

EMPIRICAL MANUSCRIPT

Hereditary Deafness in a Former Fishing Village on the Dutch Coast

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Abstract

In communities with an increased prevalence of hereditary deafness, social, and linguistic adaptations are found in response. Aulbers (1959) describes a high prevalence of deafness in a fishing village on the Dutch coast: Katwijk aan Zee. This article aims to assess the current prevalence of deafness in Katwijk, as well as the current sign language situation there. To this end, data were collected from various sources, including governmental studies on public health, archives, a genealogical database and interviews with deaf inhabitants of Katwijk. The various types of data confirm the presence of a higher prevalence of deafness in Katwijk that continues to date. Linguistic and anthropological research is needed to establish to what extent this has affected the experience and position of deaf people and their sign language usage in Katwijk.

Revisiting Aulbers (1959): Hereditary Deafness in Katwijk aan Zee

Half a century ago, Aulbers (1959) found a high prevalence of hereditary deafness in Katwijk aan Zee, a Protestant fishing community on the Dutch coast, located in the province of Zuid-Holland (South-Holland). He listed 20 people with hereditary deafness in 12 families in Katwijk. Only one family in this group was not related to the other families, having ancestors from outside of Katwijk. On the related families, Aulbers (1959: 76) noted that:

“Genealogical research established that these families are closely related. Also, all but one of the parents of the probands of these families are kinsmen of each other. Only the father of family 107m is not from Katwijk, the mother is; she is also related to the other families.”

Aulbers noted that it is highly likely that the same recessive gene is responsible for the hereditary deafness in the families in his study. He stated that Katwijk aan Zee constitutes a genetic isolate. He also provided a pedigree of the family ties between the deaf people in the 11 related families. Shared ancestry was presented as far back as 13 generations. The pedigree further showed that deafness was evenly distributed over gender. It also showed three marriages between deaf persons, and two

marriages between a deaf and a hearing person. Strikingly, neither the deaf–deaf marriages, nor the deaf–hearing marriages resulted in deaf offspring. Deaf siblings, however, were more common: Of the 11 nuclear families with deaf offspring, three had two or more deaf children.

The aim of Aulbers' study was to see whether the hearing status of heterozygote carriers of a recessive gene for deafness differed from non-carriers. As such, the study contained very little further information relevant for the historical, sociological, or linguistic study of deafness in Katwijk. On page 76, it is mentioned that the 11 related families with deafness “...stem from the strongly closed fishing population of Katwijk.” and that “...all families practice the same religion...”. He also mentioned that in Katwijk “...one does not find marriages between two hereditary deaf (sic) with children.” (Aulbers, 1959: 76). In personal communication (16-04-2013), Aulbers explained he was able to trace the high prevalence of deafness in Katwijk based on information on deaf pupils from three schools for deaf children, including the Effatha deaf school in Voorburg. In addition, he mentioned not having kept any materials pertaining to the study.

The aim of the current study is to examine to what extent a heightened prevalence of (hereditary) deafness is found in

present day Katwijk aan Zee, and if so, to what extent this has (had) social and linguistic effects.

Public Health Monitors on Hearing Loss and Hereditary Conditions in Katwijk and Katwijk aan Zee

To find out what the contemporary prevalence of (hereditary) deafness is in Katwijk aan Zee, results from public health monitors were collected and compared. Thus, the following set of sources were collected and consulted:

1. The results of the standard screening of hearing status in all new-born babies and young children living in Katwijk.¹
2. Health Monitor 2012 [Gezondheidsmonitor 2012]: A national survey on hearing loss in the Dutch population. This study used a large-scale survey, asking for self-reports about people's ability to follow a spoken conversation in various contexts (with hearing aids if necessary).²
3. Local Health Policy 2009–2012 [Nota Lokaal Gezondheidsbeleid 2009–2012]: A survey on the elderly population of Katwijk, including some information on hearing loss in this population.³

It is important to note that the aforementioned sources concern the present day municipality of Katwijk, a conglomerate of various communities, including Katwijk aan Zee—this will be explained in more detail in the section introducing Katwijk aan Zee.

The data from the public health monitors do not provide clear-cut answer to the question whether (hereditary) hearing loss is relatively frequent in Katwijk or not. On the one hand, various results indicate a lower than average prevalence of hearing loss in Katwijk. Thus, the standard screening of new-born babies reveals an prevalence of hearing loss of 0.2% in Katwijk, which is lower than the Dutch average of 0.3%. Similarly, the recent national survey on hearing loss in the Dutch population (Health Monitor 2012) revealed a lower prevalence of hearing loss for Katwijk (3.3%) than for the country as a whole (4.2%). Thirdly, the standard surveying of new-born children and 5–6-year olds indicates the presence of hearing loss in family members in only 2.5% of the cases in Katwijk, against almost 6% in the Netherlands on average, suggesting that hereditary hearing loss is relatively uncommon in Katwijk. On the other hand, other results from the same monitors do indicate a higher than average prevalence of hearing loss in Katwijk. Thus, the standard screening of 5–6-year old children reveals a higher prevalence of hearing loss in this segment of the population for the municipality of Katwijk (15%), and an even higher prevalence for the former village of Katwijk aan Zee (16%, compared to a national average of 11%). A survey on the elderly population of Katwijk revealed an prevalence of hearing loss in this segment of the population of almost twice the national average (i.e., 13% against 7.3%, Local Health Policy 2009–2012).

In brief, the available sources provide no convincing evidence for the continued presence in Katwijk of a heightened prevalence of family-based hereditary deafness as described by [Aulbers \(1959\)](#). However, reliable demographic data that allow for a reliable comparison of the prevalence and distribution of deafness in a particular community or area are notoriously difficult to come by (cf., [Johnston, 2004](#)). Indeed, a heightened prevalence of deafness may have easily slipped the radar of the large-scale public health monitors, especially because the sources give results for the present day municipality of Katwijk, a population unit much larger than the former village of Katwijk

aan Zee. In the discussion section, I will discuss the usefulness of the public health sources further. In view of the fact that the lack of evidence may be the result of the methodologies used in these studies, additional sources of information were collected. Thus, information on the genetic profile of Katwijk aan Zee was collected and compared to the profiles of communities with a high prevalence of rare hereditary conditions including deafness. In the following section, a resume of demographic characteristics of communities with a high prevalence of hereditary deafness is presented, followed by a demographic sketch of Katwijk. This in turn is followed by a resume of linguistic and social adaptations to a high prevalence of hereditary deafness found in other communities.

Communities with a High Prevalence of hereditary Deafness (GHIDs)

Communities with a high prevalence of deafness have been identified in various places around the world (see [Nyst, 2012](#) for an overview). Like other communities with a heightened prevalence of a rare genetic mutation, such communities typically have (had a history of) a restricted gene pool, resulting from endogamous marriage patterns. The practice of endogamous marriages and the resulting genetic isolation may have various motivations, from practical ones to cultural or religious ones. An example of a practical motivation is geographical isolation. Tristan da Cunha, a British island between Africa and Latin America, is an example in case. Due to its remote position in the Atlantic Ocean, marriage between two persons who share multiple ancestors was standard practice. When the entire population of the island was evacuated in 1963, the community was highly inbred and the prevalence of “congenital abnormalities” (including retinitis pigmentosa, congenital heart defect, and deafness) was found to be twice as high as in the British population ([Black, Lewis, Thacker, & Thould, 1963](#): 1023). Various other examples are known where genetic isolation, coupled with geographical isolation, led to a high prevalence of deafness, including the islands of Martha's Vineyard ([Groce, 1985](#)) and Providence Island ([Washabaugh, 1986](#)). The reduction of genetic variation resulting from the establishment of a new population by a very small number of persons from a larger population is referred to as the *founder effect*. In other cases, genetic isolation follows from endogamous marriage patterns based on socioeconomic or religious grounds. Examples of this are the Muslim enclave of Alipur in a largely Hindu area in India ([Panda, 2012](#)), or the (now migrated) Jewish community of Ghardaia in Algeria ([Lanesman & Meir, 2012](#)). In other communities, marrying blood relatives is common practice in the wider cultural area.

The higher prevalence of a rare genetic condition may also dissolve. Thus, due to natural dynamics, the genetic condition may “die out” without a change in the endogamous marriage pattern. In other cases, changes in the social setting or the degree of geographical isolation may lead to changes in the degree of genetic isolation and consequently to a declining prevalence of the particular genetic condition. In the next section, I will discuss to what extent the community of Katwijk aan Zee can be considered genetically isolated.

Katwijk aan Zee: A Genetic Isolate?

Present day Katwijk is a fusion of two older villages: *Katwijk aan Zee* (Katwijk at the Sea) and *Katwijk aan den Rijn* (Katwijk on the Rhine) and a few other communities. Until around 40 years ago, sea fishing was the main economic activity of Katwijk aan

Zee, shaping the lives of the fishermen and their families (van Deursen, 2011). Already in 1540, life in Katwijk aan Zee was dominated by the sea fishing: of its 200 houses, 150 were occupied by fishermen, who together held 49 vessels. The central role of sea fishing in the economy of Katwijk came to a sudden halt when a complete ban on fishing for herring was promulgated in 1977. Nowadays, fishing is one of the economic activities of Katwijk in addition to others, including tourism, industry, and services. The community of Katwijk aan Zee can—at least historically—be qualified as a maritime community as defined by Davids (1997: 41–71). Like other Dutch fishing communities, Katwijk is known for its conservative, reformed Christian character. According to van Deursen (2011), only 12.5% of the population of Katwijk could be considered not of Christian denomination. The number of inhabitants of Katwijk has fluctuated considerably due to the numerous catastrophes in its history. These include two pest epidemics (in 1573, 1625, and in 1669–1670) and various storm surges, the worst of which—the All Saints storm surge of 1570—washed away entire parts of the village (van Dijk, 2006). In 1867, a cholera epidemic killed 1880 people, 34% of the entire population (van Dijk, 2006). Life got easier for the inhabitants of Katwijk during the first half of the 20th century, when beach tourism started and Katwijk became a popular colony for successful painters. Between 1865 and 1959 (the year of Aulbers' study), the population exploded from 5,449 to 28,734 inhabitants. Due to continuingly high fertility rates, Katwijk now has a population of 43,207.⁴

In her comprehensive description of maritime communities in the Netherlands in the 17th century, de Wit (2008: 191–192) mentions that marriages between partners of similar age and—more importantly—similar social background were preferred. Thus, sons of fishermen preferentially married daughters of fishermen, ideally from the same place. Even within these groups, there was stratification, with sons of steersmen preferentially marrying daughters of steersmen. It seems reasonable to assume that over time, such a marital pattern would narrow down the gene pool in a fishing community like Katwijk, as suggested by Aulbers' finding that deafness runs in fishing families. Indeed, Katwijk is renowned for its high degree of consanguinity. In a book on consanguineous marriages, van der Stok (1888: 8) makes a strong claim, stating that:

"In Katwijk aan Zee, where consanguineous marriages are so common too, that, on a population of over 3500 souls, it is difficult to find six municipal councilors who are not in an outlawed degree of consanguinity [translation mine, VN]".⁵

If in fishing community like Katwijk, the preference to marry between fishing families of the same place is further specified, for example, adding the preference of children of steersmen's families to marry each other, this restricts the gene pool even further, hence increasing the chance of founder effects in the families involved. Indeed, founder effects have been identified in various maritime communities in the Netherlands, such as Urk—where the Van Buch disease has spread—, and Volendam, where the *Volendamse ziekte* or the "Volendam disease" has spread. In Katwijk, a founder effect has caused the spread of a rare autosomal dominant brain disease known as HCHWA-D [Hereditary Cerebral Hemorrhage With Amyloidosis—Dutch type (Wattendorff, Bots, Went, & Endtz, 1982)]. Locally, the condition is referred to as the *Kattukse Ziekte*, literally the "Katwijk Disease". Cases of the same disease have been identified in Scheveningen, a fishing village with close ties with Katwijk. The disease is mainly concentrated in three founder families, possibly reflecting further stratification of marital preferences within the fishing

families as described by de Wit (2008: 191–192). The gene mutation responsible for HCHWA-D is estimated to have taken place before 1700 (Maat-Schieman, Roos, & van Duinen, 2005).

Another indication of a high degree of consanguinity is the relatively large set of typical Katwijk surnames. Many of the typical Katwijk surnames fall in the category of surnames that are qualified as *regional names* by Bloothoof (2011), that is, surnames that are mainly found in a particular region. Bloothoof argues that regional names may be informative of local culture as well as of the genetic properties of the male ancestors of families, because their Y-chromosome is kept in the patrilineal line that is directly linked to their surname. In an analysis of regional names in the Netherlands, Bloothoof (2011: 17) finds that Katwijk has the highest percentage of the country, with 43% of the Katwijk population bearing a regional name. The Katwijk regional names of *van der Plas*, *van Duijn*, and *Heemskerk* are in the top seven of most frequent regional names in the Netherlands.

Communities with a high prevalence of hereditary deafness are well-known outside the scientific fields of genetic and medical studies because of the linguistic and social adaptations shared by these communities around the world. In the following section, the main adaptations are discussed, after which the multimethod, targeted search for deaf signers in Katwijk aan Zee is presented.

Social and Linguistic Adaptations to a High Prevalence of Hereditary Deafness

A heightened prevalence of deafness often has a striking impact on the linguistic landscape of a community. In most documented cases, this has led to the spontaneous genesis of a sign language (Zeshan & de Vos, 2012). Interestingly, a seemingly small rise in the prevalence of deafness from less than 0.5–2% or higher is found to be sufficient to trigger the development of a local sign language (Nyst, 2012). In recent years, interest in such microcommunity sign languages has rapidly increased, as they raise a number of issues relevant to linguistics and sociolinguistics.

Firstly, microcommunity sign languages turn out to be highly relevant for language typology, as several of them are found to have structural characteristics that set them apart from the better studied sign languages of large Deaf communities, or macrocommunity sign languages. Thus, structural features found to be virtually universal in macrocommunity sign languages include the use of classifier predicates expressing motion and location and spatially inflecting verbs expressing agreement (Johnston, 1989). Various microcommunity SLs turn out not to be using these structures and in some cases they have developed unique, alternative structures. For a typological overview of microcommunity sign languages, see de Vos and Pfau (2015).

Secondly, microcommunity sign languages contrast maximally with macrocommunity sign languages when it comes to intergenerational transmission. The transmission of macrocommunity sign languages is marked by the fact that the vast majority of deaf signers are born in hearing families, with no regular exposure to native, adult sign language input. Thus, for these children, the acquisition of the macrocommunity sign language is assumed to mainly take place at the deaf school rather than at home. Especially in schools where no adult deaf teachers are employed, deaf children are likely to mainly acquire sign language from other deaf children. It is argued that the small percentage of deaf children born to deaf parents may play a special role in this type of peer-to-peer transmission, as they are likely to have a head start in the development of their signing skills. In view of the restricted access to adult sign language input, and

the central role of peer-to-peer transmission, several authors claim that American Sign Language (ASL) recreolizes with every new generation of deaf school kids acquiring it (Gee & Goodhart, 1985). In view of the fact that many macrocommunity sign languages share this pattern of transmission, creolization is argued to be an explanation for the structural resemblances found between macrocommunity sign languages and spoken Creole languages (Fischer 1978; Gee & Goodhart 1985, 1988). More generally, the striking similarities in sociolinguistic setting of most of the macrocommunity sign languages studied so far is proffered as an explanation for the equally striking degree of structural similarity found in them (Johnston, 1989: 209). In communities with a high prevalence of deafness that runs in families and—in several cases—the absence of deaf education, the pattern of transmission can safely be assumed to be very different. That is, it is likely that in such communities most deaf children do have a deaf relative. Moreover, due to the higher prevalence of deafness more hearing people have at least some command of the local sign language. As such, the adult sign language input that deaf children get in these communities is likely to be considerably richer than in the case of macrocommunities. Interestingly, the difference in transmission pattern between the two types of signing communities indeed coincides with considerable structural differences, as described above.

Thirdly, due to the rare conditions that trigger their emergence, the sign languages of communities with a high prevalence of hereditary deafness seem to have shorter life cycles than other sign languages. Thus, many if not most microcommunity sign languages described in the literature appear to be very young, not more than a few generations old [e.g., Al Sayyid Bedouin Sign Language (Meir, Sandler, Padden, & Aronoff, 2010)]. As such, they offer a rare opportunity to study the genesis and emergence of languages. Despite their young age, however, many microcommunity sign languages seem to be heading towards the end of their lifecycle. As mentioned at the beginning of this article, their continued use may be endangered by a natural decline in the prevalence of deafness. Alternatively, various changes in the social and sociolinguistic makeup of the microcommunity may lead to the endangerment of the microcommunity sign language. Often, these endangering dynamics are triggered or accelerated by the introduction of deaf education (Fox, 2007; Kisch, 2007; Kusters, 2009: 6; Nonaka, 2004; Nyst, 2007). When deaf children from the microcommunity start going to deaf (boarding) schools, in many cases they are emerged in the macrocommunity sign language. As a result, the macrocommunity sign language may replace the microcommunity sign language as the dominant language of the younger generations, with obvious threats for the vitality of the microcommunity sign language. In some cases, the introduction of deaf education—and through it access to the larger deaf community and its sign language—coincides with other social changes, including less restricted marital patterns. Indeed, this latter combination is what led to the extinction of the microcommunity on Martha's Vineyard east of the United States (Groce, 1985). In a few cases, deaf education in the microcommunity sign language is available (e.g., in the case of Bengkala in Indonesia (de Vos, 2012). Zeshan and de Vos (2012) present a collection of papers on linguistic aspects of a large number of microcommunity sign languages, as well as a collection of sociolinguistic sketches of them.

Finally, microcommunity sign languages are argued to have a relatively high proportion of hearing signers [see e.g., Groce (1985); Marsaja (2008) for Kata Kolok; Nonaka (2014) for Ban Khor Sign Language; Nyst (2007) for AdaSL; and Washabaugh

(1986) for Providence Island SL]. As such, the sign languages are exposed to bimodal language contact in an intensive and stable way. Large Deaf communities are claimed to be typically bimodal bilingual as well, being (a) a minority group in daily contact with a majority using a spoken language and (b) its members having been actively trained in the surrounding spoken language during school years. The study of microcommunity sign languages allows us to compare the type of contact induced features in macro- and microcommunity sign languages, and to evaluate the effects of various sociolinguistic features in which the two types of community are found to differ.

Various communities with a high prevalence of hereditary deafness have been studied by anthropologists, including the Al Sayyid community in the Negev in Israel (Kisch, 2004, 2007, 2008), Adamorobe in Ghana (Kusters, 2011), Ban Khor in Thailand (Nonaka, 2004, 2014) and Bengkala in Indonesia (Branson, Miller, Marsaja, & Negara, 1996; Branson, Miller, & Marsaja, 1999) and Marsaja (2008). Kusters (2009) presents a review of the anthropological literature on communities with a high prevalence of hereditary deafness. One of the themes she discusses is the participation of deaf people in village life, which—in many cases—is claimed to be very similar to the participation of hearing people in the same community. However, various cases of differences are pointed out. Thus, for various communities it is reported that deaf people do not occupy high positions in the local government. Another theme she addresses is the inequities reported in marriage rates and choices. In various communities, the marriage rate among deaf people is lower than among hearing people. There appear to be differences between microcommunities in the tendency for deaf people to marry with deaf or hearing partners. Finally, Kusters (2009) discusses the presence of a distinct deaf subcommunity for most communities with a high prevalence of deafness. She describes how various discourses—both from inside and outside of the community—may influence the social behavior and self-image of deaf people.

In addition to linguistic and sociological studies of communities with a high prevalence of hereditary deafness, one historical study of a community with a high prevalence of hereditary deafness is the well-known study by Groce (1985) of Martha's Vineyard. This sign language of this community is argued to have contributed to the development of present day American Sign Language. The reasoning behind this is that deaf signers from Martha's Vineyard were among the first generations of signers at the first school for the deaf in the United States. As part of the small group of deaf children coming to school with a full-fledged sign language, they are likely to have contributed this sign language to the creolization process as argued for by Gee & Goodhart (as discussed above). As mentioned earlier, the prevalence of deafness on the island of Martha's Vineyard dropped, as a result of which the sign language—the only reported case of a microcommunity sign language in a Western context—ceased to be used a few decades ago, before being documented.

Research Question and Methodology

Recapitulating the results so far for the prevalence of deafness in present day Katwijk shows that, on the one hand, the data of Aulbers (1959) and the genetic profile of Katwijk aan Zee suggest that it is well possible that this community still has a heightened prevalence of hereditary deafness. The data from the public health monitors on the other hand are not consistent nor detailed enough to confirm or contradict this. In view of the inconsistent results from the latter sources, alternative methods were used to find out to what extent the prevalence

of hereditary deafness is still higher in Katwijk aan Zee than the national average. Thus, a targeted search for deaf inhabitants of Katwijk—in the present and the past—was done with the support of the church for deaf people in Katwijk (IC Katwijk), in addition to online, archival, and genealogical research. Extensive online searches were launched to find information on the Internet, using queries like (the Dutch equivalents of) “deaf”, “deaf people”, “hearing loss”, “hard of hearing”, “sign language” (as well as a number of terms for deafness and deaf people now considered derogatory) in combination with “Katwijk”. The identification of deaf signers benefitted mostly from an informal snowball method with the support of the church for deaf people in Katwijk and the help of a deaf research assistant from Katwijk aan Zee [see also Hyde and Power (1992: 170) and Nyst, Sylla, and Magassouba (2012) for this method in identifying deaf signers in Australia and Mali, respectively]. The list of names of deaf people was supplemented with additional names by going through the archives of the deaf school nearby. Finally, a genealogical analysis was done. In Katwijk, there is considerable interest in the history of the town as reflected among others in an active genealogy group as part of the Historical Society of Katwijk. They maintain an online genealogical database holding information on over 300,000 persons.⁶ With the aid of this website and two volunteers of the genealogy group, an analysis of the shared ancestry of the deaf people on the list was made.

In addition, sign language samples were collected with nine deaf signers (six men and three women) from Katwijk, between the ages of 20 and 83. All of the signers are former pupils of the Effatha School. The signed samples consist of interviews and short stories. The data were collected by a team of two deaf research assistants: Linda van Duijn and Arno Roeleveld. The interviews were summarized by Linda van Duijn, and are currently in the process of being annotated in ELAN, a software tool for video annotation.

Results: Hearing Loss, Deaf People and Sign Language Usage in Katwijk

The various methods used led to a multitude of data, which are presented below under two themes. Thus, firstly the results pertaining to the number of deaf individuals identified in the past and the present in Katwijk, and the family ties between them are presented. Then, the linguistic and social reflections of deafness in Katwijk are discussed.

Deaf Kattukers in the Past and the Present

Using the aforementioned approaches, around 80 deaf people born or living in Katwijk have been identified, about half of whom are alive. Thirty of the deaf persons identified have a full sibling who is deaf. In the database of deaf people from Katwijk, two family names are particularly recurrent. Twenty-two deaf people have a parent who is born with the most recurrent family name. Fourteen deaf people have a parent born with the second most frequently found family name. The youngest deaf person with one of the two frequent family names was born in 2011. The analysis of the shared ancestry of the deaf people, made with the help of the Historical Society of Katwijk, revealed that most of the deaf people on the list have multiple shared ancestors, which complicates the task of reconstructing the genetic history of deafness in Katwijk. Although the genealogical database proved a very helpful tool, the exercise of identifying the genetic affiliation of the deaf persons identified so far proved to

be very challenging for various reasons. First of all, only information on deceased people in the database was available to us. Secondly, the tradition of naming people after their relatives on the one hand, and the frequent recurrence of the same family names on the other, has resulted in a dataset with many people bearing the same name and even the same year of birth. A full analysis of the genetic relations requires extensive genealogical and genetic research. However, the preliminary results suggest that the higher prevalence of family-based deafness continues to exist in present day Katwijk. Thus, whereas a continued presence of the family-based hereditary deafness is not visible in population-wide studies and monitors, a targeted search for deaf people based on social networks, archives and the internet does indicate its presence in Katwijk.

Social and Linguistic Adaptations to Deafness in Katwijk

If indeed hereditary deafness appears to still have a significant presence in Katwijk, it is likely that this has led to social and linguistic adaptations. Indeed, the online searches quickly revealed that Katwijk has a very active deaf church, with an acclaimed 40 members, weekly church services, a coffee group for elderly deaf people, a bible club for deaf adults, and a crafts club for deaf children. The church recently celebrated its 60th birthday and has expanded considerably over those years. In addition to the bible club of the deaf church, there is a second bible club affiliated to a different national bible club. Apart from these religious organizations, there appear to be no other deaf-based organizations.

Quite a number of deaf-deaf marriages are found, whereby at least three deaf partners moved to Katwijk to marry a deaf person from Katwijk. According to various deaf and hearing people, deaf people are not allowed to work as fishermen for their own safety, as people on deck are “warned for danger by shouting”. The observations on social adaptations are anecdotal and preliminary, however, and historical and anthropological research is needed to study this in-depth.

Linguistically speaking, perhaps the most striking adaptation to multigenerational deafness seems to be the spontaneous emergence of a local sign language. Preliminary analysis of the interview data, however, shows that current sign language usage does not present an independent type of sign language. In other words, the signing is recognizably a form of NGT, or Dutch Sign Language. In fact, the recordings various forms of NGT, with a large degree of variation in the linguistic performance of each signer. To some extent, this variation runs parallel to processes found in the wider Dutch signing community, which recently underwent an actively steered standardization process. Thus, the youngest signer uses a signing variety that does not seem to stand out in any way from standardized sign language variants used by deaf youngsters from outside of Katwijk. Interestingly, this signer is attending a deaf school different from the former Effatha school. Older signers on the other hand were found to use structures more influenced by the word order of spoken Dutch. Again, this is a pattern commonly observed in older signers in the rest of the country as well. In other respects, the sign language usage in the interviews seems to pattern in a way that is less recognizable as mainstream Dutch Sign Language usage. Thus, in some cases, a repeated atypical usage of a common sign was found. In other cases, an uncommon sign was used more than once for the same concept. Moreover, two deaf signing linguists familiar with deaf signers from Katwijk indicate that

deaf signers from Katwijk have a distinct signing style. In short, closer analysis of this and other material is needed to establish the degree to which patterns of sign language structure and use differ in Katwijk as compared to other varieties in the Netherlands. In particular, the Effatha variant of NGT will be an important base line for comparison, as the Effatha deaf school has provided deaf education for most deaf people from Katwijk in the past century.

Deaf Education and Sign Language Use

The oldest documented deaf person from Katwijk is Elisabeth Keyzer (1819–1837), whose father was a fish monger. At the age of 11, she registered as an internal pupil of the Guyot School in Groningen, the first school for deaf children in the Netherlands (Tijsseling, 2014). The school's records furthermore show that 7 years later, she was one of three pupils who died of tuberculosis at school that year. She is probably the first deaf person from Katwijk to have attended a deaf school. The student registers of the Guyot School show that Elisabeth was the only deaf pupil from Katwijk for over a century. The second pupil from Katwijk at that school was a child of one of the many families evacuated during World War II, due to the construction of the Atlantikwall in Katwijk.

Ever since the opening of the Effatha School, this school seems to have been the preferred school for most deaf children from Katwijk. The history of deaf people in Katwijk is closely tied to it. Of Calvinist Protestant denomination, the school was first established in 1888 in Leiden, but soon thereafter moved to Dordrecht and finally settled in Voorburg in 1926. In 1981, an additional branch was opened in Zoetermeer. In 2002 and again in 2009, various deaf schools, including the Effatha schools in Zoetermeer and Voorburg, merged with several other deaf schools (Tijsseling, 2014). Initially, student registers were carefully written up, providing detailed information about each student, his/her parents, nature and cause of hearing loss, speech skills, character, and the number of years spent in school, as illustrated by the transcript of Neeltje V., the first deaf pupil from Katwijk, below.

“Dochter van Cornelis V., visscher te Katwijk aan Zee en van Arendje O., werd geboren 28 September 1901 te Katwijk aan Zee en in de Ned. Herv. Kerk gedoopt. Zij werd opgenomen 1 September 1915 voor rekening van de Diaconie der Ned. Herv. Kerk en het Burgerlijk Armbestuur. Waarschijnlijk is Neeltje doof geboren, of is haar doofheid ontstaan op zeer jeugdigen leeftijd door stuipen. Zij is totaal doof. De ouders zijn geen bloedverwanten. Zij hebben zeven kinderen, waarvan Neeltje het vierde is. Haar zuster Arendje is ook doofstom (zie 109). Andere gevallen van doofheid of hardhoorendheid komen in de familie niet voor. Neeltje is altijd goed gezond en is goed van karakter. Den 31^{den} December 1919 werd Neeltje van de lijst der leerlingen afgevoerd. Haar vorderingen waren ruim voldoende, alleen haar spreken kon beter geweest zijn. Zij werd door haar ouders naar huis gehaald, omdat zij reeds 18 jaar oud was.”

“Daughter of Cornelis V., fisherman Katwijk aan Zee and Arendje O., was born 28 September 1901 in Katwijk aan Zee and baptized in the Dutch Reformed Church. She was admitted 1 September 1915 on behalf of the Parish of the Dutch Reformed Church and the Civil Poor Relief. Neeltje was probably born deaf, or her deafness was caused by convulsions at a very early age. She is totally deaf. The parents are not blood relatives. They have seven children, of whom Neeltje is the fourth. Her sister Arendje is also deaf and dumb (see 109). Other cases of deafness or hearing loss do not occur in the family. Neeltje is always in good health and has a good character. On the 31st of December 1919, Neeltje was withdrawn from the list of students. Her progress was amply sufficient,

only her speaking could have been better. She was taken home by her parents, because she was already 18 years old.” [Translation VN]

Interestingly, the absence or presence of a kinship relation between the parents, as well as the presence of hearing loss in family members was also mentioned. In various cases of children from Katwijk, the information provided on a kinship relation between the parents proved inconsistent with our genealogical data. Thus, in several cases it was claimed that the parents were not blood-related, whereas our genealogical analysis does reveal a genetic link. The student registers can be accessed in the Effatha archives which are stored in the municipal archives of Voorburg (Den Haag).

Student numbers kept rising and from 1932 onwards the registers are no longer hand-written, but printed. The amount of information given for each student is considerably reduced, with only name, place, and year of birth being provided. In addition, in the listings of former students, the occupation of students is mentioned as well. In 1915, when Effatha has around 45 pupils, the first students from Katwijk appear in the registers; that is, the above-mentioned Neeltje V, then 14 years old, and her 2 years younger sister Arendje. In the decade that followed, the number of pupils from Katwijk rapidly increases. In 1926, when Effatha has a total number of pupils of 97, 7 pupils are from Katwijk, and 1 pupil is from a Katwijk family living in the neighboring village of Noordwijk.

Effatha had boarding facilities for their pupils, but in addition they managed to offer daily transport to some pupils living nearby. From 1956 onwards, this service was extended to Katwijk as well. A year later, between 1957 and 1958, Effatha's teaching activities were temporarily extended to Katwijk as well, when a tuberculosis outbreak contaminated 15 pupils. As 11 of them were hospitalized in Katwijk, a teacher of the Effatha School, himself an inhabitant of Katwijk, teaches these children in hospital.

Although most deaf children from Katwijk seem to have attended the Effatha School, this is not the case for all of them. Some children visited Effatha only briefly and changed to other schools or dropped out altogether. In Effatha's annual reports, complaints are regularly made about the number of Protestant deaf children who attend other schools than Effatha, due to the relatively high fees of the Effatha school. This may have held for deaf children from Katwijk as well.

Like all Dutch deaf school, Effatha's language policies changed over the years, as described by Tijsseling (2014) in her study of the history of deaf schools in the Netherlands. Having been established shortly after the Milan Congress in 1880, the institute used an oralist approach during the first century of its existence. In the period 1919–1929, teachers and board of the Effatha School were particularly worried by the use of signs by deaf pupils (Tijsseling, 2014). Thus, during a teachers' meeting, complaints were made that the deaf maids had “a devastating effect” on the speech skills of the students built up by the teachers. Several measures were taken to avoid the use of signs, especially in the older pupils. Thus, younger children were separated from older ones, and extra supervision was put in place to prevent the older children from using signs in their free time. Around 1985, attitudes started changing in favor of the use of signs in deaf education and sign supported Dutch was introduced. In the nineties of the last century, bilingual education was introduced. In 2000, the school offered its apologies to its former pupils for having punished the use of sign language in earlier decades.

An inventory of lexical variation in NGT 35 years ago revealed both age-related variation as well as school-related variation (Schermer, Harder, & Bos, 1988). Around 40 concepts with a sign specific to Effatha (referred to as *Voorburg*) are listed in this publication and reproduced in the online Van Dale dictionary.⁷ However, some of these signs are identical to the signs used in other variants, particular in the South-West of the Netherlands. What does seem to be unique for the Voorburg/Effatha variant is the use of particular handshape-location combinations that were used in Effatha in speech therapy to visualize particular sounds, that is, the system of *klankgebaren*, literally “sound signs”. Also, a preference for sign supported speech may be characteristic of former students from Effatha. Apart from the variation study in 1981, no further studies have explicitly addressed the Effatha variant of NGT. The NGT Corpus does include recordings of 20 former pupils of Effatha, but so far no annotation or analysis has been done on them.

All in all, the Effatha variant of NGT is understudied, both synchronically as well as diachronically. Little is known about the genesis of the Effatha variant of NGT. Due to the paucity of documentation, it is difficult to reconstruct which elements contributed to the formation of the Effatha variant. For some deaf schools, the initiators made deliberate attempts to use signs to communicate with the deaf pupils. This was, for example, the case for the first deaf school in France. With the Effatha School using a non-signing policy from its onset, it is clear that the teachers made no deliberate attempts to expose the pupils to signs. However, they did contribute the sound signs system. In addition, other contact features transferred from spoken Dutch (including mouthings, loan translation, and perhaps even word order) might be attributed to the teachers.

At this point, one can only speculate on the origin of the manual signs of the Effatha variant. A possible scenario is that the deaf pupils themselves played a pivotal role in the development of the sign language emerging in school. In analogy to the documented genesis of Nicaraguan Sign Language (Senghas, Kegl, Senghas, & Coppola 1994), one might assume that children would have brought the signs they used at home to school, where a new common sign language would emerge. It is generally assumed that children from deaf families—already exposed to adult deaf sign language models at home—have an above-average influence on the repertoire of signs used in the school community. Just like deaf pupils from Martha’s Vineyard may have contributed Martha’s Vineyard Sign Language to the formation of American Sign Language (Groce, 1985: 71; Lupton & Salmons, 1996: 81), deaf children from Katwijk may have contributed the sign language from their homes to the emergence of the Effatha variant. Another source for the signs of the Effatha variant may have been one of creation rather than of transmission. Thus, in the interviews, one of the elderly signers from Katwijk mentions that she—together with her friend and her deaf brother—used to invent their own signs. Unfortunately, she did not remember any examples. It is likely that other children—including those from other places than Katwijk—may have been creating new signs as well.

At the same time, it is likely that deaf pupils were not the only ones influencing sign language patterns in the school. Virtually from the start of the school, deaf assistants have been working in the school. It is likely that they played a significant role in the emergence of the Effatha variant as well. They may have had different kinds of influence, depending on their linguistic background. Those who attended a deaf school may have contributed signs from that school. It is probable that

most of the deaf staff were former pupils of Effatha. However, in the first decades of the school’s existence, the deaf staff may have consisted of former students of other deaf schools as well. Alternatively, the deaf staff in the early decades of the school may not have had the chance to attend a deaf school. As such, they may have contributed their own homesigns, or—in the case of deaf children from deaf parents—the family sign language to the emerging school sign language.

A central question at this point is whether indeed deaf children from Katwijk were exposed to adult signing before coming to Effatha. Was there a sign language specific to Katwijk prior to 1915, when the first deaf children started attending the Effatha school? In view of the high prevalence of family-based hereditary deafness, together with the close-knit character of the community suggests that there is a good chance that this was the case. Even nowadays, now that most of the signs used in Katwijk seem to be part of the (Effatha variant of) NGT, it may still be the case that there are particular linguistic patterns or lexical items that are particular to Katwijk. More linguistic and historical research⁸ is needed to answer this question.

Discussion

The main aim of this article was to establish whether the prevalence of hereditary deafness in Katwijk is still heightened and concentrated within particular families, as described by Aulbers in the fifties of the last century. Public health studies monitoring hearing status in the population of Katwijk and the Netherlands in general do not indicate such a higher prevalence of (hereditary) deafness in Katwijk. A targeted search for deaf people in Katwijk however, indicates the contrary.

A heightened prevalence of hereditary deafness is repeatedly found to affect the experiences of deaf people in these communities as compared to communities with an average prevalence of deafness. In addition, the heightened prevalence of deafness may impact on the linguistic patterns in the community, typically leading to the emergence of a local sign language. The likelihood of a local sign language in the past and in the present has been discussed extensively in the preceding section, as well as the possible influence this may have had on the emerging Effatha variant of NGT and vice versa. What remains to be discussed here is the appropriateness of data from public health monitors for the identification of a heightened prevalence of hereditary deafness.

Demographic data that allow for a reliable comparison of the prevalence and distribution of deafness in a particular community or area are notoriously difficult to come by (cf., Johnston, 2004). In part, this results from the multitude of categories, definitions, methodologies, and criteria that can be used in screening a population in terms of hearing loss. It is even more difficult to make estimates on the demographics of sign language usage on the basis of data on hearing loss in a given population, as there is no one-to-one relation between the two. For the targeted search for deaf inhabitants of Katwijk, various methods were used, including inquiring through existing social networks, archival research, and extensive Internet searches. The results of these searches do suggest a higher prevalence of deafness in Katwijk. In addition, genealogical analysis provides evidence that a considerable number of the deaf people identified are blood related. The discrepancy between the results of the large-scale monitor studies on the one hand and the targeted searches on the other suggest that a heightened prevalence of

recessive, autosomal hereditary deafness easily slips under the radar of standard public health studies.

Several phenomena may explain the inadequacy of the standard health studies consulted in this study. A first explanation may be that studies using sampling will fail to pick up on hereditary deafness, due to the extremely low frequency of it. Thus, the average prevalence of non-syndromic, autosomal recessive hereditary deafness in the Netherlands is estimated at 0.025% (Marres and Cremers, 1989). Probably, this average should be adjusted, as deaf people tend not to live evenly distributed over the country. A survey study on Australian Sign Language users finds that "... deaf signing people are essentially urban dwellers Hyde and Power (1992:173). Few of them live outside metropolitan areas, and then mostly in larger provincial towns". Thus, certain places are known to house relatively large numbers of deaf inhabitants, such as towns with deaf schools or other important deaf facilities. Examples of such towns and cities in the Netherlands are Amsterdam, Rotterdam, Groningen, Voorschoten, Zoetermeer, and Ede. In view of the concentration of deaf people in these places, the average in places without significant facilities for deaf people should be even lower than 0.025% as a consequence. Present-day Katwijk aan Zee has a population of 13,910 (CBS statline, 2012⁹). If the prevalence of hereditary deafness has dropped to the national average or below, the number of persons with hereditary deafness should be four or lower.

Another explanation for the discrepancy concerns those studies asking for self-assessments of the respondents. The particular sociolinguistic setting of a CHID may bias answers to the questions asked in these studies. Thus, in the standard monitoring of new-born babies and 5–6-year olds, parents are asked about the presence of hereditary diseases in the family. However, perceptions of deafness in terms of disease may vary. In families with deafness in general, but in particular in families with hereditary deafness in CHIDs, deafness may be less typically considered a disease, but rather as a communicative trait. Thus, in her anthropological study of a CHID in Israel, Kisch (2008: 283–284) notes: "Moreover, the common familiarity with deaf people and sign language facilitates the production and sharing of a unique experiential knowledge, grounded in daily experiences and practices. In this context, deafness is not easily subjugated to its medical model."

Possibly contributing to a more positive attitude towards deafness in CHIDs is the historical grounding of deafness in the community, which are often claimed to have had deaf people for as long as anyone can remember [Frishberg (1987) for Adamorobe; Groce (1985) for Martha's Vineyard]. In some communities, a deaf person seems to have been among the first settlers of the community [e.g., in Adamorobe (Nyst, 2007) and Martha's Vineyard (Groce, 1985)]. This provides an ideal opportunity for a particular gene variant to spread broadly throughout the expanding community over time. This phenomenon is referred to as a "founder effect" in genetic studies. Nyst (2007: 26) argues that this founder effect not only affects the gene pool of the community, but potentially the social perception of deafness in the community as well.

In the study focusing on hearing loss in teenagers and adults (Gezondheidsmonitor 2012), the type of questions asked may have biased the results as well. This study seems to have been motivated by the rapid increase in hearing loss due to exposure to loud music. In this study, respondents were asked to what extent they normally have problems following a conversation—if necessary with a hearing aid—with one other person and in a group of more than three persons. One's ability to do so, however, is

importantly affected by the coping strategies developed by a person with hearing loss. Thus, someone with recently discovered and treated hearing loss might be much less able to follow a conversation with another person than someone who was born with extensive hearing loss, but who, for example, wears a hearing aid, is trained in lip-reading, and has a stable circle of conversational partners with accessible communication either using sign language, or visually accessible speech, or a combination of both. Interestingly, 0.0% of the respondents in Katwijk between the ages of 19 and 64 years indicate being unable to follow a conversation with one other person. In brief, the framing of the questions in this study seem to be more suited for detecting untreated hearing loss, than for detecting hereditary deafness.

Conclusion

Half a century ago, a high prevalence of hereditary deafness was found in Katwijk (Aulbers, 1959). This article revisits the situation in Katwijk, with the aim of assessing (a) to what extent the prevalence of hereditary deafness in Katwijk is still heightened there and (b) to what extent it shares sociolinguistic features with other communities with a high prevalence of hereditary deafness. Analysis of the results of various public health monitors does not consistently show a higher prevalence of hearing loss in Katwijk. Medical studies describe the widespread occurrence of another genetic condition in Katwijk, showing the general susceptibility of the gene pool for the above-average spread of rare genetic configurations. However, a targeted search for deaf people from Katwijk in the present and the past indicates the continued presence of the higher prevalence of family-based hereditary deafness described by Aulbers (1959). This shows that population-wide monitors and sample studies on hearing loss are not the best tool to estimate the prevalence of recessive hereditary deafness in a community, due to their low frequency. This holds true for estimates on the number and distribution of sign language users as well. A combination of alternative methods was used to search for deaf signers and the likelihood of genetic cause underlying their deafness, including an informal snowball method, archival research, and Internet searches. Genealogical analysis revealed multiple shared ancestors for the majority of deaf people on our list.

The continued presence of a high prevalence of hereditary deafness in Katwijk raises the question to what extent the sociolinguistic features described for other communities with a high prevalence of hereditary deafness are found in Katwijk as well. Exploratory interviews with nine deaf inhabitants of Katwijk clearly illustrate that the sociolinguistic situation of deaf people in Katwijk is heavily influenced by deaf education, in particular by the orthodox protestant Effatha School in nearby Voorburg and Zoetermeer. A 1981 study on lexical variation revealed the presence of an Effatha or Voorburg variant of Sign Language of the Netherlands. Little is known about this variant, but it is clear that much of the language patterns found in the interviews reflect linguistic practices at Effatha.

Further Research

This leaves open a number of interesting questions for further research. A first question of interest concerns the communication of deaf Kattukers prior to 1915, when the first deaf children from Katwijk started attending the Effatha school. In analogy to other communities with a high prevalence of deafness, it is likely that they used a sign language variant that was particular

to Katwijk. A second question is to what extent vestiges of such a distinct Katwijk variety can still be distinguished today, despite the pervasive influence of signs from Sign Language of the Netherlands, in particular the Effatha variant, in the form of sign supported Dutch. To start finding answers to these questions, more research is needed, using methodologies from lexicology and oral history. Apart from linguistic issues, the high prevalence of hereditary deafness is likely to have affected the social position of deaf people in Katwijk. Historical research into the daily lives of deaf people will shed new light on the history of deaf people in the Netherlands, in the context of a small town, rather than of a deaf school.

Notes

1. I thank the Municipal Health Service (GGD Holland-Mid-den) for making these data available for the present study.
2. Retrieved from <http://www.cbs.nl/nl-NL/menu/themas/gezondheid-welzijn/cijfers/incidenteel/maatwerk/2013-gezondheidsmonitor2012-mw.htm>.
3. <http://www.ggdghorkennisnet.nl/?file=1178&m=1310633708&action=file.download>, p. 64.
4. The population numbers given here are the numbers for Katwijk aan Zee and Katwijk aan den Rijn taken together. Retrieved from www.katwijk.nl. Last accessed: 27-03-2015
5. Original quote: "In Katwijk aan Zee, waar ook onderlinge huw-erlijk zoo veelvuldig zijn, dat het, op eene bevolking van ruim 3500 zielen, moeielijk valt zes gemeenteraadsleden te vinden, die elkander niet in een bij de wet verboden graad van bloedver-wantschap bestaan."
6. <http://geneakatwijk.webtrees.net/>.
7. <https://www.gebarententrum.nl/gebaren/van-dale-ngt-uitgebred/>.
8. Another interesting element in the Deaf history of Katwijk is the life of deaf painter Jan Zoetelief Tromp (1872–1947). Born in Indonesia in 1872, Tromp was sent to The Netherlands to visit a deaf school in Rotterdam in 1877. At that time, a strict oralist approach was used there. After completing the Academy of Fine Arts in Amsterdam, he was adopted in the social circle of famous painters who regularly stayed in Katwijk to depict Katwijk's sea life. In 1899, he married Marie Blommers, daughter of a famous painter. From 1919 to 1930, they lived in Katwijk in Villa Saskia on the boulevard (www.janzoetelieftromp.nl, visited on 02-03-2015). Not much is known about how Tromp's deafness affected his work or private life. When Tromp was painting portraits, his wife Marie would be present to facilitate communication with the model (E. van der Dussen of the Jan Zoetelief Tromp Foundation, personal communication). In 2011, a color glass window in the Old Church of Katwijk ("de Klijnhaler") was identified as a work of Tromp (<http://hervormdegemeentekatwijk.nl>). In that same year, an exhibition was devoted to Tromp in the Katwijk Museum.
9. Retrieved from <http://statline.cbs.nl/Statweb/publication/?DM=SLNL&PA=70904ned&D1=3&D2=8948-8949,8957,8961,8966,8974,15248-15249,15251&D3=&VW=T>.

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Conflicts of Interest

Prof Allard van der Beek has shares (<5%) and performs consultancy work (< 4 hr/week) for "Evalua Nederland B.V." (www.evalua.nl).

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