more suitable to grasp the social construction of disease experience and the patterns of consensus and conflict in a given area [15, 16]. Each group comprised 6-8 persons of both sexes, aged 50-65 years, as this would be a relevant target group for zoster vaccination.

Eight patients and six relatives – of whom three were related to participating patients – were recruited through newspaper ads in Copenhagen, Denmark. Eligible participants had had HZ or PHN within the past year, or were close relatives to such a patient, and had no serious co-morbidity or professional knowledge about HZ or vaccination. The baseline group comprising six persons was recruited via random digit calling. No personal information was collected about the participants who received a study information sheet and granted their informed consent.

The focus groups were held at a conference room in Copenhagen and moderated by the principal author (GLM) who was assisted by a fellow anthropologist. The semi-structured interview guide used [16] began with

questions on participants' perceptions of HZ: its causes, prevalence, management and severity. Patients and relatives were then asked about the disease's effects on their daily lives. Corresponding to the term "shingles", all participants used the Danish term "helvedesild" ("hellfire"), to indiscriminately conceptualize HZ as well as PHN, so this concept was used in the interviews. Finally, participants' views on zoster vaccination were discussed. The open-ended questions were based on a literature search using PubMed, Embase, CINAHL and PsycInfo and the search terms (MeSH and free text; in singular and plural): "herpes zoster", "postherpetic neuralgia", "immunization" and "vaccine" combined with "age", "patient", "acceptance", "barrier", "attitudes", "knowledge", "psychological" and "quality of life".

The interviews were transcribed verbatim and analysed using NVivo, a software programme for the analysis of qualitative data (QSR International), and a social constructivist approach [17]. This framework is used to investigate a diversity of statements with a view to generating clusters of meaning around a given topic. It involves an examination of the terminology used to speak about the topic and how it is related to other issues. This created a pattern of the participants' significant perceptions of HZ and views on zoster vaccination. All methodological and analytical steps were discussed with the assisting anthropologist.

*Trial registration:* not relevant.

#### RESULTS

##### Shingles illness perception

No patients or relatives recognized the first symptoms as HZ; they thought it was e.g. an insect bite, arthritis, eczema or sty. This lack of recognition caused all patients but one to delay seeking treatment. Presently, most patients and relatives had learned that shingles is somehow related to chicken pox, rising age and lowered immunity. Half of the patients knew of the concept of

Acute herpes zoster is common in persons above 50 years old. Its most common complication, post-herpetic neuralgia, affects 10-20% of patients in this age group.



HZ, but none had heard of PHN. Both groups wanted to know more about the perspectives of a cure and of pain management, in particular. Only one patient received psychological support; all had tried different medical treatments with varying effects. Some had also used herbal remedies, nerve blocks or acupuncture. At best, these treatments provided short-term pain relief, but many found that the sedative effect of the medical alternative of morphine was too deadening.

Patients and relatives considered shingles to be mostly unknown among people in general, i.e. persons without personal experiences with the condition. In line herewith, the baseline group showed poor knowledge of shingles and only had a vague idea of the condition as something painful. Only one knew that shingles is related to chicken pox and must be treated quickly. Many mistakenly believed they had received chicken pox vaccination as children and hence were not at risk of developing shingles. The baseline group thought that shingles is uncommon and none had heard of the concepts of HZ or PHN.

#### Quality of life effects of shingles

All patients agreed that shingles caused a dreadful pain similar to electric shocks running through their bodies, heads or nerves, or gushing over the skin like a burn. One patient's eye was affected and two had had abdominal protrusions. Movement or skin contact could be unbearable. Wearing clothes, bathing or finding a painless position to rest was difficult and many patients therefore suffered from sleeplessness, fatigue and weight loss.

The disabling pain had substantial QoL effects for the patients who were desperate for pain relief. Some empathised with alleged shingles-related suicides, one had considered it herself as had the father of one of the relatives.

Still, nearly all patients had forced themselves back to work after few weeks on sick leave for fear of losing their jobs. One had been made redundant. They felt that other persons underrated shingles because it is invisible and sounds trivial. They often isolated themselves or pretended to feel better so as not to tire or worry their relatives. Relatives were often worried and stressed by the impact of shingles on the patients, whom they described as tormented, tired and touchy. Some said that "their" patient had become old or changed personality.

#### Attitudes towards zoster vaccination

All participants were surprised to hear about the prevalence of shingles and none in the baseline group had ever feared getting it. All agreed that public acceptance of zoster vaccination relied on knowledge about the disease, management options and vaccination. Half of the



TABLE 1

Participant	Gender	Duration of HZ/PHN	Relation to patient	Participant characteristics.
<i>Focus group 1</i>				
Patient A	Female	6 years		
Patient B	Female	15 months		
Patient C	Female	2 months		
Patient D	Female	10 years		
Patient E	Male	4 months		
Patient F	Male	8 years		
Patient G	Male	2 years		
Patient H	Male	3 months		
<i>Focus group 2</i>				
Relative A	Female	15 months (mother)	Daughter	
Relative B	Female	8 years (brother)	Sister	
Relative C	Female	2 years (partner)	Partner	
Relative D	Male	2 years (father)	Daughter	
Relative E	Male	2 months (wife)	Husband	
Relative F	Male	8 months (wife)	Husband	
<i>Focus group 3<sup>a</sup></i>				
Baseline A	Female			
Baseline B	Female			
Baseline C	Female			
Baseline D	Female			
Baseline E	Male			
Baseline F	Male			

HZ = herpes zoster; PHN = post-herpetic neuralgia.

a) Baseline refers to participants with no personal experiences with herpes zoster.

participants were wary of vaccines which they feared could produce viral resistance or be unsafe in large numbers, i.e. if more adult vaccines were introduced. They worried about side effects and the difficulty of choosing between vaccines. The patients' stated interest in zoster vaccination depended on its ability to treat or prevent a subsequent attack. In that case, all would want it at almost any cost – as would the relatives who had experienced shingles at close hand. Personal experiences thus made even the very sceptical tilt towards acceptance of zoster vaccination.

After being informed about the prevalence and severity of shingles, most baseline participants were positive towards zoster vaccination. All but two participants felt that, if warranted to be safe, everybody in the target group should get the vaccine free of charge or at a low cost, like the flu shot which all believed should be offered to the elderly and frail. No participants found seasonal flu grave enough to warrant vaccination of *themselves*, but contrary to the flu and due to the general unawareness of shingles, they thought that most people would find it difficult to make a personal decision about zoster vaccination.

Most participants saw the childhood vaccination programme (CVP) and travel vaccines as matters of



## TEXT BOX

I'm generally opposed to vaccines. I sort of believe that the body has to create its own immune defence. But then again, vaccination is a good idea against ... smallpox and diphtheria, you know, the life-threatening diseases. In relation to shingles, I would prefer that people were informed about it and could be treated rather than vaccinating everybody, but, still, I'd definitely consider it if the possibility was there – even though I'm opposed to vaccination, because now I've seen what it's like.

*Sister of a brother with shingles for eight years.*



## TEXT BOX

I have two very powerful experiences. One was when my father was screaming with pain: "They are burning me with a red-hot iron!" He's got it [shingles] across the eye and one side of his face. I've never seen my father like that. The second experience was when – after a year or so – he told me that he'd considered how to commit suicide. That's how painful it is ... He gets morphine and uses a chilli-based cream and some painkillers too and yet, he's still in pain. It's very persistent. As soon as his medicine stops working, he starts making these hand movements across his eye because the pain runs in some nerve there. It's racking him with pain. It's tough when your father says: "I'd drive down to the holiday cottage and gas myself". That's not nice. Then you know it's bad.

*Daughter of a father with shingles for two years.*

My wife's [shingles] is placed the same place as your father's, and it's bad because it seals the eye up. And she sits there with that characteristic movement ... It really affects you as a spouse who loves her; it stresses a bit every time she does that. And well, she does that almost incessantly and she sighs and so on.

*Husband of a wife with shingles for eight months.*

course. But many felt that vaccination as a whole earned a bad reputation after the exaggeration of the swine flu pandemic; perhaps nurtured by experts with conflicting interests. This reinforced their view that objective vaccine information should be issued by impartial health authorities. Still, when it came to personal choice, the GP's recommendation was decisive.

## DISCUSSION

This study used qualitative methods to gain a nuanced insight into 50-65-year-old Danes' views on HZ and zoster vaccination. The method of inclusion used may involve some selection bias as persons with negative views may be more likely to volunteer. At the interviews, it was, however, made clear that all attitudes, positive or negative, were relevant to the study. The results can be generalised analytically, though not statistically [15].

This study broadens the knowledge about shingles' QoL effects on patients' lives. Depending on the relation, relatives were also affected to varying degrees; some would worry at some distance, while particularly those cohabiting with the patient were marked by daily caring, sleep disruptions, etc. As a first of its kind, the study shows that participants' views on zoster vaccination were linked to their perceptions of shingles specifically, and of health and vaccination as a whole. This is in line with the Health Belief Model (HBM) which suggests that health behaviour is determined by personal perceptions of a disease and the means available to limit its occurrence [18]. The main determinants of behaviour are the perceived *seriousness* of a disease and the *susceptibility*

to getting it. Also, the *benefits* of a new behaviour must outweigh the consequences of continuing the old behaviour as well as the *major barriers* against vaccination, for instance. In this study, the participants saw travel vaccines and the CVP as almost mandatory measures. Inversely, they expressed a threshold of tolerance towards (optional) adult vaccination to prevent "domestic" diseases, i.e. a barrier towards accepting *several* vaccines against presumably less serious diseases than those you may catch in "exotic" travel destinations. The participants feared that a large total amount of vaccines may have negative health effects. The HBM also includes individual variables such as culture and past experiences. Our participants' views on zoster vaccination were closely related to their personal shingles experiences – or lack thereof.

This study suggests that acceptance of zoster vaccination in Denmark will rely on public awareness about shingles and the treatment and preventive options available. Furthermore, the study confirms that at present such knowledge is poor. In the USA, a survey showed that in the first year after the vaccine's release, uptake was only 1.9%. A total of 72.9% of the respondents were unaware of the HZ vaccine, 34.8% felt that they did not need the vaccine, 12.5% said that they were not at risk, and 9.5% did not have confidence in doctors or in medicine. Still, 77.8% would accept the vaccine if it was recommended by their doctor [19]. This corresponds to the views of our participants. Depending on the cost of vaccination, this may lead to a socially unequal uptake, however. In Denmark, public information should stress that chicken pox vaccination was never part of the CVP due to concerns about raising the HZ incidence and a possible disease shift towards older age groups [20].

This study shows that being in a target group included in the general recommendations does not automatically mean that people feel personally concerned. Reflections on vaccination are subjective and not always coherent from a biomedical perspective, but they must be taken in account as they are the driving force behind people's health-related choices. For target group persons to consider vaccination, information is required along with individual risk-assessment and a direct recommendation from their GP.

**CORRESPONDENCE:** Gitte Lee Mortensen, AnthroConsult, Fynsgade 24, 2. th., 8000 Aarhus C, Denmark. E-mail: glm@anthroconsult.dk

**ACCEPTED:** 16 September 2011

**CONFLICTS OF INTEREST:** Disclosure forms provided by the author are available with the full text of this article at danmedbul.dk.

**ACKNOWLEDGEMENT:** The author wishes to thank social anthropologist Marie Bjørnager Jensen for her assistance with the focus group interviews and scholarly collaboration.

The complete list of references can be obtained from the author.

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