

2012

The Psychosocial Burden upon a Positive Chronic Hepatitis B Diagnosis Amongst First Generation Turkish Immigrants



Name:

Roddy van der Horst

Daily Supervisor:

Kees Dirksen, MD, MPH

External Supervisor:

Dr. Jim van Steenberghe

VU supervisor:

Dr. Tjard de Cock-Buning



Gemeente Den Haag

awpg

Academische Werkplaats
Publieke Gezondheid
Noordelijk Zuid-Holland

Acknowledgements

I am grateful to the following people for their help by providing feedback during the study: Dr. J. van Steenberghe, Prof. Dr. T. de Cock-Bunning, Dr. W.A. Gebhardt, Prof. Dr. R. Reis, Dr. W. van Brakel and Drs. R. de Groot, Netherlands Leprosy Relief. Also, I want to thank my daily supervisor Kees Dirksen, MD, MPH, for providing feedback and for helping to approach and recruit the patients during the study.

In addition, I would like to express my gratitude to the GGD Rotterdam, especially to dr. van der Veen, for providing 12 additional transcripts of Turkish HBV carriers in Rotterdam, which allowed for valuable insight in the drivers behind hepatitis B related stigma.

Finally, I am grateful to the respondents in The Hague for their willingness to participate in the study.



Personal & Internship placement Information

Topic: Psychosocial Burden upon a Positive Chronic Hepatitis B diagnosis
Amongst First Generation Turkish Immigrants

Organization: GGD Den Haag (AWP NZH)
Address: Westeinde 128
2512 HE Den Haag

Name Student: Roddy van der Horst
Specialization: International Public Health
E-Mail: roddy.vanderhorst@hotmail.nl
Telephone: +31 649894927

Name of external lecturer: Dr. Jim van Steenbergen
(name, telephone 071-5262946
and email address) j.e.van_steenbergen@lumc.nl

Daily Supervisor: Kees Dirksen, MD, MPH

Abstract

Hepatitis B is responsible for a high disease burden worldwide, since approximately 350 million people are currently chronically infected with the hepatitis B virus (HBV). In the Netherlands the prevalence of hepatitis B is low. However, for certain risk groups and immigrants from HBV high endemic countries the prevalence is comparatively much higher than for the general Dutch population. Consequently besides the existing hepatitis B policies for risk groups, the GGD initiated Hepatitis B screening projects among first generation Chinese immigrants in the four main cities of the Netherlands. However, the GGD received several indications from patients that forms of stigma occur towards chronic HBV carriers within minority communities. Health-related stigma is one of the primary causes of stress, alienation and discrimination, which can act as a barrier to prevention and care for infectious diseases such as chronic hepatitis B. Therefore, this study focuses on the extent to which stigma occurs and assesses the psychosocial impact of hepatitis B on the lives of Turkish immigrant chronic hepatitis B carriers in The Hague, since the Turkish community composes of the largest group of immigrants diagnosed with chronic hepatitis B of The Hague.

Twelve transcripts of a previous study with HBV carriers in Rotterdam aimed at developing an evidence-based guideline for counselling chronic hepatitis B patients were re-analysed for this purpose. Furthermore, a validated generic stigma semi-structured interview design was used to interview 15 chronic HBV carriers in The Hague. In addition, 4 key informants, i.e. one Dutch GP and one Turkish-Dutch GP who frequently see Turkish HBV carriers, a Turkish social worker and an internist (physician specialized in internal medicine) were interviewed in order to acquire broader information about HBV-related stigma in the Turkish community. Also, the information provided by the key informants was compared to the data acquired from the chronic carriers (both of Rotterdam and of The Hague), in order to determine under which conditions stigma took place.

Ungrounded preventive measures, restricted participation and exclusion appear to be an everyday reality for a majority of the Turkish HBV carriers. Around half of the Turkish HBV carriers of The Hague stated that they (had) suffered from various forms of enacted stigmatization, these acts of stigma ranged from prejudices to social exclusion of Turkish chronic HBV carriers. In addition, these patients stated more frequently that they suffered from felt normative stigmatization, because they felt that society in general holds negative views about hepatitis B. All these acts of stigmatization can be correlated to the lack of hepatitis B knowledge within the Turkish community which results in enacted stigma, and the lack of knowledge of those stigmatized, which results in internalized stigma and felt normative stigma. It turned out that the knowledge of the majority of the respondents (both of The Hague and Rotterdam) was mediocre at best regarding HBV transmission routes and was poor when assessing the knowledge concerning the prognosis of hepatitis B. Therefore, it is likely to assume that the knowledge within the Turkish community is also poor, since even those who are diagnosed with the disease have little to no knowledge about the disease.

As a response to these forms of stigma, coping strategies are adopted by Turkish HBV carriers in order to deal with stigma and the disease. These coping strategies (mainly emotion focused coping)

ranged from limited disclosure of hepatitis B to others, overall lack of active engagement of patients with practitioners during consultations, and generally the lack of actively searching for information by respondents. On the other hand, the nature of hepatitis B disclosure is mainly to acquire (emotional) support, advice and information about the disease. Therefore, it can be argued that respondents generally rely on information of family members when employing problem focused coping strategies and are therefore more susceptible to forms of enacted and internalized stigma.

In conclusion, hepatitis B and its associated stigma affect the social lives of first-generation Turkish HBV carriers, even in a low-endemic hepatitis B country as the Netherlands. Poor knowledge about the disease is identified as the main driver behind forms of stigma, in both the enacted stigma of Turkish-Dutch community and the internalized stigma of first generation Turkish immigrants diagnosed with chronic HBV. Therefore it is prudent to put more emphasis on increasing the knowledge (mainly on HBV transmission routes) of Turkish HBV carriers during consultations, in order to make Turkish HBV carriers less vulnerable to forms of enacted stigma since they will subsequently not view these acts of stigma as valid. Also it would be prudent to assess hepatitis B-stigma in other (large) immigrant groups from intermediate or highly hepatitis B endemic countries to assess if similar psychosocial disruptions occur, in order to determine if it is necessary to adapt hepatitis B consultations for more immigrant groups from intermediate or high endemic HBV countries.

Table of Contents

Acknowledgements	0
Personal & Internship placement Information	2
Abstract	3
Abbreviations	7
Chapter 1: Introduction and Background information	8
1.1 Global Epidemiology of the Hepatitis B Virus	8
1.2 Hepatitis B prevalence in the Netherlands	10
1.2.1. Hepatitis B screening programs	11
1.3 Health-related stigma and hepatitis B	12
1.3.1 What is stigma?	12
1.3.2 Hepatitis B related stigma	13
1.4 Research objective and aim of the study	15
1.4.1 Problem statement: Stigma amongst Turkish immigrant chronic hepatitis B carriers	15
1.4.2 Objective:	15
1.4.3 Main Research Question:	15
Chapter 2: Theoretical framework: the impact of stigma on the daily life of Turkish-Dutch chronic HBV carriers	16
2.1 Intrapersonal forms of stigma (self-stigmatization)	17
2.2 Interpersonal forms of stigma	18
2.3 Accurate knowledge of the disease	19
2.4 Psychosocial distress, Coping strategies & Behavioural responses	21
2.5 Measuring Coping strategies of Turkish HBV carriers	22
Problem-focused strategies and emotion-focused strategies	22
2.6 Main Research Question & Sub-research Questions	23
Chapter 3: Study Methodology	25
3.1 Design	25
3.2 Literature Search	25
3.3 Study Sample	26
3.3.1. Response rate interviewees	27
3.3.2. Key informants	27
3.4 Validated Interview Design and Data collection	27
3.5 Data analysis	28
Chapter 4: Results	29
4.1. Results transcripts Turkish HBV carriers Rotterdam (2004):	29
4.1.1. Hepatitis B related knowledge	29
4.1.2. Hepatitis B related stigma	31
4.1.3. Coping	32
4.1.4. Psychological distress	34
4.2 Results: Turkish hepatitis B carriers in The Hague	36
4.2.1. Hepatitis B related knowledge	36
4.2.2. Interpersonal forms of hepatitis B related stigma	39
4.2.3. Intrapersonal forms of hepatitis B related stigma	40
4.2.4. Role of practitioners	42
4.2.5. Coping	43
4.2.6. Psychological distress	46

4.3 Results: Key informants.....	48
4.3.1. Hepatitis B Knowledge of the Turkish community	48
4.3.2. Hepatitis B related stigma.....	48
4.3.3. The role of culture and social structures on coping	49
4.3.4. Psychological distress	51
4.3.5. Improvement of hepatitis B consultations.....	51
Chapter 5: Discussion	53
The extent of hepatitis B-related stigma amongst Turkish first generation immigrants diagnosed with chronic HBV	53
Drivers behind hepatitis B stigmatization	53
Knowledge	54
Social structures	54
Coping strategies and psychosocial distress	55
Psychosocial distress	57
The impact of coping behavioural responses on the social life and health of Turkish-Dutch chronic hepatitis B carriers	57
Limitations of the study	58
Overall Conclusion.....	59
Adapted framework according to the results and conclusion.....	60
References:	62
Appendices.....	68
Appendix A: Semi structured interview design Turkish HBV carriers (In Dutch)	68
Appendix B: Semi structured interview design key informants (In Dutch)	71
Appendix C: Age distribution respondents.....	73
Appendix D: Points of interest when consulting Turkish-Dutch HBV carriers	74

Abbreviations

AIDS	=	Acquired immunodeficiency syndrome
ECDC	=	European Centre for Disease Prevention and Control
EMIC	=	Explanatory Model Interview Catalogue
GGD	=	Municipality Health Service(s) [Gemeenschappelijke GezondheidsDienst]
GP	=	General practitioner
HBV	=	Hepatitis B virus
HBeAg	=	Hepatitis B e antigen
HBsAg	=	Hepatitis B surface antigen
HCC	=	Hepatocellular carcinoma
HCV	=	Hepatitis C virus
HIV	=	Human Immunodeficiency Virus
ISMI	=	Internalized Stigma of Mental Illness
MSM	=	Men who have sex with men
P-Scale	=	Participation Scale
RVP	=	Dutch National Immunization Program [Rijksvaccinatieprogramma]
STD	=	Sexual transmitted disease
TB	=	Tuberculosis
WHO	=	World health organization



Chapter 1: Introduction and Background information

1.1 Global Epidemiology of the Hepatitis B Virus

Hepatitis B is responsible for a high disease burden worldwide, since approximately 350 million people are currently chronically infected with the hepatitis B virus (HBV). In addition, nearly 2 billion individuals have been infected at some point in time, and around 4-5million new infections occur annually. Furthermore, it has been reported that around 600,000 people die due to hepatitis B - related liver disease on an annual basis (Parana et al. 2005). The majority of the HBV-infected individuals reside in the developing world, mainly in the Asian-Pacific region (excluding Japan Australia and New Zealand) and Africa (figure 1). The total population at risk in these highly endemic regions constitutes for around 45% of the world population (McMahon. 2000; Matthews et al. 2008). Most of the disease burden, associated with HBV infections, occurs among chronic HBV carriers. A chronic infection may lead to chronic liver disease, death from cirrhosis or hepatocellular carcinoma in up to 20-30% of those chronically infected (WHO. 2002). As a consequence, it has been reported that HBV is the principal agent of chronic liver disease and hepatocellular carcinoma (HCC) in many high HBV prevalent countries, contributing to nearly 80% of all liver cancer cases (Cotler et al. 2012; Ma et al. 2007; McMahon et al. 2000; Spiegel et al. 2007). In addition, HBV is described as one of the most common factors for liver transplantation worldwide (Franciosi et al. 2012). As a consequence of these staggering statistics, HBV infection is a major public health concern in countries reporting a high hepatitis B endemicity among its population (Matthews et al. 2008).

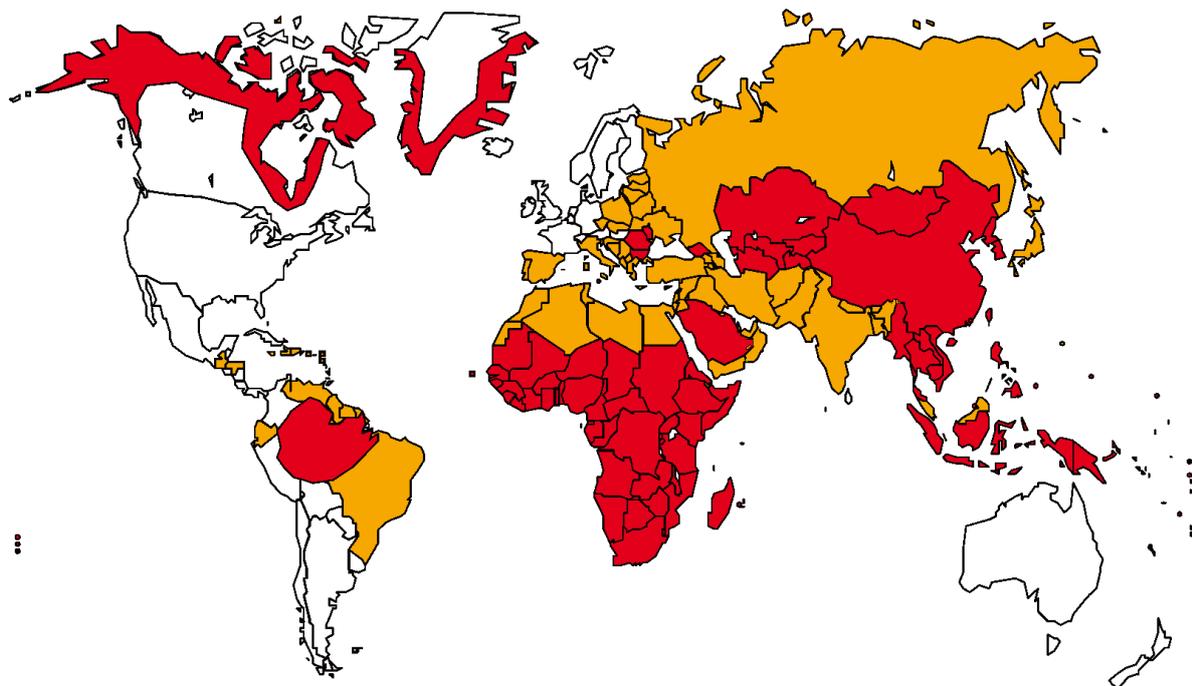


Figure 1 Geographic distribution of hepatitis B endemicity. White: Low (HBsAg prevalence <2%), Orange: Intermediate (HBsAg prevalence 2%–7%) and Red: High (HBsAg prevalence ≥8%) [Source: WHO. 2002].

The transmission of HBV can eventualize through infectious blood or body fluids, which occurs through various routes, namely: vertical transmission, early life horizontal transmission and adult life horizontal transmission (Custer et al. 2004). Vertical transmission constitutes of the transmission of

HBV between a mother with a chronic infection and her child, before, during or immediately after childbirth. Whereas, early life horizontal transmission encompasses transmission via person-to-person contact, through sores, open cuts and sanitation habits. Thirdly, adult life horizontal transmission occurs through sexual transmission, exposure to medical procedures or via the use of instruments to inject (Custer et al. 2004; Mathews et al. 2008).

As already hinted HBV infections can likewise occur in several forms: 1# an acute HBV infection can spontaneously resolve and lead to protective immunity, 2# result in a chronic infection or 3# in rare cases result in acute liver failure with a high risk of dying (Mathews et al. 2008). A transition from an acute form of hepatitis B to a chronic hepatitis B infection indicates a failure of the immune system to successfully eradicate the virus. It has to be noted that the overall risk of acquiring chronic HBV varies by age and decreases over time. The risk of contracting a chronic infection is highest among those who acquire HBV perinatally (80-90%). The risk of contracting HBV decreases during childhood (up to 5 years of age) to around 30%. During adulthood the risk of contracting chronic HBV after infection is further reduced to approximately 5%, however amongst men who have sex with men (MSM) and drug users the proportion of those becoming chronically infected were 23% and 28% respectively (Mathews et al. 2008; Van Houdt et al. 2012).

The severity of the infection varies from patient-to-patient, which depends on several factors. First of all, the effectiveness of the immune system is a major factor in the acquirement of chronic hepatitis B by individuals. It was determined that adults with a deficit immune system are more prone to contract chronic hepatitis B after HBV infection, compared to their healthy counterparts (Afsar et al. 2009). In addition, the role of the immune system in hepatitis B explains why individuals at a younger age have a higher risk of contracting chronic HBV (Mathews et al. 2008). If the immune system fails to respond when someone is infected by the HBV, the patient undergoes the so called immune tolerant phase. The immune tolerant phase is characterized by a high level of virus particles in the blood stream and normal live functions. This phase may persist for decades and is associated with a low risk of progression to advanced liver disease (Mathews et al. 2008).

Secondly, the specific sub-genotype of the hepatitis B virus is an important indicator of the progression of the disease and indicates how contagious HBV is. It has been reported that some genotypes have a longer lasting prevalence of HBeAg, which is a marker of active viral replication. Active viral replication has been associated with a higher potential for vertical transmission. Therefore, early life horizontal transmission accounts for a higher hepatitis B infection endemism in regions with a lower HBeAg HBV prevalence (Custer et al. 2004; Lim et al. 2006). Currently, eight different HBV strains (A-H) have been recognized, which vary geographically (Mathews et al. 2008; Ezzikouri et al. 2008). It has been suggested by several authors that the HBV strains encountered in the Asia pacific region are the cause of an increased risk in vertical viral transmission, due to a longer lasting HBeAg prevalence, compared to the dominating HBV strains encountered in other regions in the world (Custer et al. 2004; Dehesa-Violante & Nunez-Nateras. 2007; Mathews et al. 2008). Based on this information it is evident that people from the Asian-Pacific region have a higher risk of contracting chronic HBV at birth, whereas the risk of contracting chronic HBV in other parts of the world is higher during early childhood (horizontal transmission).

The prevalence of hepatitis B and the transmission patterns of the virus strains amongst a population are therefore important indicators to health care policymakers, especially when involving country specific populations (behaviour risk groups, ethnic groups and immigrants from certain geographic areas) (Custer et al. 2004). Furthermore, advances in hepatitis B treatment have reemphasized the importance of global hepatitis B surveillance programs and early detection of active disease so that effective antiviral treatment can be instituted (Ng et al. 2011). Consequently, the world health organization (WHO) has advised worldwide universal vaccination, both in countries where HBV is highly endemic and in low endemic countries (WHO. 2002).

1.2 Hepatitis B prevalence in the Netherlands

Unlike some countries in Asia and Africa, where HBV prevalence can reach up to 12% of the total population, the prevalence of chronic hepatitis B is comparably low in the continental United States and Western Europe (the low endemic countries) (WHO. 2002; ECDC. 2010). The hepatitis B prevalence of the Netherlands has been estimated between 0.2%-0.5% of the total population (Koedijk et al. 2010; Mostert et al. 2006). On an annual basis, the incidence rate in the Netherlands is between 200 to 300 cases of acute hepatitis B and approximately 1500 cases of chronic hepatitis B (Houweling et al. 2010). In highly endemic HBV countries, hepatitis B induced liver cancer is the most widely reported form of cancer (WHO. 2002). Based on these statistics, it is likely that first generation immigrants from intermediate and highly hepatitis B endemic countries are more susceptible to acquire liver cancer and die of the consequences of the disease compared to their Dutch counterparts. However, in the past hepatitis B screening programs in the Netherlands focused mainly on preventing hepatitis B transmission of behavioural risk groups (injection drug abuse and unprotected sex as the primary methods), opposed to protecting immigrant groups.

Table 1: Overview hepatitis B risk groups [source: Esveld. 2001]

Risk Groups
Neonates of HBV positive women
Individuals with an occupational risk
Individuals with many sexual contacts
Intravenous drug users
Susceptible contacts of chronic HBV carriers
Travellers to intermediate and highly endemic regions
Children in asylum seeker centres
Individuals diagnosed with the Down syndrome
Immigrants from endemic HBV regions
Neonates with at least one parent from an endemic HBV region

During the 1980s, the total number of hepatitis B reported cases dropped sharply, this phenomenon was linked to advances in HBV preventive measures (e.g. avoiding blood to blood contact by taking

hygienic measures), which were originally intended for HIV but proved to be also effective in preventing transmission of HBV (Health Council of the Netherlands. 2009). Due to the comparative low prevalence and incidence rate of hepatitis B, the Netherlands adopted a HBV vaccination program targeted at preventing neonatal infection in 1989 by screening the hepatitis B status of pregnant women and subsequent immunisation of new-borns of mothers who proved to be chronically infected. In 2002, an additional program started to vaccinate all new-borns with at least one parent from a region where hepatitis B is prevalent. Vaccination targeted at risk groups started in 2002 in order to screen for chronic HBV carriers, opposed to implementing a universal HBV vaccination program as recommended by the WHO (van Houdt et al. 2009; WHO. 2002). Starting from 2011 onwards, hepatitis B vaccinations were included in the children Dutch National Immunization Program (RVP), in order to prevent a (chronic) hepatitis B infection of occurring in new-borns (Koedijk et al. 2010).

1.2.1. Hepatitis B screening programs

Since 1989, over 185,000 pregnant women in the Netherlands are screened for HIV, HBV and Syphilis, on an annual basis. These screening programs allow for preventive treatment of new-borns of pregnant HBV carriers and thereby reducing the overall risk of children contracting chronic HBV at birth significantly (Houweling et al. 2010; Op de Coul et al. 2010; Matthews et al. 2008). It has been estimated that due to the screening program an estimated 50-75 chronic HBV infections in neonates are prevented, and the incidence rate is reduced to approximately 1 annually (Op de Coul et al. 2010). It has to be noted that the screening program is not aimed at preventing secondary complications (i.e. cirrhosis) by mothers carrying the virus.

However, mother-to-child HBV transmission at birth only consists of a small portion of the hepatitis B disease burden in the Netherlands. Since, the number of (new) cases of chronic hepatitis B in the Netherlands is largely determined by the immigration of carriers from countries where hepatitis B is prevalent. Consequently, it has been estimated that only 15% of all chronic carriers turn out to have contracted the disease in the Netherlands, opposed to 85% abroad (Houweling et al. 2010). It has been determined that the prevalence of HBV amongst the biggest immigrant groups in the Netherlands is between 2.6 - 4.8% of the total immigrant population (ECDC. 2010). As a consequence of the higher HBV prevalence among first generation immigrants, most new HBV cases are detected in the urban areas in the west of the Netherlands, which contains areas with significant immigrant populations. Naturally, the HBV incidence rate in these urban areas is significantly higher compared to the average number of new HBV cases in the Netherlands (Baaten et al. 2007; Koedijk et al. 2010). The largest of these immigrant groups at risk in urban areas of the Netherlands are people of Chinese, Surinamese, Moroccan, Sub-Saharan, and Turkish origin (Baaten et al. 2007; Veldhuijzen et al. 2009)

As a response to the higher HBV prevalence, the Municipality Public Health Service (GGD) initiated several HBV blood screening programs and ethnic specific HBV screening projects amongst first generation immigrants. The first results of one of the large-scale HBV screening project in Rotterdam, conducted among 1100 participants, indicated that 8.5% of the Dutch-Chinese participants were chronically infected with HBV (Koedijk. 2010). This allowed for preventive HBV treatment of 94 carriers and thereby preventing liver cirrhosis, chronic liver disease and HCC

Furthermore in 2009, the Turkish community in Arnhem was screened for HBV and HCV. A total of 709 people participated in the screening program, and 3,0% of the participants were identified as HBV carriers (Richter et al. 2012). In The Hague no screening projects directly aimed at the Turkish community have been initiated so far. Currently, the Turkish community in The Hague represents 7,4% (36,905 individuals) of the total population in 2011, as one of the largest immigrant communities in The Hague. This particular immigrant community is mainly of East-Turkish origin, which is important to note since large regional differences in hepatitis B prevalence have been reported in Turkey, from 2.53% in the west to 4.25% in the east. Consequently, the hepatitis B prevalence of Turkish immigrants in a low endemic EU country such as the Netherlands is likely to reflect the prevalence of their region of origin (Crul et al. 2009; Toy et al. 2011). Chronic HBV is an important health problem in the Turkish community in The Hague, since the Turkish community is the highest reported group of chronic HBV cases in The Hague, accounting for over 30% of all reported HBV cases annually¹. The GGD is planning to increase voluntary screening in the Turkish community; in order to detect individuals suitable for treatment and thereby preventing further transmission of chronic HBV amongst the Turkish-Dutch population.

As already stated earlier, it has to be noted that between 20-30% of the chronic HBV carriers will experience complication. On the other hand, 70-80% of the carriers will not experience serious complications during their life. Therefore, the disease will remain relatively asymptomatic for the vast majority of the carriers, during the remainder of their life (Matthews et al. 2008). Consequently, it would be beneficial for both the patient and the GGD to assess the impact of hepatitis B diagnosis on the lives of the patients after screening. Especially since the GGD received some indications that forms of hostility and exclusion of hepatitis B carriers occurred in Chinese communities, after conducting a large scale screening program in 2009². In addition, previous studies, conducted in the United States, indicated that HBV-related stigma is common amongst immigrants due to misconceptions about the disease (Cotler et al. 2012; Ma et al. 2007; Taylor et al. 2009).

1.3 Health-related stigma and hepatitis B

Before elaborating on the relation between HBV and stigma, a brief introduction of stigma will be given; more precisely under which circumstances stigma is called health related stigma in context of this study.

1.3.1 What is stigma?

In ancient Greece, slaves were considered valuable property and to prevent their escape and ensure the return of runaways, slaves were tattooed. The tattoo instrument used, made a mark called a 'stigma' (Greek for 'to prick' is stig). In those times, stigma was considered to be a physical mark of the outsider and/or slave. Nowadays, stigma is characterized as a negative response towards human differences (ILEP. 2011; Scambler et al. 2009). These responses are characterized by obvious visible signs or differences in behaviour and more subtle approaches towards stigmatized people (see *Figure 2*).

The individuals who are considered different are often labelled, these labels tends to have stereotypes that go along with these. Based on these stereotypes, people tend to separate themselves from those reduced to the stereotype. These actions lead to loss of status of the

1) Dirksen. 2012. Van reactief naar proactief. Attachment Chronic hepatitis B: a study of the carrier population of The Hague [in Dutch]. [not yet published]

2) Observation of GGD employees of the department of infectious disease control The Hague

stigmatised person and subsequently lead to negative behaviour (discrimination) towards those stigmatized (ILEP. 2011; van Brakel. 2005).

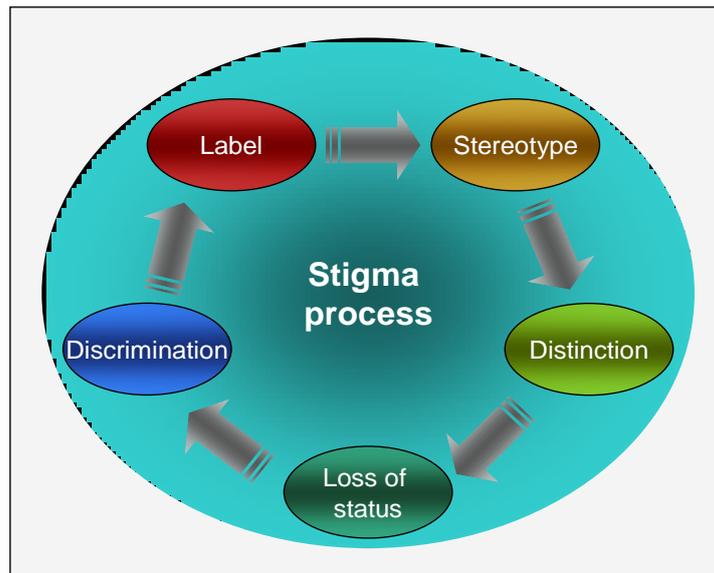


Figure 2: stigma as a social, cultural and moral process (adapted from ILEP. 2011).

However, stigma can also manifest itself in different ways when the individual experiences feelings of fear, low self-esteem, shame and isolation. These signs are all forms of **self-stigma**, which occurs when people become ashamed of their condition due to the attitude of others. As a consequence, people may develop a negative self-image (ILEP. 2011). If stigma occurs when a disease or medical state is associated with a condition that is perceived to be undesirable, it is considered health-related-stigma (van Brakel. 2005). It has to be noted that in the context of contagious disease, like hepatitis B, a groundless fear of danger and contagion plays a prominent role in stigma (Weiss. 2008). [\(See chapter 2 for a more comprehensive view of stigma in the context of this study\)](#)

1.3.2 Hepatitis B related stigma

Although hepatitis B is one of the most prominent chronic infection diseases in the world, the psychosocial impact of the disease has not been extensively studied compared to other prominent chronic diseases, such as HIV and TB. It has to be noted however that a lot of parallels between HIV and HBV persist, such as: the pandemic nature of the diseases, the incurability of life-time carriers, and the vulnerability of health care workers and sex workers. Also some notable differences between the diseases are noted, namely: a vaccination is available for HBV and HIV is more infamous compared to HBV (Cotler et al. 2012; Houweling et al. 2010; Muraskin. 1988; Taylor et al. 2006). Also it has to be stressed that chronic HBV is a relatively asymptomatic disease, meaning that carriers are completely unaware of their condition until they are diagnosed, therefore they are unprepared when they are promptly diagnosed with the disease. Nevertheless, studies assessing HBV stigma, mostly use stigma instruments based on constructs from validated HIV stigma tools.

In the context of this study it is prudent to assess the impact of hepatitis B diagnosis on the lives of HBV carriers, since HBV screening may expose chronic carriers to self-stigmatization, social and economic discrimination and a possible psychological trauma. Especially when considering that patients with non-cirrhotic HBV endorse more psychosocial symptoms than physical symptoms when

asked to consider how HBV impacts their overall quality of life (Spiegel et al. 2007). Previous studies investigating HBV-related stigma indicated a poor understanding of routes of HBV transmission among Asian Americans, as a cause of stigma (Cotler et al. 2012; Taylor et al. 2006). It was indicated that approximately three quarter of the Chinese study participants understood that hepatitis B infection can lead to serious health problems, however only 23% understood that hepatitis B is not transmitted by eating food that has been prepared by an infected person or by sharing food with an infected individual (16%) (Taylor et al. 2006). Another study conducted amongst American-Cambodians revealed that knowledge deficits were a significant factor in Cambodians behaviour and attitude towards hepatitis B (Taylor et al. 2009). Cotler and colleagues (2012) indicate that stigma amongst American-Chinese participants is high due to a highly persistent fear of contagion, which was consistent with the finding of knowledge deficits amongst Chinese immigrants, encountered in the study (Cotler et al. 2012; Taylor et al. 2009). Spiegel et al. (2007) linked health-related quality of life to stigma, by developing the hepatitis B Quality of Life Instrument version 1.0. The study focused on HBV-carriers and indicates that patients with a chronic HBV-infection attribute a wide range of negative psychological, social, and physical symptoms to their condition, even in the absence of cirrhosis or cancer. Spiegel indicated stigma as one of the most prominent causes for these symptoms.

These studies made the relation between knowledge and attitude, amongst patients and members of the community, towards HBV clear. However, these studies did not assess the behavioural response of the patient upon hearing the diagnosis and which factors influence the response and behaviour of carriers. Ng and colleagues (2011) conducted a study amongst Americans diagnosed with HBV to assess the psychological and social impact upon receiving a positive HBV diagnosis. Furthermore, it was determined that patients with hepatitis B face uncertainty at a positive diagnosis and that the received information and support at the early stage of the disease determine the patient's treatment adherence and follow up (Ng et al. 2011). The study illustrated that the emotional response of patients on a positive diagnosis varied significantly from patient to patient, ranging from "shocked," "disbelief," "upset," "scared," "anxious," "not surprised" to acceptance. As already illustrated in the earlier studies discussed, Ng et al. (2011) indicated a direct relation between knowledge and the initial response by the patients. Those who were unaware of the complications of hepatitis B were less distressed and more likely to delay in seeking medical treatment. Whereas, carriers who were aware of the complications of chronic HBV, were more anxious. In addition, only a few patients were willing to discuss their condition openly with others; this behaviour was attributed to the perceived fear of carriers of being discriminated by their social environment (Ng et al. 2011). Support from significant others is believed to be crucial to buffer the impact of a wide variety of stressful life-events including chronic illness (Ng et al. 2011; Petrak et al. 2001). In addition, it was reported that a significant proportion of the patients tried to cope with the disease by ignoring their condition and the potential complications (Ng et al. 2011).

1.4 Research objective and aim of the study

1.4.1 Problem statement: Stigma amongst Turkish immigrant chronic hepatitis B carriers

The morbidity and mortality of HBV-related complications is significantly higher in first generation immigrants from higher endemic regions, compared to the Dutch-born population. As already indicated, this difference in morbidity and mortality is attributed to the higher HBV prevalence amongst immigrant populations, compared to a <0.5% HBV prevalence in the general Dutch population. Consequently, hepatitis B is an important health problem amongst first generation immigrants in the Netherlands. As a response to the higher prevalence amongst immigrant groups from high endemic countries, the GGD initiated screening programs amongst first generation Chinese immigrants in the four main cities of the Netherlands. The primary aim of these HBV-screening programs was to identify as many HBV carriers as possible and thereby allow the carriers to receive effective treatment in order to prevent life threatening complications. However, the GGD received several indications from patients that forms of social exclusion and discrimination occur towards chronic HBV carriers within minority communities and families¹. Therefore, it is prudent to assess to what extent stigma takes place, since it influences patient behaviour in seeking medical treatment adherence to transmission preventive measures. In addition, the majority of the HBV patients experiencing the chronic form of the disease never develop symptoms during their lifetime and therefore will remain unaware of their hepatitis B status. As a consequence, if stigma has negative consequences for asymptomatic carriers it will reduce the quality of life of chronic HBV carriers. If that is the case, hepatitis B counselling after screening should be adapted in order to deal effectively with the causes of stigma.

1.4.2 Objective:

Stigma strongly influences psychosocial distress and the subsequent coping strategies of chronic HBV carriers. This project aims to elucidate the psychosocial distress, coping strategies and behavioural outcomes (e.g. seeking medical care, treatment adherence and informing susceptible contacts) faced by first generation Turkish immigrants, after hepatitis B screening indicated them as chronic hepatitis B carrier.

1.4.3 Main Research Question:

To what extent and in which forms does hepatitis B-related stigma occur in the Turkish community, and what is the impact of stigma on the social life of Turkish chronic hepatitis B carriers in terms of psychological distress, coping strategies and behavioural outcomes?

1) Observation of GGD employees of the department of infectious disease control The Hague

Chapter 2: Theoretical framework: the impact of stigma on the daily life of Turkish-Dutch chronic HBV carriers

Stigma is known to complicate management and treatment of chronic diseases, since it affects the carrier's health-seeking behaviour, treatment adherence and it affects the willingness of carriers to execute and comply with transmission preventive measures. Furthermore, stigma affects the political commitments for disease control, since stigma may encourage neglect amongst policy makers. Whereas the recognition of the impact of health-related stigma may encourage them to advocate for disease control (van Brakel et al. 2006; Weiss. 2008). Consequently, health-related stigma has been described as ultimately increasing morbidity and mortality globally (Holzemer et al. 2007; Steward et al. 2008).

For this study we developed a framework (Figure 2.1) in order to understand the roots and effects of stigma upon a positive chronic hepatitis B diagnosis. This framework is an adapted version of Steward and colleagues (2008) theoretical framework for HIV stigma. In most cases stigma is described as a negative response towards human differences. Therefore, stigma, in this context, is described as a social process distinguished by exclusion, rejection, blame or devaluation of an individual or group. This social process can manifest itself in forms of discrimination of individuals by the non-stigmatized majority. In the case of chronic diseases, such as hepatitis B, it refers to people being treated differently and/or behaving differently, because of a chronic HBV carrier status. Subsequent acts of hostility and discrimination towards individuals are grouped under the concept *interpersonal experiences of stigma* in this framework (ILEP. 2011; Scambler. 2009; Steward et al. 2008; van Brakel. 2005).

As already stated in [paragraph 1.3](#), stigma is mostly associated with acts of discrimination and hostility towards individuals based on human differences, by the general public. However, it is important to note that stigma can also occur in other forms, most prominently in forms of self-stigmatization. Self-stigmatization refers to someone, who is being stigmatised or to someone who perceives stigma for a long period of time, starting to believe what others say and think about them as truthful. Forms of self-stigmatization may occur when an individual experiences loss of self-esteem, dignity, fear, shame, hopelessness and guilt, due to his/her condition. As a consequence, individuals may accept diminished expectations (from others) about themselves due to their condition, and therefore start to behave in a manner that they believe corresponds to what other people expect of them (ILEP. 2011; Steward et al. 2008). These forms of self-stigmatization are grouped under the concept *intrapersonal experiences of stigma* in the original framework designed by Steward and colleagues (2008).

Steward and colleagues (2008) propose that accurate knowledge about the disease is a major determinant of attitudes of both the stigmatized and those stigmatising towards the disease. A poor understanding of transmission routes of the disease can lead to fear and prejudice towards hepatitis B carriers, among both chronic carriers and members of a community. Therefore these forms of knowledge influence self-stigmatization, which in turn influences the carrier's decision to disclose or

conceal their HBV sero-positive status to others. As a consequence, stigma can adversely affect persons with a chronic form of hepatitis B and present a barrier to people to take adequate measures against transmission of the virus to others, especially since it is easier for chronic HBV patients to conceal their hepatitis B seropositive status, compared to HIV patients, for which this framework was originally developed (Guirgis et al. 2011; Matthews et al. 2008; Steward et al. 2008).

Table 2a overview of the different forms of stigma described in the framework

Interpersonal forms of stigma		Intrapersonal forms of stigma	
Enacted Stigma	discrimination and hostility directed at a person and or group, usually accompanied by expressions such as "people like that" – "us" versus "them"	Internalized Stigma	The believe of individuals what others say and think about them as valid. These beliefs lead to social exclusion of people in the same way as discrimination
Vicarious Stigma	Stories of stigmatization against others. These stories feed acts of enacted stigma and raise awareness of negative attitudes	Felt Normative Stigma	Expectation or fear of discrimination and the awareness of negative attitudes or practices in society

Table 2b examples of the different forms of stigma described in the framework, in the context of hepatitis-B isolation when eating dinner

Interpersonal forms of stigma		Intrapersonal forms of stigma	
Enacted Stigma	You as hepatitis B carrier should not be allowed to eat at the same table as us.	Internalized Stigma	What others say about me is true, I should not eat at the same table as other people, since I might infect them.
Vicarious Stigma	I heard he is not allowed to eat with them, because he is a hepatitis B carrier	Felt Normative Stigma	I don't want others to know I have hepatitis B, since I might face discrimination such as eating separately

2.1 Intrapersonal forms of stigma (self-stigmatization)

Intrapersonal forms of stigma concerns the personal experiences and self-esteem of those stigmatized. This model conceptualizes two dimensions to experienced self-stigma, namely: a sense of shame and a fear of HBV carriers to be stigmatized by others and the believe that a HBV carrier accepts stigma as valid. Steward and colleagues (2008) depict these two dimensions of self-stigma as *internalized stigma* and *felt normative stigma*.

Internalized stigma is described as 'The extent to which an individual accepts stigma as valid' (Steward et al. 2008). This description refers to people starting to believe what others may say and think about them as truthful. Consequently, these personal beliefs lead to social exclusion of people in the same way as discrimination accomplishes, since people who subject themselves to internalized stigma may decide to socially exclude themselves. Internalized stigma can occur to both the non-stigmatized majority and the stigmatized minority. In the former, stigma is internalized by individuals of the non-stigmatized majority, which results in animosity towards the stigmatized minority, since

they believe that social exclusion of individuals is justified. In the latter, internalization by members of the stigmatized minority entails the process in which stigmatized individuals accept the apparent exclusionary views of members of the majority (Steward et al. 2008; Weiss. 2008).

Felt normative stigma refers to the subjective awareness, of negative attitudes or practices in society towards a condition/characteristic, of stigmatized individuals, and consequently entails the expectation or fear of discrimination. Consequently, felt normative stigma can induce a stronger motivation of individuals with a stigmatized condition to take action to protect themselves from experiencing enacted stigma (Steward et al. 2008). Such actions include attempts by hepatitis B diagnosed individuals to appear as members of the non-stigmatized majority. The outcome of an individual deciding whether to disclose their HBV seropositive status is illustrated by the dotted arrows in *Figure 2.1*. Successful passing as a member of the majority may indeed significantly reduce the likelihood of an individual, of the stigmatized minority, experiencing interpersonal forms of stigma (Steward et al. 2008).

In the context of this study the assessment of intrapersonal forms of stigma will focus specifically on the ways in which self-stigmatization manifests itself, also the underlying causes of self-stigmatization will be explored. Steward and colleagues (2008) framework (adapted in figure 2.1) state that forms of internalized stigma may be strongly influenced by inaccurate knowledge of the disease (Scambler. 2009; Steward et al. 2008). This statement is based on the fact that the level of knowledge about the chronic disease will influence whether a person actually believes that enacted stigma and vicarious stigma ([see paragraph 2.2](#)) are valid. Hence, if the stigmatized individual has **little to no knowledge about the disease**, it is argued by several authors that they are **more prone to accept forms of enacted stigma and vicarious stigma as valid** (ILEP. 2011; Steward et al. 2008). Cotler and colleagues (2012) assessed to what extent knowledge about hepatitis B influences the behaviour of Chinese immigrants in the United States. The study indicated that approximately 70% of the Chinese immigrants in the US believed that HBV could be transmitted to others by sharing food, and therefore believed that forms of social isolation were justified in order to avoid contagion. A similar study conducted in the Netherlands was aimed to determine the level of HBV knowledge amongst the Turkish-Dutch population of Rotterdam. Van der Veen and colleagues (2010) indicated that first generation Turkish immigrants in Rotterdam appeared to have less knowledge about HBV compared to the second generation Turkish-Dutch and it was reported that over 70% of the Turkish population never thought about the disease. In addition, knowledge about transmission and prevention of HBV was moderate amongst the Turkish-Dutch population, while there was little to no knowledge about the serious consequences of HBV (van der Veen et al. 2010). The study concluded that even though hepatitis B is a serious health concern in the Turkish-Dutch community, hepatitis B knowledge is limited (van der Veen et al. 2010; Richter et al. 2012). Spiegel et al. (2007) linked lack of HBV knowledge amongst HBV carriers with ungrounded concerns about hepatitis B transmission, such as processing food carefully.

2.2 Interpersonal forms of stigma

Interpersonal forms of stigma focus on the devalued status that society attaches to a condition or attribute, this status entails acts of discrimination and hostility towards HBV carriers (Scambler.

2009). Interpersonal forms of stigma are subdivided in the concepts of *enacted stigma* and *vicarious stigma* (Steward et al. 2008).

Enacted stigma envelops manifested forms of discrimination and hostility of a community or person directed at a HBV carrier because of his or her discerned stigmatized status. Enacted stigma is an indicator of the prevalence of stigmatizing attitudes among people in a local community/family (Steward et al. 2008). Usually, these acts of discrimination are accompanied by expressions such as “people like that” – “us” versus “them”. Subsequently, these expressions often lead to loss of status of the stigmatized person in a community or family (ILEP. 2011). Enacted stigma supports the view that the person with the disease is imperfect rather than morally at fault (Scambler. 2011). Imperfect refers to individuals being different of what is considered socially accepted. Morally at fault refers to a moral deficit, reflecting infringements against social norms and values, which is not the case in sense of stigma since it reflects infringements on physical appearance due to a condition. In the case of hepatitis B, it is important to acknowledge that enacted stigma almost exclusively occurs when a person discloses his/her status as a chronic hepatitis B carrier to others (Scambler. 2009). Furthermore, it is important to note that forms of enacted stigma are not limited to acts of discrimination and hostility, but also includes the lack of supportive behaviours for a chronically infected individual by family, community members and policy makers (Rahangdale et al. 2009; Chaudoir et al. 2010).

Vicarious stigma entails the notion that perceptions of stigma of individuals are often shaped by stories of discrimination against stigmatized individuals. These stories allow for stigma to become more socially accepted, as a consequence these stories feed acts of *enacted stigma*. In addition, social acceptance of enacted stigma raises the awareness among those fearing stigmatization, of the negative views in society (*felt normative stigma*) (Steward et al. 2008).

The influences of enacted and vicarious forms of stigma on intrapersonal stigma are illustrated in the framework. It has to be noted that, enacted, felt normative, and internalized stigma were associated with higher levels of depression (Steward et al. 2008). Based on this information, a previous study amongst the Turkish-Dutch population regarding hepatitis B of van der Veen et al. (2009) can be put into context. Sensitivity regarding sexuality in relation to hepatitis B, amongst the Turkish-Dutch population, was reported by van der Veen and colleagues (2009). Based on this information van der Veen (2009) reported that being ashamed for the suspicion of others may be a reason for HBV carriers not to seek medical treatment. Therefore, in the context of this study, several key informants should be approached in order to confirm or disprove the felt normative stigma of the respondents as forms of enacted stigma.

2.3 Accurate knowledge of the disease

Variations in the enactment and experience of stigma and its effects on illness and behaviour have been attributed to *accurate knowledge of the disease* (Steward et al. 2008; Weiss. 2008). The amount of knowledge about the condition, especially the transmission routes, appears to be a major determinant in attitudes of a community towards a stigmatized individual and also influences how those stigmatized experience the disease (Cotler et al. 2012; Yang et al. 2006). Therefore, knowledge underlies the motivation behind stigmatizing practises of the chief agents of stigma, including health care workers, family, community members, and the stigmatized individuals.

It has been reported that accurate knowledge of the disease is negatively influenced by cultural specific beliefs and religious beliefs (Rahangdale et al. 2009; Steward et al. 2008). Jones (2000) indicates, in her theoretical framework of levels of racism, that social structures, cultural traditions, and governmental institutions play an important role in justifying stigma. Especially, since the government is the actor that controls resources and is the one with the power to act. Therefore, if the government has no concern for equity amongst its citizens it will influence health outcomes (Jones. 2000). Cultural traditions and social structures refer to the culture specific connotation of a disease and the social reaction to symptoms of the disease. Especially when referring to the so called honour-shame cultures in non-western societies. In these societies, it has been reported that chronic diseases can bring shame to a community or family (ILEP. 2011) Therefore, characteristics that are viewed as undesirable will influence the members of a community whether to stigmatize chronic carriers or not (ILEP. 2011; Jones. 2000; Weiss. 2008).

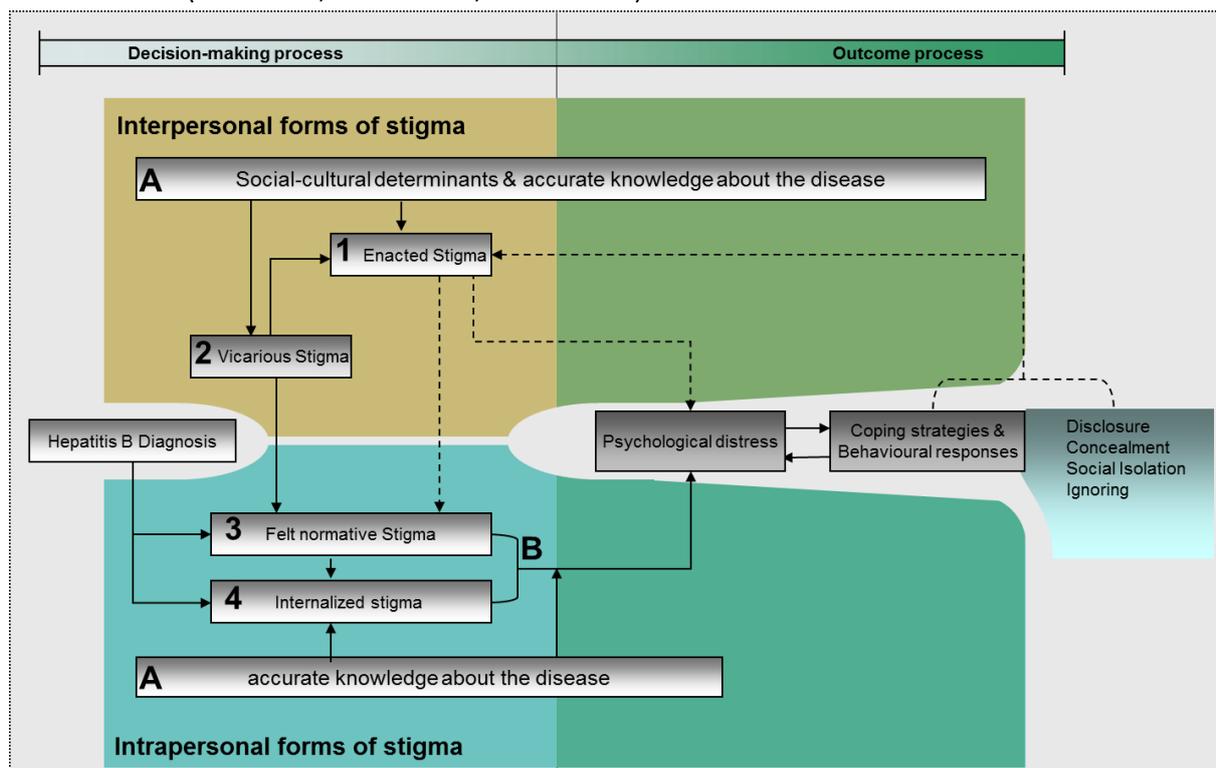


Figure 2.1: Theoretical framework: the impact of stigma on the daily life of Turkish-Dutch chronic HBV carriers [adapted from Steward et al. 2008]. Solid arrows indicate the routes followed when a positive hepatitis B diagnosis of a patient occurs after screening. Routes covered with dotted arrows only occur when the chronic hepatitis B status of an individual is disclosed to others. The first component of stigma captures **interpersonal actions** and covers the concepts enacted stigma and vicarious stigma. **(1) Enacted stigma** refers to overt acts of discrimination and hostility directed at a person because of his or her perceived stigmatized status. Enacted stigma is influenced by vicarious stigma. **(2) Vicarious stigma** entails stories of stigmatization against others. These stories feed acts of enacted stigma and raise awareness of negative attitudes. This level of awareness is covered by the first concept of **Intrapersonal forms** of stigma, namely: **(3) Felt normative stigma**. **Felt normative stigma** is described as the expectation or fear of discrimination and the awareness of negative attitudes or practices in society. The stories and acts of enacted stigma accompanied by the awareness of negative attitudes within a community may lead to internalization of stigma. **(4) Internalized Stigma** refers to the believe of individuals what others say and think about them as valid. This believe of carriers that stigma against them is legitimate is also influenced by the **(A) accurate knowledge of the disease**. **Accurate knowledge about the disease** refers to the understanding of modes of HBV transmission and

individual possesses. A poor understanding of the disease would make individuals more vulnerable to internalized stigma, since they are more susceptible to hold the acts of stigma as valid. However, when the acts of (1) **Enacted stigma** and (2) **Vicarious stigma** are limited or are not known to the carrier the (3) **felt normative stigma** is low. Consequently, the amount of (A) **accurate knowledge** an individual possesses will be the major factor influencing (4) **Internalized stigma**. Influenced by the level of (3) **felt normative stigma** and (4) **Internalized stigma**, (B) **psychosocial distress** will be experienced by a chronic carriers. Furthermore, carriers will react to this distress by adopting (B) **coping strategies** and change their (B) **behaviour**.

Accurate knowledge does not only influence stigma, it also influences coping strategies and psychological distress. Coping strategies refers to an individual seeking to master, minimize or tolerate stress or conflict in relation to HBV and refers to efforts by an individual to solve personal and interpersonal problems (Chaudoir et al. 2010). In the context of HBV stigma, coping strategies of chronic carriers consist of responding to stigma experiences by isolating themselves, maintaining silence and/or secrecy, considering disclosure, and eliciting support. In previous studies, a relationship between coping with HBV and familiarity with the disease was examined. These studies indicated that there is a high level of anxiety amongst chronically infected individuals, due to uncertainty about the progression of the disease (Cotler et al. 2012; Ng et al. 2011; Spiegel et al. 2007; Taylor et al. 2006; Taylor et al. 2009). Consequently, fear persisted among those diagnosed with HBV of obtaining liver cancer, liver failure, life expectancy and health worsening. Based on these findings, it was argued that the overall *quality of life* of chronic HBV carriers was reduced significantly (Cotler et al. 2012; Spiegel et al. 2007). Van der Veen and colleagues (2010) already indicated that the amount of knowledge about the origin of the disease, the routes of transmission and potential complications amongst the Turkish-Dutch population is moderate. Based on this information, the Turkish community forms one of the primary communities for assessing the psycho-social burden (in forms of stigma) of HBV-carriers after HBV-screening.

2.4 Psychosocial distress, Coping strategies & Behavioural responses

Based on the levels of internalized and felt-normative stigma experienced by the chronic carrier a level of psychological distress is experienced by chronic carriers. In addition, chronic carriers exhibit certain behaviour and coping strategies influenced by the psychological distress.

Psychological distress is associated with higher levels of enacted, vicarious, felt normative and internalized stigma and entails the psychological condition of individuals due to forms of stigma or lack of stigma (Scambler. 1993). Distress entails how people are affected by forms of stigma and in their decisions in dealing with the disease (coping strategies). Consequently, stigma is an important social determinant of the effectiveness of hepatitis B medical treatment through its influence on the patient seeking medical treatment and interferes with adherence to treatment (Alizadeh et al. 2008; Steward et al. 2008; van Brakel et al. 2006; Weiss. 2008).

Coping strategies in general refer to a response to perceived stress. In the case of this study it refers to individuals coping with the psychological and social consequences of knowing their HBV seropositive status (Chaudoir et al. 2010; Nowack. 1989). Effective coping results in changes so that the situation is no longer problematic, thereby these coping strategies may reduce stress levels

(adaptive and constructive coping strategies). However, coping strategies can also increase stress levels (maladaptive coping strategies) (Chaudoir et al. 2010; Eiser. 1990). *Coping in context of infectious chronic diseases*, such as hepatitis B, is characterized by several factors. Initial responses to a positive diagnosis vary; denial is reported commonly as an initial response when dealing with an infectious disease (McCain et al. 1992). This is expected to be more prominent regarding a HBV positive diagnosis, since the diagnosis is promptly, and therefore chronic carriers are psychologically unprepared in accepting a positive diagnosis. This is a major difference, when comparing HBV with HIV/AIDS, since learning one's diagnosis as being HIV-positive is preceded by a process of deciding to be tested (McCain et al. 1992). McCain and colleagues (1992) indicate that active behavioural coping of patients diagnosed with a chronic disease was related to lower total mood disturbance and a higher self-esteem.

Furthermore, the distress of dealing with the uncertainty of disease progression and fear of transmission influences certain coping strategies (Matthews et al. 2008; McCain et al. 1992). These coping strategies vary from chronic carriers isolating themselves from their social contacts, maintaining silence and/or secrecy, ignoring the disease, considering disclosure, or eliciting support (Lekganyane et al. 2011). Disclosure is the act in which a discloser reveals information to a confidant about the discloser's concealable stigmatized status, which was not previously known by the confidant (Chaudoir et al. 2010). As already indicated in the introduction of this framework non-disclosure of a chronic hepatitis B status and concealment may lead to serious health-consequences for the patient and close-ones. Especially since the patient is unable to effectively adhere to treatment, when deciding to conceal his/her seropositive status. However, it has to be noted that the act to disclose leads to changes in social interactions between those disclosing their status and their confidants, which in turn may result in changes in a social context (forms of enacted stigma: e.g. discrimination, hostility) (Steward et al. 2008). Also it has to be taken into consideration when a chronic carrier decides to conceal a hepatitis B seropositive status it can lead to an increased level of internalized stigma. Since, a carrier has to cope with the psychological burden of having the disease, without being able to disclose his/her status to others (Chaudoir. 2010). McCain and colleagues (1992) state that such 'avoidance' coping strategies, are related to a lower self-esteem and are positively correlated with depression.

2.5 Measuring Coping strategies of Turkish HBV carriers

Lazarus and Folkman proposed that stress consists of three processes in 1984. The first process **primary appraisal** is the anticipated threat of a problem of a patient. Consequently the patient decides whether the problem is something to bother about. Based on this decision the patient decides upon a potential response to the threat, this process is called **secondary appraisal**. Subsequently, **coping** is the process of actualizing that response. Traditionally, coping strategies have been divided according to the focus of the strategies into two kinds of broad strategies. These strategies include: **problem-focused strategies** and **emotion-focused strategies** (Andersson et al. 2003; Carver et al. 1989).

Problem-focused strategies and emotion-focused strategies

Problem-focused coping envelops individuals dealing with the cause of the problem. This involves the individual trying to understand the situation by seeking information, and by learning new skills and approaches to deal with the problem (Andersson et al. 2003). 1# active coping (active steps to

circumvent or remove the problem), 2# planning (thinking on how to cope with the stressor), 3# suppression of competing activities (putting other activities aside in order to deal with the problem), 4# restraint coping (not acting prematurely), 5# seeking of instrumental social support (seeking advice and information) (Carver et al. 1989).

Emotion-focused coping aims to manage emotional distress associated with the situation. Examples of emotional distress are: embarrassment, fear, anxiety, depression, excitement and frustration. Dealing with emotional distress can be achieved through: 1# seeking of emotional social support (seeking moral support, understanding and sympathy), 2# positive reinterpretation (coping aimed at minimizing stress), 3# acceptance (acceptance of the reality of a stressful situation), 4# denial (refusal to believe that the stressor exists or act as the stressor is not real), 5# turning to religion (tendency to turn to religion in times of stress). It has to be noted that most stressors induce both types of coping strategies, but usually one strategy predominates (Carver et al. 1989).

2.6 Main Research Question & Sub-research Questions

The overall aim of this study is to identify to what extent stigma and subsequent psychosocial distress occur within the Turkish-Dutch community, and how Turkish-Dutch chronic HBV carriers cope and respond to psychosocial distress. This study aim was formulated in the following main research question:

To what extent and in which forms does hepatitis B-related stigma occur in the Turkish community, and what is the impact of stigma on the social life of Turkish chronic hepatitis B carriers in terms of psychological distress, coping strategies and behavioural outcomes?

Based on the routes of stigma covered in the framework and the assessment of the six dimensions of stigma in daily life the following sub-research questions, accompanying the main research question, were formulated. These sub-research questions aim to answer the overall main research question.

1#. 'To what extent and in which forms does HBV-related stigma (both inter- and intrapersonal) occur amongst Turkish first generation immigrants?'

The first sub-research question aspires to elucidate which forms of stigma occur and to what extent. Questions will be posed in the interview design, in order to assess the changes in social interactions between chronic carriers and members of the community. Social interactions are described as determinants for what kind of stigma occurs. These questions will partially be based on the concepts of social interactions covered in the stigma model, in order to assess the extent to which stigma occurs in the social environment.

2# 'What is the role of socio-cultural determinants in the acts of stigma towards chronic hepatitis B first generation Turkish immigrants?'

Sub-research question 2 strives to identify the views of Turkish-Dutch chronic hepatitis B carriers and members of the Turkish-Dutch community behind the acts of stigma. Previous studies and theoretical models have reported that socio-and cultural determinants shape the way people view conditions (ILEP. 2011; Jones. 2000; Steward et al. 2008). As [already stated earlier](#), van der Veen and

colleagues (2009) identified the following socio-cultural determinants as dominant in the Turkish-Dutch community: social support, sensitivity regarding sexuality, reputation, responsiveness to authority, religious responsibility, cleanliness and religious doctrine regarding health and disease. Sub-research question 2 therefore aims to elucidate which of these determinants play a role in HBV-related stigma, by asking indirect questions tailored to these socio-cultural determinants.

3# 'What is the role of knowledge in the acts of stigma towards chronic hepatitis B first generation Turkish immigrants?'

Misconceptions about HBV transmissions have been reported as a major factor influencing the level of stigma. This question aspires to clarify the role of knowledge on how stigma is internalized and on how forms of interpersonal stigma are fuelled by (lack of) knowledge about the disease. Questions in the interview design will therefore assess knowledge about the ways in which hepatitis B transmission occurs according to the interviewees. Knowledge about transmission routes is considered crucial, since fear of contagiousness has been reported as playing a prominent role in stigma towards infectious diseases such as hepatitis B (Cotler et al. 2012; Spiegel et al. 2007; Weiss. 2008).

4# 'What kind of coping strategies are used by Turkish-Dutch chronic hepatitis B carriers, in order to deal with the psychosocial distress associated with hepatitis B-related stigma?'

As already made clear in the introduction of the framework, coping strategies determine how a carrier deals with the disease and influences whether carriers take the necessary measures to prevent HBV transmission to their close ones. Several ways of coping with infectious chronic diseases by those infected have been reported in the past, e.g. disclosure, concealment, social isolation and ignoring the health-condition. If a chronic HBV carrier takes actions to conceal the disease, it has been argued that it may pose to be more difficult to adhere to treatment and to prevent transmission. This sub-question aims to assess the effect(s) of this choice on preventive measures, seeking treatment and treatment adherence. These choices can range from avoiding close contact with others to the decision to stop preventive treatment.

5#. 'What is the impact of coping strategies and subsequent behavioural responses on the social life and health of Turkish-Dutch chronic hepatitis B carriers?'

This sub-research question aspires to determine the impact of stigma on the lives of chronic HBV carriers. The impact of stigma refers to the social restrictiveness Turkish-Dutch chronic HBV carriers experience. This envelops disruptiveness in social interactions, which includes interactions between chronic carriers and family, kinship relations, friendship, marriage, relations with associates and social interactions in the work environment. These social disruptions could either be a choice of a carrier (intrapersonal), but could also be imposed by their social environment (interpersonal). These choices are therefore significant factors to determine which forms of stigma are more prominent.

Chapter 3: Study Methodology

During this chapter the methodologies used as a guideline during this study will be discussed in detail. The following sub-sections will cover the [design of the study](#), the criteria for [the literature search](#), the [study sample](#), the [validated interview design](#) and the [data analysis](#).

3.1 Design

The aim of this study was to assess hepatitis B related stigma towards first generation carriers within the Turkish community by conducting interviews. In order to gain an overview of stigma, these interviews were primarily focused on the views and thoughts of chronic HBV carriers. In addition to the views of chronic HBV carriers, several key informants were interviewed in order to gain insight in the forms of interpersonal stigma (enacted and vicarious forms) encountered in the Turkish-Dutch community.

This study aimed to be observational and descriptive, using a qualitative approach. A qualitative approach was used, since semi-structured interviews are a far more personal form of research than questionnaires and allow for structured personal input of the interviewees (Berg. 2004; Reeves et al. 2008). Furthermore, a semi-structured interview design allows for obtaining reliable, comparable qualitative data in the forms of transcripts (Cohen & Crabtree. 2006). In addition, not enough information about stigma in relation to HBV in the Turkish community was available to create effective and validated stigma questionnaires for use in the Netherlands. The generic stigma questionnaires which were available did not seize the unique situation surrounding chronic HBV and therefore questionnaires are not used during this study (ILEP. 2011). These generic tools fail to cover the nature and progression of hepatitis B, which is mainly asymptomatic. Therefore hepatitis B disclosure and concealment are entirely optional for the patient, opposed to most chronic infectious diseases with more visible symptoms (Matthews et al. 2008).

3.2 Literature Search

Before creating an interview design, a literature search was conducted, in order to acquire sufficient background information about health related stigma, hepatitis B and hepatitis B-related stigma. In addition, the background information provided valuable information for HBV-specific questions for the interview design. The following search engines were used in order to obtain literature, namely: Pubmed, Jstor, and Lancer. In addition to information acquired via search engines, links provided on the website of the Dutch National Institute for Public Health and the Environment (RIVM) were used to acquire additional literature, specifically hepatitis B data about The Netherlands. Furthermore, the database of the International Consortium for Research and Action Against health-related Stigma (ICRAAS) was accessed in order to acquire literature and theories about stigma¹. The following search terms were used to acquire the articles (hepatitis B screening) MeSH / title abstract keywords/ the lancer/ 25 hits; ((hepatitis B) AND (screening)) AND (stigma)) / Jstor/ 190 hits; (health related stigma) AND (hepatitis B)/ Pubmed / 9 hits; ((psychological distress) AND disclosure) AND HIV / Pubmed / 40 hits. Subsequently, more articles were obtained using the so-called snowball effect, meaning that articles were found based on the references of the articles acquired via the search engines. In addition, articles were provided by Dutch researchers who assessed chronic-infectious-disease related-stigma in the Netherlands (e.g. validated standardized stigma interview design and validated participation scale).

¹ <http://www.kit.nl/-/INS/8603/Royal-Tropical-Institute/KIT-Information-and-Library-Services--/ILS-Information-products/ILS-Dossiers/ILS-Dossiers-Health?tab=3>

3.3 Study Sample

The study sample was composed of Turkish first generation immigrants, who were identified as chronic HBV carriers in both Rotterdam and The Hague, by the Municipal Health Services (GGD). Patients were recruited from the database of the GGD, for interviews. Subsequently, the patients were screened by telephone and interviewed as they came forward. The patients were eligible to participate when they were able to give informed consent, were willing to participate and were diagnosed with HBV over a year ago (Marshall. 1996). In total 15 chronic HBV carriers were interviewed in The Hague consisting of 10 male and 5 female respondents (*figure 3.1*). A maximum variation sample was used in this study, which entails that the interviewees were diagnosed at different time periods, since previous studies suggested that a person will likely react differently right upon a positive HBV diagnosis as a person who was diagnosed five years ago (Ng et al. 2011; Spiegel et al. 2007).

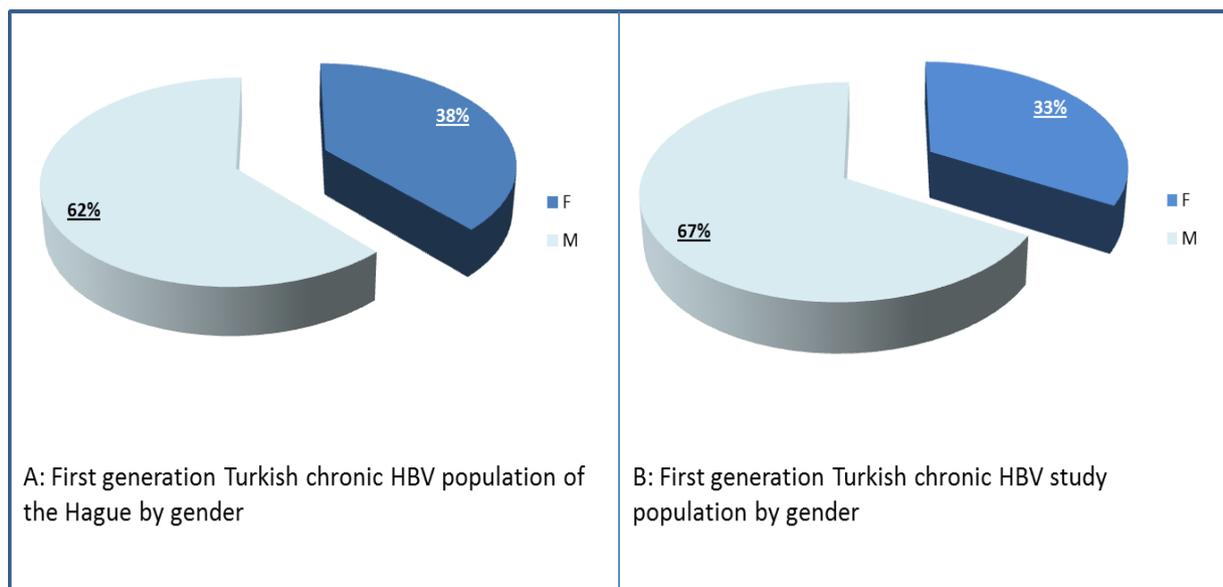


Figure 3.1 distribution of the population according to gender. A) An overview of the overall population of Turkish chronic HBV carriers of The Hague according to gender (period: 2011). B) Overview of the gender distribution of the interviewees.

It has to be noted that the interviews will involve acts of translation, in some cases. Especially since the interviewees consist of people who may not speak the dominant language in the country. As a consequence, when involving interpreters, they are seen a part of the knowledge generation process. Furthermore, it has to be taken into account that certain aspects of a language cannot be reproduced in a translation (Temple et al. 2004). Therefore, when involving interpreters, it is crucial to prepare them to ensure that they have essential knowledge about the purpose of the study (Williamson et al. 2011). In addition, matching the interpreters and the interviewees based on socio-demographic characteristics is prudent, since these interpreters are therefore more likely to be perceived as credible and trustworthy by the interviewees (Williamson et al. 2011). However, in the end it was decided not to use interpreters for interviews; due to high costs, loss of data (since certain aspects of a language cannot be reproduced in a translation) and unsuccessful recruitment of interpreters of the same socio-demographic background.

Besides making use of information acquired via interviewees in The Hague, additional information about the causes of stigma was acquired by assessing 12 transcripts of interviews conducted in Rotterdam for a previous study (Pars et al. 2007). This study was aimed to develop an evidence-based guideline for counselling chronic hepatitis B patients by interviewing 45 chronic HBV carriers. 12 of these 45 chronic carriers were of Turkish origin and were assessed according to the concepts covered in the framework. It has to be noted that the interview design of this study was not aimed at assessing stigma but rather to assess the knowledge of the respondents, therefore it proved to be difficult to assess stigma using this data.

3.3.1. Response rate interviewees

The overall response rate of the respondents in The Hague was relatively high at 65%, when being approached for an interview. On the other hand, 22% of those approached refused to participate in this study. Furthermore, 13% of those approached for an interview, initially agreed to participate in the study, but later refused or did not show up during the interview. It has to be noted that in 80% of all the cases family members were present during the interview.

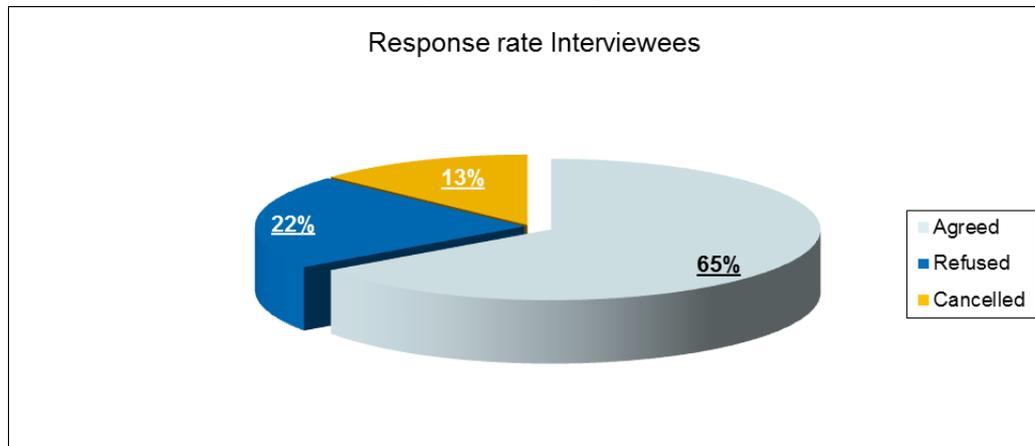


Figure 3.2 interview response rates of Turkish HBV carriers. A total of 65% of the HBV carriers approached agreed to take part in the study. Whereas 22% refused, and 13% initially agreed to participate but later declined.

3.3.2. Key informants

In addition to chronic HBV carriers, key informants were approached to provide additional information about HBV-related stigma in the Turkish community of The Hague. These 4 key informants composed of 2 general practitioners (one Dutch GP and one Turkish-Dutch GP) dealing with Turkish patients, a Turkish social worker and an internist (specialist physician in internal medicine at the hospital) specialized in hepatology.

3.4 Validated Interview Design and Data collection

When permission for conducting an interview was obtained from a participant, they were subsequently approached for an interview at a location of their choice. The interviews were

conducted using a validated semi-structured interview design, tailored to the framework, in order to assess the social impact of a positive chronic hepatitis B diagnosis. This semi-structured interview design was previously used to assess HIV-related and leprosy-related stigma in India and leprosy-related stigma in The Netherlands (de Groot et al. 2011; Stevelink et al. 2011). This design was based on three generic questionnaire-based scales, namely: the Explanatory Model Interview Catalogue (EMIC), the Internalized Stigma of Mental Illness (ISMI) Scale and the Participation Scale (P-Scale) (Stevelink et al. 2011). The EMIC is used to measure the level of perceived stigma. The ISMI Scale is used to measure alienation, stereotype endorsement, perceived discrimination, social withdrawal and stigma resistance and the P-Scale is able to measure the level of (social) participation (Stevelink et al. 2011). The interview design was based on a generic scale, which eliminates disease-specific items and approaches stigma as a widespread phenomenon experienced by people with a variety of conditions. In addition, the design aims to focus on a client perception perspective, which was determined to be important in the context of this study, since people with similar health conditions may experience or perceive different levels of stigma (van Brakel et al. 2006; Stevelink et al. 2011). The validated interview design includes the following items: hepatitis B knowledge, disability, self-esteem, disclosure, relationships, restrictions and discrimination. In order to give a measurement about the amount of stigma that takes place, participation scales were included in the interview design. These scales were incorporated from a validated, for use in the Netherlands, P-scale (van Brakel et al. 2006).

3.5 Data analysis

The interviews were recorded, after acquired consent, in order to accurately interpret the perspective and experiences of the interviewees. Subsequently, the recordings were transcribed and the anonymity of the interviewees was secured.

Open coding of the transcripts was conducted using the qualitative data analysis program ATLAS-Ti version 5.2. Open coding strives to break down data and compare these pieces of data (Smit. 2002). Thereafter, analysis of the qualitative data was conducted by connecting these codes and clustering overlapping themes in all transcripts and visualizing the relations between those using ATLAS-ti 5.2. These themes are flexible and may be modified during the analysis. The methods described by Berg (2004) and Taylor-Powel & Renner (2003) were mainly used to assist in analysing the data. This methodology makes use of guiding questions of analysis. These questions are subdivided into two categories. The first category consists of 'what' and 'how' questions that helps to establish the problems and issues within the study population. Secondly, 'who', 'where' and 'what' questions focus on specific actors, events and activities that relate to the issues of interest (Berg. 2004). These questions were not aimed to make a quality judgement about the gathered themes, but these instead aimed to identify and clarify topics, and how these affect the life of people. These topics encompass time periods and events of interest (e.g. HBV diagnosis, disclosing HBV-positive status to others) (Berg. 2004; Smit. 2002; Taylor-Powel & Renner. 2003).

Chapter 4: Results

In this section the data obtained from the interviews, conducted during this study, will be discussed. These results will be subdivided into three sub-sections: [transcripts of the Turkish HBV carriers of Rotterdam](#), [transcripts of the Turkish HBV carriers of The Hague](#) and [the transcripts of the Key informants](#). Each of these sub-sections is partitioned according to the concepts covered in the framework.

4.1. Results transcripts Turkish HBV carriers Rotterdam (2004):

In 2007, a study aimed to develop an evidence-based guideline for counselling chronic hepatitis B patients was published by Pars et al. 2007. A total of 45 interviews were conducted amongst chronic HBV carriers in Rotterdam in 2004, of those 45 respondents 12 were of Turkish origin. This Turkish study population consisted of 5 females and 7 males, ranging from the age of 25-56, and were included in the analysis of this study, in order to gain insight into the amount of hepatitis B-knowledge and coping strategies amongst Turkish HBV carriers. This data was compared to the data acquired from the [interviews](#) of this study. Since the aim of this previous study was to establish an evidence-based guideline, hardly any questions related to stigma were posed to the respondents. Therefore the transcripts contain little to no data about stigma and stigma will consequently not be compared with the data of the Turkish HBV carrier of The Hague, obtained in this study.

4.1.1. Hepatitis B related knowledge

The need for practical information was often mentioned by the patients. All respondents either posed questions to the interviewee regarding hepatitis B transmission, progression of the disease and vaccination. In the following sub-sections the amount of knowledge among the respondents will be highlighted.

Routes of hepatitis B transmission:

The respondents were asked if they knew via which transmission routes chronic hepatitis B could be transmitted to others (*Figure 4.1*). All respondents (n=12) stated that they knew that the disease could be transmitted to others via blood and sexual intercourse. Even though all the respondents correctly reported blood as a transmission route, most respondents did not mention blood-to-blood contact specifically as a transmission route. In addition, half of the respondents falsely believed that the disease could be transmitted to others via saliva by sharing glasses and cutlery with non-infected individuals. Withal, the toilet was mentioned as a main transmission route by 2 respondents and 2 other respondents declared towels as a common transmission route. Transmission via air (through breathing), bath and hereditary disease were all mentioned once as a transmission route by different respondents.

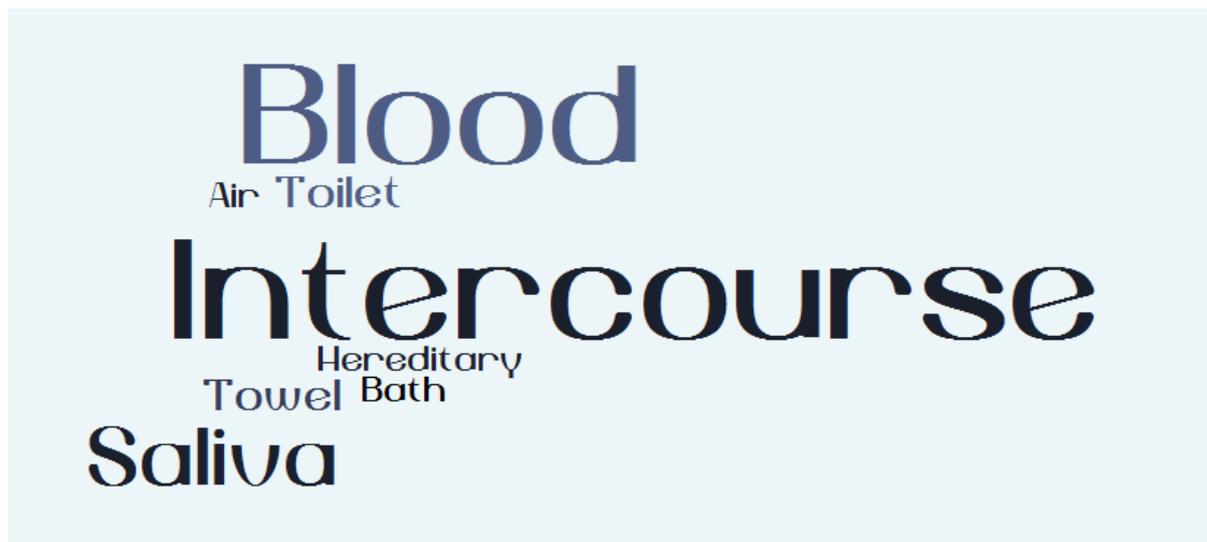


Figure 4.1. Word cloud of hepatitis B transmission knowledge amongst Turkish HBV carriers (n=12). All respondents stated that hepatitis B could be transmitted via blood and sexual intercourse. In addition, half of the respondents (n=6) mentioned that the disease was transmitted to others via saliva.

Progression and possible outcomes of hepatitis B:

Besides being asked about the routes of transmission, the respondents were also asked about their views regarding hepatitis B prognosis. A significant proportion of the respondents (n=4) stated that they did not know how the disease would progress, or believed that chronic hepatitis B did not pose any health threats. The remaining respondents (n=8) mentioned a wide range of possible consequences of the disease. 2 respondents believed the disease to be similar in nature as HIV/AIDS. However, they both stated that they did not believe that the disease is dangerous to others, since it was not active. This belief of lack of danger to others was shared with an additional 3 respondents.

‘There were more antibodies than viruses, that is why it is gone.’ 25-year-old Male.

‘No, I do not believe I am contagious, otherwise I would have experienced symptoms.’ 51-year old male

Even though some respondents did not know the possible (long-term) health consequences of the disease, a large proportion of the respondents (n=4) stated the chronic hepatitis B could cause liver damage in the long term. 2 out of these 4 respondents specifically mentioned liver cancer as a possible consequence and another respondent mentioned liver cirrhosis as a consequence of chronic hepatitis B. In addition to complications of the disease, a number of respondents (n=3) stated that chronic hepatitis B is a lifelong disease and therefore cannot not be cured, whereas the other respondents did not make any statements regarding hepatitis B being a lifelong disease.

Purpose of vaccinations

In addition to questions about transmission routes, the respondents were asked questions about the purpose of vaccinations. A proportion of the respondents (n=5) stated that vaccinations were meant to protect others from contracting the disease. However, a larger proportion (n=7) of the respondents either did not know the purpose of vaccinations or believed that vaccinations served a

different purpose (mainly, protecting the respondent from hepatitis B). Interestingly, the amount of knowledge about the **progression of the disease** did not seem to influence the **knowledge about the purpose of vaccination**, since 2 out of 5 respondents who knew the purpose of vaccinations did not know the disease prognosis.

4.1.2. Hepatitis B related stigma

Stigma was not widely reported in these transcripts, since the interview design did not include questions aimed to assess the level of stigma experienced by the respondents. However, some respondents still reported some forms of stigma.

Interpersonal forms of stigma

Enacted stigma

Three respondents mentioned that family members and/or acquaintances responded in fear when they heard about the respondent carrying chronic hepatitis B. One respondent reported that his wife was worried about contracting the disease (even though she was vaccinated), and he stated she told him to buy condoms otherwise she would become a chronic HBV carrier. Another respondent stated that the neighbours told her the disease is being transmitted via the toilet and told her she should not share a glass with others. In addition, she reported that she heard, in her social environment, that she should vaccinate her children a second time in order to protect them of acquiring hepatitis B. The third male respondent reported that his wife asked him on more than one occasion why he is a chronic HBV carrier, since her HBV diagnosis was negative. Another respondent stated that he received an angry response of his employee when he called in sick due to hepatitis B. Furthermore, his employee stated that the respondent should be able to work perfectly fine with hepatitis B and he should not call in sick. In addition, the respondent stated that the GGD initially told him to eat and drink separately. The remaining respondents did not report acts of enacted stigma, instead they mentioned that their family responded normally upon hearing that the respondent was a chronic HBV carrier.

Vicarious stigma

Acts of vicarious stigma were not widely reported by the respondents (n=2). One respondent mentioned that one of his friends told him he got fired by his employee, when his employee found out that the friend of the respondent was a chronic HBV carrier. A 37-years-old female respondent stated that she heard stories about a contagious virus from others, causing a wide range of illnesses including hepatitis B.

Intrapersonal forms of stigma

Similarly to interpersonal acts of stigma, no questions were posed to the respondents regarding intrapersonal forms of stigma. Nevertheless, quite a number of respondents made statements regarding felt normative stigma and/or internalized stigma.

Felt normative stigma

A third of the respondents (n=4), interviewed in 2004, mentioned several forms of felt normative stigma (perceived acts discrimination by members of the community). One respondent stated that he

would not be hired, when employees would know he is chronic hepatitis B carrier. Another respondent stated that he did not receive any negative responses from his wife upon hearing his chronic hepatitis B status. However, he anticipated that his wife would react in a hostile manner when she would have been diagnosed with hepatitis B as well. Also, a 56-year-old male respondent stated that he did not know how others felt about hepatitis B, but he did not expect it to be positive. A 42-year-old male mentioned that he would expect that people would gossip about him if he were to buy condoms. He stated that the gossip would be most likely about him visiting prostitutes or cheating. In addition, he reported that if he would discuss the disease openly with others, they would only know him as *'the mister with that disease'*.

Internalized stigma

In addition to the reported felt normative stigma, slightly less than half of the respondents (n=5) reported a range of internalized stigma. For instance, a 51-year-old male respondent called chronic hepatitis B as bad as AIDS; in addition he stated that when hepatitis B would become 'active' it would be even worse. Withal, a 33-year-old woman stated that she believed her husband contracted chronic hepatitis B because of her. One male respondent mentioned that he felt like he was the only one with the disease, and believed the disease to be similar to AIDS. Even though he compared hepatitis B to AIDS, he also stated that he did not believe that he could transmit the disease to others. A 37-year-old woman believed she could infect the children of her sister, since the children of her sister are not vaccinated.

4.1.3. Coping

During the analysis of the transcripts of Pars and colleagues (2007) a wide ranges of coping strategies were reported by the respondents. These coping strategies ranged from acceptance to ignoring and will be discussed accordingly, in the following sub-sections.

Hepatitis B transmission preventive measures

The respondents were asked what kind of preventive measures they took in order to prevent hepatitis B transmission. Preventive measures taken by the respondents are one of the indicators of what kind of coping strategies are employed by the respondents (emotion-based coping or problem-based coping). Ignoring the disease and not taking preventive measures is attributed to emotion based coping strategies, whereas taking preventive measures is seen as actively engaging with the problem and therefore as problem-based coping.

A significant proportion of the respondents (n=8) stated that they used preventive measures, in order to prevent the disease from spreading to others. Whereas, 4 respondents stated that they did not take any preventive measures, it has to be noted that all respondents that stated that they did not take any preventive measures were male respondents (*see figure 4.2*). Furthermore, of those respondents who stated they took preventive measures, a significant proportion (n=6) stated that they were careful when bleeding; mentioning cleaning blood, and keeping their distance from others. In addition, 4 of these 6 respondents mentioned keeping separate tooth brushes and/or shaving sets. Withal, 2 female respondents stated that they cleaned the toilet on a regular basis with bleach, in order to prevent HBV transmission. One of these 2 respondents did not take any additional preventive measures, but she did state that she took tranquilizers in order to cope with hepatitis B.

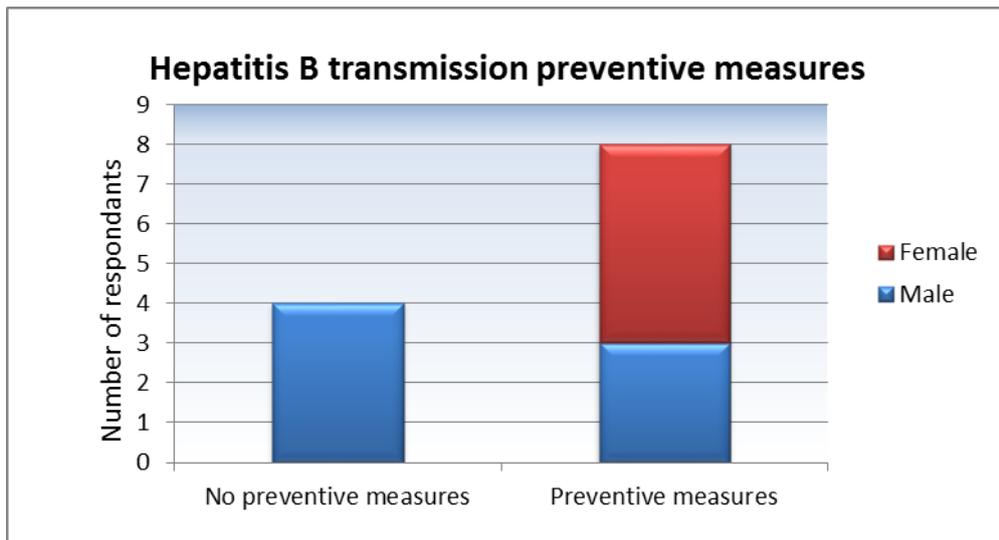


Figure 4.2. Respondents statements regarding measures to prevent hepatitis B transmission. 4 male respondents stated that they did not take any measures to prevent hepatitis B transmission to others.

A few respondents (n=3; two males and one female) stated that they used condoms during sexual intercourse in order to prevent transmission of the disease to their loved ones. In addition, 2 respondents (1 female and 1 male) stated that they would have liked to use condoms, but did not dare to use condoms citing anticipated negative responses of their spouse. Furthermore 1 male respondent stated that he took a shower before engaging into sexual intercourse with his wife, in order to prevent hepatitis B transmission.

'I try to clean the toilet with bleach, after every time I use it.' 33-year-old Female

'We shower in advance before having sex.' 25-year-old male

'I currently do not use protection, and I do not dare to discuss the topic.' 45-year-old female

Social participation and social activities

Most respondents (n=11) stated that they discussed hepatitis B with family members, the remaining respondent only discussed hepatitis B with friends. 3 out of the 11 respondents, who stated that they discussed chronic hepatitis B with relatives, mentioned that they could not discuss the disease with their partner. However, most respondents said that they received support from their family, since they were able to discuss it with their relatives when needed. Furthermore, 8 out of the 11 respondents, who stated that they discussed chronic hepatitis B with relatives, mentioned chronic hepatitis B only to their family and did not discuss it with someone else (including the GP, friends or distant relatives). In relation to social activities, one respondent mentioned that he felt tired because of hepatitis B and that he was not able to perform his job adequately. The other respondents did not mention limitations in social activities due to hepatitis B.

'I only told my family about it, my brother and my sister.' 51-year-old male

Religion

A proportion of the respondents (n=3) mentioned religion in relation to coping. 2 respondents stated that they did not worry about the progression of the disease, since they will leave it in the hands of god. Withal, a 38-year-old female respondent stated that god had protected her relatives till this day.

'I will leave it to god, time will tell.' 33-year-old female.

'He never had the disease till this day, so god has protected him.' 38-year-old female

4.1.4. Psychological distress

Psychological distress was categorized into three categories ranging from initial fear and subsequent loss of fear (n=5) to initial fear and sustained fear (n=5) to no psychological distress (n=2).

Initial fear and subsequent loss of fear (n=5)

A proportion of the respondents (n=3) reported that they experienced initial fear and sadness when they heard about their positive chronic hepatitis B diagnosis for the first time. The remainder of these respondents (n=2) stated that they feared for their family after hearing the diagnosis. A 33-year-old female respondent stated that besides experiencing fear, she also felt anger towards practitioners who did not diagnose her before.

All of these respondents (n=5) stated that after receiving consultation about chronic hepatitis B, they no longer feared the disease. However, a 25-year-old male respondent stated while he does not fear the disease anymore, he did fear people with open wounds, stating that he did not know what kind of diseases they have. In addition, he stated it is hard for him to believe that he actually has a disease. The other 4 respondents made similar statements, stating that they did not feel ill or sick.

'I was shocked, but after the consultation they told me it was not that bad, so I felt more relieved.' 51-year-old male

'I was initially shocked when I heard the news, also because of my wife and child.' 25-year-old male

Initial fear and sustained fear (n=5)

A number of respondents (n=5) stated that they experienced initial fear and sadness, and still experienced fear for what may happen to this day. All of these respondents (n=5) stated that they feared for the progression of the disease. 2 of the respondents mentioned that they feared for their life, furthermore the other 2 stated that every time they experienced pain, they feared the disease would strike.

'I went nuts it felt like receiving the death penalty' 42-year-old male

'It feels like carrying an extra sword with me' 31-year-old female

No distress (n=2)

The remaining respondents (n=2) stated that they did not worry about the disease upon hearing the diagnosis. Stating it was a normal disease.

'I am not worried.' 39-year-old male

'I did not lay awake during the night.' 32-year-old male

4.2 Results: Turkish hepatitis B carriers in The Hague

In this paragraph the data of the Turkish hepatitis B carriers interviewed during this study will be discussed.

4.2.1. Hepatitis B related knowledge

In this sub-paragraph an overview of the knowledge of the respondents (who are all Turkish hepatitis B carriers of The Hague) will be given. Several questions were posed to the respondent aimed at uncovering the knowledge of Turkish chronic carriers regarding the transmission of the disease, the progression of the disease and the prevalence of the disease.

Routes of hepatitis B transmission:

First of all, the respondents were posed questions about the routes of hepatitis B transmission, in order to assess the knowledge of first generation Turkish HBV carriers (*figure 4.3 & table 4.0*). All respondents (n=15) stated that they knew that hepatitis B is transmittable to others via blood. However, a much smaller number of these respondents (n=6) stated that the disease could only be transmitted to others via blood to blood contact. In addition to blood transmission, more than half of the respondents (n=9) stated that the disease could also be transmitted to others via sexual intercourse.

However, a large number of respondents also made various statements regarding 'false' transmission routes. As already indicated in the background information hepatitis B can be transmitted via blood contact or sexual intercourse, 'false' transmission routes are transmission routes mentioned by the respondents that deviate of the accepted transmission routes. For instance, a number of respondents (n=6) reported that the disease is transmittable to others via saliva. An almost similar number of respondents (n=5) stated that the toilet was a main route of hepatitis B transmission. Additionally, one respondent stated that hepatitis B could be transmitted amongst a community via a common source of drinking-water.



Figure 4.3 Word cloud of Hepatitis B transmission knowledge amongst Turkish HBV carriers in The Hague (n=15). 15 stated that the disease could be transmitted via blood. 9 respondents believed the disease to be transmitted via sexual intercourse. 6 stated that hepatitis B is transmittable via saliva. 5 believed the toilet to be a transmission route. 1 respondent stated that hepatitis B is transmittable via a common source of drinking water.

Table 4.0: Routes of transmission according to the respondents, the number indicates which respondent made which statement and transmission routes in green compose the correct transmission routes (identified as routes of hepatitis B transmission in the literature). All respondents stated that hepatitis B is transmittable to others via blood, however only 6 respondents (in red) specifically mentioned blood-to-blood contact. 9 respondents stated that the disease could be transmitted via sexual intercourse, 5 respondents mentioned hepatitis B transmission via the toilet, 6 carriers reported saliva as a common transmission route and 1 respondent stated that hepatitis B could be transmitted via a common source of drinking water.

Transmittable via blood (n=15: n=6)	Transmittable via intercourse (n=9)	Transmittable via toilet (n=5)
1, 2, 3, 4, 5, 6, 7, 8, 9, 10, 11, 12, 13, 14, 15	1, 2, 6, 8, 9, 11, 12, 14, 15	1, 2, 3, 8, 10
Transmittable via Saliva (n=6)	Transmittable via common source of drinking water	
3, 6, 8, 10, 13, 15	7	

Summary:

Most respondents could **not correctly identify the hepatitis B transmission routes** (the meaning of blood-to-blood contact was not clear) or mentioned **false HBV transmission routes** (transmission routes which are not known to be capable of transmitting hepatitis B).

Progression and possible outcomes of hepatitis B:

Besides questions about the routes of hepatitis B transmission, the respondents were posed questions to probe their knowledge about the progression of chronic hepatitis B. When asked questions about the progression of hepatitis B, about half of the respondents (n=7) stated that they

did not know anything about the progression of the disease, whereas the remaining respondents (n=8) stated that they did possess knowledge about the disease progression. 5 out of these 8 respondents, who claimed to have knowledge about the progression of the disease, incorrectly stated that hepatitis A, B and C were all stages of the same disease (see table 4.1). Furthermore, 1 of these 5 respondents was convinced that the final stage of the hepatitis disease is cancer. In addition to the incorrect belief amongst a group of respondents that hepatitis A, B, C are stages of the same disease, 4 respondents reported that they did not believe that the form of hepatitis B they carried is contagious and therefore posed no danger to others. It also has to be noted that 4 others stated that the disease was either gone or would disappear in the future. However, according to the literature chronic hepatitis B is still contagious, albeit to a lesser extent as acute hepatitis B.

Table 4.1: Beliefs amongst respondents (n=15) regarding the disease progression of hepatitis B.

Table 4.1 A: Statements by different respondents. The number indicates which respondent made which statement.

	Not contagiousness (n=4)	Hepatitis A, B, C are stages of the same disease (n=5)	Hepatitis B is gone/ will disappear (n=4)	No idea progression of the disease (n=7)
Respondent	3, 5, 7, 9	1, 2, 7, 8, 13	1, 4, 8, 10	4, 5, 6, 7, 11, 14, 15

Table 4.1 B: Statements by different respondents. The number indicates which respondent made what statement. The statements in green are possible consequences confirmed in the literature.

	Liver cirrhosis	Liver Damage (unspecified) (n=5)	Liver Cancer (n=3)	Lung Cancer	Death (n=4)
Respondent	2	2, 3, 8, 9, 13	1, 6, 13	10	2, 3, 8, 13

A number of respondents (n=8) made statements about possible complications that may arise in the future. 5 respondents stated that liver damage is a possible long term complication of hepatitis B; 1 of these respondents specifically mentioned **liver cirrhosis**. In addition to liver damage, 3 respondents mentioned **liver cancer** as a possible (long-term) complication of hepatitis B, whereas another respondent believed that **lung cancer** was a possible complication in the future. Withal, 4 respondents stated that **death** could be a final outcome of hepatitis B, when not taking care of the disease.

Summary

Knowledge regarding the hepatitis B prognosis was poor, only a few respondents were able to correctly identify some possible outcomes of the disease. In addition, there was the believe amongst a third of the respondents that **hepatitis A, B, C are all stages of the same disease (stage B was not that dangerous)**.

Prevalence of hepatitis B

In addition to the questions posed about HBV transmission and the progression of the disease, a number of respondents (n=6) made statements regarding the prevalence of hepatitis B in Turkey,

therefore these statements are included in the results. Respondents stated that hepatitis B is a rather common disease in Turkey, and that most people do not know they contracted the disease. A total of 3 respondents stated that they believe that 30-40% of the Turkish population were hepatitis B carriers, and 2 respondents believed that 70% of the Turkish population were chronic HBV carriers. Whereas, turkey has been indicated as an intermediate with a reported hepatitis B prevalence between 2-7% (ECDC. 2010).

Table 4.2: Hepatitis B prevalence rate in Turkey according to the respondents.

	Hepatitis B common disease	Hepatitis B prevalence of 30-40% (n=3)	Hepatitis B prevalence of 70% (n=2)
Respondent	15	3, 9, 10	2, 8

4.2.2. Interpersonal forms of hepatitis B related stigma

The main aim of the study was to assess to what extent HBV-related stigma occurred within the Turkish community. Interpersonal forms of stigma (stigma from others) covered in this paragraph are divided into 2 sections: enacted stigma and vicarious stigma.

Enacted stigma

Acts of discrimination and exclusion towards those diagnosed with chronic hepatitis B, were reported by a number of respondents (n=7) *table 4.3*. A total of 5 respondents reported acts of enacted stigma related to food, by family members. 4 respondents mentioned that family members cooked meals independently of the respondents. In addition to the mention of independent cooking of meals by family members, 2 of these respondents stated that family members wanted the respondents to eat separately. Furthermore, 2 other respondents stated that their family feared of contracting the disease from the respondents by sharing cutlery with one another.

In addition to enacted stigma related to eating food, respondents (n=3) reported that social interactions with others were disrupted because of acts of enacted stigma. Respondents reported that they were told by family members not to interact with others by either talking (n=2), touching (n=3) and breathing (n=2). In addition, it has to be noted that a number of respondents (n=4) stated that their relatives and friends expressed fear of contracting the disease.

Table 4.3: overview of acts of enacted stigma towards the respondents.

	Cook food separately (n=4)	Eat separately (n=2)	Do not share cutlery (n=2)	The yellow disease	Disbelief illness (n=2)
Respondent	2, 6, 11, 12	2, 6	10, 12	7	7, 13
	Do not go near others	Do not touch/cuddle others (n=3)	Do not talk to others (n=2)	Do not breath near others (n=2)	Fear of contagiousness (n=4)
Respondent	6	2, 6, 12	6, 12	6, 12	8, 10, 11, 12
	Contagious via toilet	Cheating	Cancer	Death	
Respondent	8	13	13	13	

Besides forms enacted stigma related to food and social interactions, 2 respondents reported that their family did not believe the respondent had a disease. 1 of these respondent stated that because he had no yellow eyes his family did not initially believe he had the so-called 'yellow disease'. Furthermore, 1 male respondent stated that his relatives told him he would probably get cancer and die. In addition, he stated that his wife was suspicious about him cheating, since she did not have the disease herself.

'If I touched bread, nobody else wanted to touch that bread anymore.' 27-years-old male respondent

'I had to eat separately in the kitchen and I was not allowed to cuddle my little brother anymore.' 28-years-old male respondent

'People immediately feared of contracting the disease themselves.' 36-years-old female respondent

'They told me not to go near people and told me to not breathe next to others.' 51-years-old female respondent

Summary:

Around **half of the respondents reported enacted stigma** (forms of discrimination). Enacted stigma consisted mainly of respondents being obliged by others **to eat separately and being told not to go near others** (i.e. touching, cuddling, fear of contagiousness)

Vicarious stigma

Stories of enacted stigma against others (vicarious stigma) were not widely reported by the respondents, a total of 2 respondents reported forms of vicarious stigma. A 42-year-old female respondent stated that she heard stories that nobody would visit someone she knew, because he was diagnosed with hepatitis B. Whereas, a 37-year-old male respondent stated that his friend was diagnosed with hepatitis B and that nobody believed his friend and his friend subsequently died.

4.2.3. Intrapersonal forms of hepatitis B related stigma

Besides acts of interpersonal stigma (acts of others), forms intrapersonal forms of stigma were mentioned by the respondents. This paragraph divides forms of intrapersonal stigma in 2 sub-paragraphs: felt normative stigma and internalized stigma.

Felt normative stigma

Beliefs of the respondents about the prevalence of negative attitudes of family members and society towards hepatitis B were reported by a large number of respondents (n=9). A large proportion of these respondents (n=6) reported that they anticipated that fear of contagiousness was prevalent within the Turkish community. A smaller number of respondents (n=4) anticipated that people would keep their distance when they know about the respondent being a hepatitis B carrier.

Table 4.4: the anticipated forms of stigma of the respondents (n=9).

	Gossip (n=2)	Being accused of cheating (n=3)	Prejudices (n=3)	Fear of contagiousness (n=6)	Relatives keeping their distance (n=4)
respondent	1, 13	2, 8, 13	2, 13, 14	3, 9, 11, 12, 13, 14	9, 11, 13, 14
	Get fired	HBV is just like AIDS	blamed if someone gets ill	Nobody dares to talk about it	
respondent	12	9	14	11	

A number of anticipated prejudices in society were also mentioned by respondents. A total of 3 respondents feared that they would be accused of cheating when someone would know about their condition. Furthermore, 2 respondents stated that they anticipated that people would gossip about them having hepatitis B. In addition to these forms of anticipated stigma, respondents reported an anxiety of getting fired (n=1), people drawing a comparison between HBV and AIDS (n=1), being blamed if someone gets ill (n=1) and that nobody dares to talk about it (specifically mentioning the word taboo) (n=1).

'I believe people think about AIDS in the same way as hepatitis.' 34-years-old male

'People believe it is transmitted via sex, so all women believe I have cheated.' 37-years-old male respondent

Summary:

Almost **two third of the respondents anticipated for enacted stigma**. Most of them expected others would **fear contagiousness** and a lesser number of respondents expected **prejudices** of others regarding the disease.

Internalized stigma

Not many respondents (n=2) currently believe that acts of stigma by others as being valid. However, most respondents reported that they believed that the acts of stigma were valid, when just hearing their positive diagnosis. Subsequently these respondents stated that they do not believe the acts of stigma to be valid anymore. The 2 remaining respondents stated that they believed that some of the acts of stigma were valid; one stated that living healthy was crucial otherwise she might die and the other respondent stated that he could feel the disease progression getting worse over time.

It has to be noted that even though most respondents stated that they did not perceive stigma of others as valid when being asked about these acts of discrimination, a number of disturbing [coping strategies](#) suggested that some degree of **internalized stigma did exist** amongst a number of respondents. Especially since a number of respondents were told to eat separately and should not share cutlery by others. These subsequent acts of coping suggested that a number of respondents did believe these acts of stigma as being valid.

4.2.4. Role of practitioners

Since practitioners were mentioned broadly by the respondents (n=8) in relation to coping, this separate paragraph will focus on the role of the practitioners on the lives of Turkish chronic hepatitis B carriers. A number of respondents (n=6) stated that they did not (completely) trust their GP (table 4.5). It has to be noted that of these 6 respondents, 5 respondents were referring to lack of trust in Dutch GPs, whereas a 28-years-old male respondent was referring to his Turkish practitioner. A 49-years-old male stated that even though he does not trust the judgement of GPs, he does trust medical specialists at the hospital when being consulted about hepatitis B. This statement is in stark contrast with the opinion of another respondent, who stated he did not trust any medical specialist at all. It has to be noted that most of these respondents did not mention a level of distrust or trust towards medical specialists at hospitals and they were solely referring to their GP when referring to their distrust in health care services.

'I do not trust a GP, a specialist at the hospital yes, but a GP not.' 49-years-old male respondent

'My trust is gone, I do not trust any practitioner anymore.' 37-years-old male respondent

It has to be noted that an equal number of respondents (n=6), as those stating distrust, believed that their GP was withholding information about hepatitis B. Since, a number of these respondents (n=3) reported that the GP did not tell them anything about the disease. Whereas, the remaining respondents (n=3) stated that even though the GP informed the respondents that they should take preventive measures, the practitioners did not inform the respondents about the need of these preventive measures. In addition, these respondents stated that the GPs did not give them information about the disease prognosis.

'If I call the GP after giving blood, everything is fine, but he does not explain anything.' 49-years-old male respondent

'My GP did not tell me anything' 33-years-old male respondent

In addition to the statements of the respondents regarding the communication between the practitioner and the respondent after a positive diagnosis, a number of respondents (n=4) mentioned that they were not informed about being a chronic hepatitis B carrier by their GP initially. These respondents stated that their status as a chronic hepatitis B carrier was already known for years by the health authorities prior to being informed.

'The GGD told me I had hepatitis B, the GP did not inform me about it.' 49-years-old male respondent

'In my patient file it was noted that I already had the disease for 20 years, but I did not know.' 50-years-old female respondent

Withal, a number of respondents (n=3) stated that they did not receive medical treatment from their GP in order to quell hepatitis B. One respondent criticized GPs more strongly by stating that he believed GPs will only give medication if the respondent is about to die because of hepatitis B.

'He is not doing anything about the disease.' 36-years-old male respondent

'Then they come in the last 6 months, in 6 months you will die, you cannot do anything about that. If they had come earlier you had the chance to keep the disease under control for 10 years.' 37-years-old male respondent

Table 4.5: overview of statements regarding the relationship between practitioners and respondents. Statements covered in red refer to Turkish practitioners, whereas statements in black refer to Dutch practitioners.

	Lack of trust GP (n=6)	GP withholding information (n=6)	Not receiving treatment (n=3)	Was not told I had the disease (n=4)
Respondent	1, 2 , 3, 8, 13, 15	1, 2 , 7, 8, 13, 15	3, 13, 15	1, 5, 8, 13

Summary:

Just over one-third of the respondents reported **considerable distrust towards GPs**. This distrust is mostly related to the believe that GPs are **withholding information** about hepatitis B from the patient.

4.2.5. Coping

Based on the amount of knowledge the respondents possess and the acts of stigma, coping strategies were adopted by the respondents. As already mentioned [in paragraph 2.5](#) coping strategies are either categorized as problem-focused coping or Emotion-focused coping, which will be further discussed in the discussion [\(chapter 5\)](#).

Hepatitis B transmission preventive measures & measures for self-preservation

Most respondents (n=12) stated that they took preventive measures in order to prevent transmission of the disease to others. The majority of these respondents (n=9) reported that they removed blood stains and took measures when bleeding (table 4.6). However, around half of these respondents (n=4, in red numbers table 4.6) stated that they cleaned blood stains with alcohol in order to completely remove the virus. In addition to removing blood, a number of respondents (n=7) mentioned keeping objects and tools separate from other people, in order to prevent HBV transmission. Of these 7 respondents, 4 stated that they kept everything separate. Everything was defined as keeping food, cutlery and other objects separately, when asking the respondents what they meant by keeping everything separate. In addition, 2 respondents stated that they kept cutlery and cups separately from others, keeping toothbrushes separately was also mentioned by 2 respondents.

Besides these measures, a number of respondents stated that they kept their distance from others (n=3), cleaned the toilet (n=2) and made use of condoms during intercourse (n=3). Whereas, 3 male respondents stated that they did not take any HBV transmission preventive measures.

'I always remove blood immediately with alcohol' 42-years-old female respondent

'The GGD told me many things, that is why I try to keep everything separate'. 34-years-old male respondent

'Just too bad it is transmittable, but if I do not know in what ways I am not going to change my life style.' 36-years-old male respondent

'I always make sure nobody grabs my fork or cup.' 28-years old male respondent

Summary:

In order to prevent HBV transmission, the respondents took a **wide range of preventive measures**. Most of these measures were related to **cleaning blood stains** and **keeping objects separately from other people**.

Acts of self-preservation

In addition to taking preventive measures to prevent hepatitis B transmission, a number of respondents (n=6) reported self-preservation measures in order to deal more effectively with the disease. Around a quarter of the respondents (n=4) stated that they drank limited to no alcoholic beverages, since it could damage the liver functions. Furthermore, 2 respondents mentioned the use of herbs; a 29-years-old female respondent stated she used herbs to quell the disease, whereas a 42-years-old male respondent stated that the use of herbs could cure hepatitis B. One respondent stated that psychiatric medication was able to reduce the stress associated with hepatitis B.

'No alcohol and no more smoking are good for the liver.' 42-years-old female respondent

'Nowadays, I just drink a beer every 3-4 months.' 36-years-old male respondent

Table 4.6 HBV transmission preventive measures (in blue) & Self-preservation measures (in red).

<u>Transmission preventive measures</u>	Keep everything separate (n=4)	Separate cups/cutlery (n=2)	Separate Toothbrush (n=2)	Remove blood (n=9), clean blood stains with alcohol (n=4)
Respondents	1, 3, 9, 13	2, 8	2, 6	2, 3, 5, 6, 7, 9, 11, 12, 14
	Keep distance from others (n=3)	Clean toilet after use (n=2)	Condom use (n=3)	No transmission preventive measures (n=3)
Respondents	6, 9, 13	3, 8	6, 9, 13	4, 10, 15
<u>Self-preservation Measures</u>	Limited alcohol use/ smoking (n=4)	Herbs (n=2)	Psychiatric medication	
Respondents	3, 8, 13, 15	10, 14	13	

Social participation and activities

Respondents were asked in what ways hepatitis B influences their daily lives. Most respondents stated that they were able to continue their daily activities like before the diagnosis. 1 respondent

stated that he quit working, because of hepatitis B. In addition, 3 respondents stated that they felt restricted, since they were not able to donate blood to blood banks.

Whereas, a number of respondents (n=6) stated that they just worked hard and everything was fine, in addition they stated that they currently did not think about the disease. A slightly higher number of respondents (n=7) stated that they acknowledged that they were carriers and moved on.

'You have to continue living, you have to move on.' 51-years-old female respondent

'My life has not changed, everything is still the same as before.' 42-years-old male respondent

Summary:

Most respondents stated that they were able to continue their daily activities in a similar fashion as before their diagnosis.

Table 4.7: Overview of the overall acceptance of hepatitis B of the respondents. 8 respondents decided to just ignore the disease, whereas 7 stated that they accepted the disease. In addition, 2 respondents (in red) mentioned that they simply did not care about the disease.

	Ignoring (n=8)	Acceptance (n=7)
Respondents	1, 4, 5, 7, 8 , 10, 13 , 15	2, 3, 6, 9, 11, 12, 14

Even though statements were made about ignoring the disease, most respondents (n=13) reported that they (initially) talked about hepatitis B with others (family members n=13, acquaintances n=7, barber n=2) *table 4.7*. However, most respondents who stated that they discussed the disease with family members mentioned that they only discussed HBV with close relatives (i.e. parents, brothers, sisters). It has to be noted that most respondents stated that they currently did not discuss the disease at all, unless someone would ask them about hepatitis B. Furthermore, it was reported that the main reason for discussing the disease with others was to seek **understanding and support**, and secondly to acquire information about the disease, since the respondents did not know much about the disease initially. The remaining respondents (n=2), who stated that they did not discuss the disease under any condition, reported that it was not interesting for them to talk about hepatitis B since they did not care about chronic hepatitis B.

Table 4.8: overview of the hepatitis B disclosure of respondents towards others.

<u>Conversations about the disease</u>	Barber (n=2)	Family (n=13)	Acquaintances (n=7)	Do not discuss the disease (n=2)
Respondents	1, 2	1, 2, 3, 4, 5, 6, 7, 8, 9, 11, 12, 13, 14	3, 5, 6, 7, 11, 12, 13	10, 15

Summary:

In most cases the respondents only **discussed the disease initially** with **close relatives** and to a lesser extent with acquaintances but **not with more distant relatives**.

Second opinion

Besides consultations with practitioners in the Netherlands, a number of respondents (n=10) stated that they also visited practitioners in Turkey in order to discuss hepatitis B during a consultation. When asked for the reasons why they consulted practitioners in Turkey, in overall the respondents responded that 2 practitioners know more than one. Some respondent cited that they did not initially believe the HBV diagnosis and that was the main reason for them to go abroad.

'I also went to Turkey for a check-up, two doctors know more than one doctor.' 31-years-old male respondent

'Yes yes, I always go and see a doctor in Turkey.' 38-years-old male respondent

Table 4.9: overview of the number of respondents who visited practitioners in the Netherlands and Turkey. 10 respondents both visited practitioners in Turkey and the Netherlands, whereas 5 respondents only went to consult practitioners in the Netherlands.

Second opinion	Yes (Turkey & Netherlands) (n=10)	No (Netherlands) (n=5)
Respondents	1, 2, 3, 4, 6, 7, 8, 10, 12, 13	5, 9, 11, 14, 15

Searching for information

Besides the reported second opinion in Turkey, a number of respondents searched for additional information about hepatitis B. 5 respondents stated that they searched for information about hepatitis B via the internet (sometimes with the assistance of relatives), and 2 reported that they acquired information about HBV by watching Turkish medical TV programs. 4 alternate respondents reported that they asked the specialist at the hospital for additional information about hepatitis B during consultations. In addition, 4 respondents reported that they relied on their family when acquiring information.

Table 4.10: Indicated sources of information of the respondents. it has to be noted that in some cases of searching via the internet, family assisted the respondents.

	Internet (n=5)	Asking specialist (n=4)	Television (n=2)	Family (n=4)
Respondents	1, 9, 12, 13, 14	1, 2, 11, 12	3, 5	2, 5, 6, 8

4.2.6. Psychological distress

Respondents were asked questions about how they responded upon hearing their diagnosis (the initial response) and in addition they were probed about how they felt currently in terms of psychological distress.

Initial response upon hearing a positive hepatitis B diagnosis

When asked about how they felt upon hearing their hepatitis B diagnosis, the respondents gave a range of responses (*table 4.11*). Most respondents (n=10) stated that they were shocked when they found out they were chronic hepatitis B carriers. Half of these respondents (n=5) stated that they were afraid they would die and therefore they experienced levels of anxiety. In addition, 4 respondents reported that they feared for the health of their relatives, upon hearing the positive diagnosis. 3 male respondents noted that they associated every illness and pain they experienced with hepatitis B. Furthermore, 3 respondents were simply frustrated, since they did not know the origin of the disease and 1 respondent did not specify why he was shocked. Most respondents stated that they currently did not suffer of forms of distress, except 2 respondents.

'I immediately believed I had a severe disease, that was my initial response.' 36-years-old female respondent

'If I had pain somewhere, I immediately believed it was due to hepatitis B.' 31-years-old male respondent

'I believed I would die at that time.' 42-years-old female respondent

Summary:

Two-third of the respondents indicated that they were in shock when initially hearing their hepatitis B diagnosis. Cumulating in a wide range of (initial) anxieties.

Table 4.11: Initial response of respondents upon hearing the positive diagnosis.

Initial shock				
	Experienced anxiety because of the unknown (n=5)	Fear for health family (n=4)	Associate pain/illness with HBV (n=3)	Frustrated because of unknown cause HBV (n=3)
Fear of dying (n=5)	3, 8, 11, 13, 14	3, 9, 11, 13	8, 12, 13	11, 12, 13
No initial shock				
	Not an interesting disease (n=2)	Common disease		Did not specify why (n=2)
	7, 15	10		2, 4

Besides respondents who stated that they were shocked upon hearing the diagnosis, a number of respondents (n=5) stated that they did not experience forms of shock upon hearing their chronic hepatitis B diagnosis. 2 respondents stated that hepatitis B was not an interesting disease, and 1 respondent stated that it was a common disease and nothing to worry about.

4.3 Results: Key informants

In this section the data acquired after interviewing the [key informants](#) will be displayed into 5 sub-paragraphs. These key informants consisted of 2 general practitioners (one Dutch GP and one Turkish-Dutch GP) dealing with Turkish patients, a Turkish social worker and an internist in hepatology (specialist physician at the hospital).

4.3.1. Hepatitis B Knowledge of the Turkish community

It was reported by key informants that hepatitis B knowledge amongst members of the Turkish community was either lacking or incomplete. First of all, a GP stated that this lack of knowledge was probably due to the fact that members of the Turkish community do not know any patients experiencing hepatitis B complications. Similarly, a social worker stated that long-term complications such as liver cirrhosis and liver cancer are often not associated with hepatitis by members of the Turkish community (including chronic HBV carriers).

In addition to lack of knowledge regarding possible long term HBV complications, key informants mentioned that there is also a lack of understanding amongst Turkish immigrants concerning the HBV transmission routes. According to all key informants, an important factor influencing the amount of knowledge amongst first generation immigrants is a **language barrier** when being consulted by a practitioner. This language barrier is attributed to the fact that most first generation are less proficient in the Dutch language and also have a higher illiteracy rate, compared to their second and third generation Turkish counterparts. Therefore, it was argued by key informants that first generation Turkish immigrants are more dependent on others for acquiring information about the disease. Furthermore, 2 practitioners stated that Turkish chronic HBV carriers asked little to no questions, compared to other ethnicities, during hepatitis B consultations.

4.3.2. Hepatitis B related stigma

In order to determine to what extent hepatitis B-stigma occurs within the Turkish community, the key informants were posed questions in relation to stigma. In overall the response of the level of stigma varied greatly between the key informants. The practitioners on the one hand stated that hepatitis B in general has no negative connotations, whereas the social worker stated that hepatitis B is subjected to taboo within the Turkish-Dutch community. In order to create a clear overview of the statements regarding stigma, these were subdivided into the following 2 sub-paragraphs: interpersonal forms of stigma (external stigma) and intrapersonal forms of stigma (self-stigmatization).

Interpersonal forms of stigma: Enacted stigma

When discussing the results of Turkish HBV carriers interpersonal forms of stigma were divided into vicarious stigma and enacted stigma in the [previous result section](#). The key informants, opposed to the Turkish HBV carriers, did not mention forms of vicarious stigma occurring within the Turkish community, therefore only acts of enacted stigma will be evaluated this section.

According to the social worker hepatitis B has a negative connotation, since it is associated with AIDS, other sexual transmitted diseases (STDs), cheating and drug use. As consequence, he stated that he

believes that members of the Turkish-Dutch community rather not visit individuals diagnosed with HBV, subsequently Turkish chronic carriers will become isolated, excluded from taking part in activities and may experience problems in social relationships. Likewise, a practitioner stated that he believes that Turkish women diagnosed with chronic HBV will most likely blame their husbands as the source of the disease, since they will suspect their husbands of cheating. In addition, he mentioned that family members will most likely not provide support to Turkish immigrants diagnosed with chronic HBV. On the other hand, a second practitioner believes that a chronic hepatitis B diagnosis will not lead to prejudices towards those diagnosed.

Intrapersonal forms of stigma

Besides addressing interpersonal acts of stigma, key informants reported forms of intrapersonal stigma. These were subdivided, according to the theoretical framework, into felt normative stigma and internalized stigma.

Felt normative stigma

Two key informants reported possible forms of felt normative stigma. The social worker stated that people who were diagnosed with chronic hepatitis B anticipated forms of enacted stigma, such as being accused of using drugs and cheating, by others. In addition, he stated that Turkish HBV carriers experienced chronic hepatitis B as a taboo, due to comparisons between HBV and HIV/AIDS. Likewise, a practitioner mentioned that Turkish male HBV carriers are aware of the prejudice of Turkish-Dutch women that hepatitis B is linked to cheating.

Internalized stigma

The same informants (the social worker and practitioner), who made statements regarding felt normative stigma in the previous sub-paragraph, made elucidations concerning internalized stigma. The social worker stated that patients previously diagnosed with chronic hepatitis B and experiencing acts of stigma, may hold acts of stigma as justified when not being properly informed about the disease. Withal, the practitioner stated that Turkish HBV carriers may experience feelings of guilt, upon hearing their diagnosis.

4.3.3. The role of culture and social structures on coping

The role of culture and social structures on the coping strategies of HBV carriers has been mentioned widely by key informants. A number of key-informants (n=3) stated that members of the Turkish-Dutch community were generally fearful of contracting diseases, in addition it was reported by 2 key informants that members of the Turkish community consequently visit practitioners on a regular basis when experiencing so-called functional complaints. Functional complaints are interruptions in a patient's health not attributed to an organic cause that can significantly affect the quality of life but. According to these 2 key-informants this desire of Turkish members to be healthy is one of the primary reasons why (most) Turkish chronic HBV carriers seek confirmation abroad (in Turkey) when they hear about their positive hepatitis B diagnosis in The Netherlands.

In addition to the Turkish-Dutch anxiety of being unhealthy, it was reported by a number of practitioners (n=2) that social structures within the community play a prominent role in how Turkish chronic carriers deal with the disease. In order to illustrate these social structures, one practitioner

stated that Turkish women invited for a hepatitis B consultation are often accompanied by female relatives (i.e. niece, daughter-in-law) and are rarely accompanied by their husbands (or male relatives). Furthermore, it was reported by the key-informant, that male Turkish chronic carriers are more prone to visit a hepatitis B consultation without their spouse compared to Turkish women. These statements clearly illustrate the male-female relationship within a family. Another notable phenomenon, according to the practitioners, is that in general Turkish chronic carriers are more passive during consultations compared to other ethnicities. Passive, in this sense means that Turkish chronic carriers are less actively engaged with the practitioner during hepatitis B consultations, since they ask the practitioners little to no questions about the disease. The Turkish-Dutch GP offers a possible explanation for the reported **lack of active engagement** of Turkish chronic carriers, namely that Turkish people have a high sense of **hierarchy**, especially when confronted with practitioners. Hierarchy was explained as Turkish HBV carriers having a certain degree of respect for practitioners and consequently are less willing to discuss the disease openly with practitioners. It is important to note that 2 practitioners stated that they interpreted this lack of active engagement as a lack of interest of Turkish HBV carriers in acquiring knowledge about the disease. In addition, since no questions are asked by Turkish HBV carriers, these practitioners are not sure if Turkish chronic carriers attending hepatitis B consultations comprehend the ways in which hepatitis B can be transmitted to others. Withal based on these observations, it is argued by 2 practitioners that in general not much is spoken by the HBV carriers about the disease at home and in the community, otherwise more questions would be posed by Turkish HBV carriers during consultations.

However, a different view about disclosure is pictured by the social worker and another practitioner (Turkish-Dutch GP). According to the social worker and the practitioner, Turkish chronic hepatitis B carriers do talk about the disease with others, in order to acquire more knowledge about the disease. However, both the GP and the social worker state that they are not sure in what context is spoken about the disease within the Turkish community, especially since it is noted that knowledge about the disease is lacking in the Turkish community. The other GP, who previously stated that he did not believe much was spoken about the disease within the Turkish-Dutch community, mentioned that if a disease causes people to become outcasts of the community, they will most likely not talk about it. It has to be noted that this statement of the GP referred to diseases in general, in addition the GP stated that it could also apply to hepatitis B when it was labelled as a dangerous disease.

Besides disclosure to acquire information, the social worker points out that when the hepatitis B knowledge of a Turkish chronic HBV carrier is inadequate; it is possible that acts of self-isolation occur. As a consequence of isolation, the practitioner stated that some Turkish HBV carriers may experience limitations in conducting the same activities as before their positive diagnosis. According to the social worker, besides seeking knowledge about hepatitis B from peers, Turkish chronic carriers attempt to acquire information about the disease by watching Turkish medical television shows and searching the internet.

In addition to the possibility of self-isolation of Turkish HBV carriers due to inadequate knowledge, a practitioner stated that he encountered a number of Turkish HBV carriers, who believed that the disease was gone after a few years. Another practitioner shared similar encounters with Turkish patients in general.

4.3.4. Psychological distress

When questions were asked to key informants regarding psychological distress endured by first generation Turkish HBV carriers, it became evident that the key informants held two distinct views in respect to distress. First of all, two practitioners stated that they did not believe that a positive HBV diagnosis would cause (psychological) distress amongst Turkish HBV carriers, both citing different reasons. One of these practitioners reported that although the patients did not exhibit distress during consultations, some did show concern regarding the disease. The second practitioner cited lack of symptoms associated with HBV as a reason why distress amongst Turkish HBV carriers is minimal. Furthermore, the practitioner stated that STDs would cause more distress amongst members of the Turkish-Dutch community, compared to hepatitis B. The remaining practitioner and social worker stated that Turkish HBV carriers do experience levels of anxiety due to hepatitis B. However, they both had different accounts for the origin of anxiety. The social worker stated that hepatitis B related anxiety is mainly caused by pressure of not being able to tell anyone about the disease. The practitioner reported that anxiety was often related to Turkish patients linking hepatitis B to death.

4.3.5. Improvement of hepatitis B consultations

During the interviews, several remarks were made by the key informants regarding ways to improve hepatitis B consultations with Turkish HBV carriers. According to the social worker, the use of literal translations of Dutch hepatitis B brochures into Turkish has a nugatory effect on making Turkish chronic carriers understand the disease and act on the information. Therefore, he argued to adapt information brochures not only by direct translation but also take the cultural context into consideration. Subsequently, when asking what he meant by cultural context, the social worker stated that he was referring to the routes of disease transmission, which are according to him based on the Dutch ways of hepatitis B transmission. Therefore, he argued to put less emphasis on transmission via intravenous drug use and sexual intercourse during consultations, and more emphasis on transmission via circumcision, earrings, shaving, blood brothers and birth. When opting for this cultural approach it was argued by the social worker that the disease receives a less negative connotation and turns into a more recognizable disease. In addition to a more specific cultural approach during consultations, he stated that GPs in general do not possess much knowledge about hepatitis B and GPs are therefore unable to properly engage in hepatitis B consultations with chronic carriers.

One of the practitioners stated that GPs have a limited time to consult with chronic HBV carriers and therefore focus on the most important aspects of hepatitis B only. These important aspects, according to the practitioners, are the transmission routes of the disease and the importance of vaccinations. In addition, the practitioner states that the guidelines, regarding hepatitis B, should be adapted in order to deal with specific circumstances encountered in different ethnicities. Another practitioner stated in this regard that information given by Dutch practitioners to first generation Turkish HBV carriers in most cases will not reach its intended purpose of informing chronic HBV carriers. The cause for this failure is mainly attributed to the language barrier. A third practitioner stated in order to overcome the language barrier and not solely rely on information brochures, a translator was used when conducting the first hepatitis B consultation, in order to ensure that the

crucial information is transmitted properly. The subsequent consultations of the third practitioner were conducted without the assistance of a translator.

Chapter 5: Discussion

The aim of this study was to determine to what extent stigma towards first generation Turkish HBV carriers occurs within the Turkish community and to determine what the consequences of stigma are on the daily life of HBV carriers in terms of psychological distress, coping strategies and social activities. In the following sub-sections the [sub-research questions](#) will be discussed in accordance with the data, in order to answer the main research question, To what extent and in which forms does hepatitis B-related stigma occur in the Turkish community, and what is the impact of stigma on the social life of Turkish chronic hepatitis B carriers in terms of psychological distress, coping strategies and behavioural outcomes?. Subsequently, at the end of this chapter an overall conclusion will be given.

The extent of hepatitis B-related stigma amongst Turkish first generation immigrants diagnosed with chronic HBV

The first sub-research question aimed to elucidate in which forms stigma occurs among the Turkish HBV carriers in The Hague. Ungrounded preventive measures, restricted participation and exclusion are reported as an everyday reality for a host of first generation Turkish HBV carriers. Since around half of the respondents (HBV carriers, The Hague, 2012) stated that they (had) suffer(ed) from various forms of **enacted stigmatization**, these acts of stigma ranged from prejudices to social exclusion of Turkish chronic HBV carriers mainly by family members. Forms of enacted stigma by friends do almost not occur within the Turkish community. Even though enacted stigma was prevalent, it has to be noted that hardly any **vicarious stigma** is observed (stories of stigma directed at others) when analysing the data of the interviews.

Besides experiencing forms of stigma from their environment (the interpersonal forms of stigma), patients stated more frequently that they suffered of forms of **felt normative stigmatization**, by anticipating for negative views about hepatitis B within society. In addition to the reported felt normative stigma, most patients stated that they initially endured internalized stigmatization when experiencing enacted stigma. Currently, most HBV carriers stated that they do not believe that these acts of enacted stigmatization are valid. However, even though most respondents stated that they did not perceive stigma of others as valid, a number of disturbing coping strategies suggested that some **degree of internalized stigma did exist** ([see coping strategies](#)).

Most likely these acts of enacted stigmatization are caused by the **lack of hepatitis B knowledge** within the Turkish community, whereas the acts of felt normative and internalized stigmatization are caused by a knowledge deficit among Turkish HBV carriers. The causes and consequences of stigma on the daily life of Turkish HBV carriers will be discussed in the subsequent sub-paragraphs.

Drivers behind hepatitis B stigmatization

The second and third sub-research questions aimed to determine the drivers behind stigmatization. When analysing the data acquired from the interviews, it was determined that [knowledge](#) and [social structures](#) are the main drivers behind stigmatization.

Knowledge

When assessing the amount of knowledge and the familiarity of the respondents (HBV carriers, The Hague, 2012) with hepatitis B, it turned out that the knowledge of the multitude of respondents was **mediocre** at best regarding **HBV transmission routes** and was **poor** when assessing the knowledge of the carriers concerning the **prognosis of hepatitis B**. Only a few respondents were able to correctly identify the HBV transmission routes and hepatitis B prognosis.

First of all, all the respondents identified blood transmission as a hepatitis B transmission route; however it became evident that the **exact meaning of viral blood transmission was not clear** to the majority of the respondents. Only a small number of respondents specifically stated blood-to-blood contact as a transmission route, whereas the others believed that the virus was transmittable if someone would simply get in touch with their blood. Furthermore, a wide range of **'false' transmission routes** were mentioned by the majority of the respondents, which clearly indicated that the routes of HBV-transmission are not well understood by the majority of the Turkish chronic HBV carriers. This lack of knowledge amongst Turkish HBV carriers regarding HBV transmission routes is echoed in the study conducted in Rotterdam in 2004, where respondents stated even more false HBV transmission routes. In addition, several key informants reported that they did not believe that there was much knowledge and awareness about the disease within the Turkish community, compared to other immigrant groups (e.g. Chinese) with a higher risk of contracting HBV compared to the general Dutch population. Some key informants specifically mentioned that they believed that the transmission routes were not clear to an amount of Turkish HBV carriers they encountered.

More disturbing is the misconception of a third of the respondents (HBV carriers, The Hague, 2012) that the different viral forms of hepatitis (hepatitis A-C) are all stages of the same disease. This explains why most respondents did not believe that the disease was dangerous, since it is stage B of the disease. Similar statements can be found in the data acquired in Rotterdam, where around half of the respondents stated that they did not believe that the disease posed any danger to others. Also around half of the respondents interviewed in The Hague stated that they did not know how the disease would progress.

As a consequence of the poor knowledge amongst the respondents, most respondents are more susceptible to forms of enacted stigma (which can lead to internalized stigma), especially since the family is their only source of information and support.

Social structures

Besides the role of knowledge in the acts of stigma, a second driver of stigma was identified namely social structures within the Turkish community. As already briefly mentioned, a multitude of the respondents of The Hague mainly rely on the support of family members when it comes to acquiring information. Only a minority of the respondents searched for additional information themselves.

Also key informants clarified that members of the Turkish-Dutch community are more differential to hierarchy compared to other ethnicities. This means that they are more likely to accept acts of stigma as valid from more influential family members, community members and even GPs.

Coping strategies and psychosocial distress

The third and fourth sub-research question aimed to determine the coping strategies and psychological distress of Turkish HBV carriers, associated with hepatitis B related stigma. As already made clear in the previous paragraphs, most respondents do not appear to have a large amount of knowledge regarding hepatitis B which led to various misconceptions and stigma. These **misconceptions contribute considerably to certain coping strategies**, especially when taking into consideration that respondents (in some cases) exclude themselves by keeping all their belongings separately and by keeping their distance from others. In addition, the lack of hepatitis B knowledge within the Turkish-Dutch community contributes considerably to enacted stigmatization, since the community members tend to make their own assumptions based on little to no knowledge which may result in stigma.

Therefore it is interesting to correlate this lack of knowledge among the chronic carriers in The Hague and Rotterdam, with the coping strategies of the respondents aimed at acquiring information. Withal, by correlating the amount of knowledge of the respondents with the coping strategies they use, it is possible to assess what kind of coping strategies are employed: either emotion-focused coping strategies or problem-focused coping strategies. After correlating the knowledge and coping strategies, it appears that most of the respondents (HBV carriers, The Hague, 2012 & HBV carriers, Rotterdam, 2004) largely employ **emotion-focused coping strategies** when it comes to acquiring knowledge about the disease and less prominently use problem-focused coping strategies. This becomes evident since most of the respondents adopt a **passive** approach when it comes to acquiring information, even though their knowledge is lacking. This phenomenon suggests that most respondents choose to preserve/suppress the emotions associated with the problem (the disease), rather than dealing with the problem itself. There did not appear to be a connection between the presence of family members during interviews and the answers given by the respondents, since in both cases mostly emotion focused coping strategies were mentioned by the respondents. Also in both cases a few respondents mentioned not taking any measures to prevent HBV transmission, indicating that presence of family members did not influence in the respondents stating that they did not take any measures to prevent HBV transmission.

The previously mentioned phenomenon of respondents mostly using emotion-focused strategies when dealing with knowledge becomes more evident since the majority of the respondents did not read the Turkish/Dutch information brochure provided by the GGD. In addition it was observed that the Turkish HBV carriers lacked active participation during hepatitis B consultations with practitioners. *Active participation is defined as the Turkish HBV carrier taking part in the discussion during a hepatitis B consultation, as opposed to the situation that the practitioner serves as the guide and the patient expected to just listen during a consultation.* A minority of the HBV carriers attributed this absence of active engagement during consultations due to lack of trust in the abilities of GPs. Consequently, due to this **lack of active engagement during consultations**, the respondents will not receive all the information about hepatitis B and may still hold various misconceptions regarding hepatitis B.

It also has to be noted that a smaller number of respondents, who appeared to have a deeper knowledge of the disease were more prone to take the right preventive measures aimed at stopping the spread of the disease. Whereas, it became clear that Turkish HBV carriers, with a deficit in

hepatitis B knowledge, fill in their hepatitis B information gaps by making their own assumptions, or base their assumptions on the opinion of others (enacted stigma). Consequently, they take ungrounded measures to prevent HBV transmission based on their own assumptions, even though most respondents stated that they did not believe that they were internalizing stigma.

According to some key informants, another possible explanation to the passive attitude of the HBV carriers is that Turkish HBV carriers are more differential to hierarchy and are therefore less likely to ask questions to practitioners during consultations, since they do not want to 'waste the time of the practitioner'. Another possible explanation is that quite a number of respondents stated that they **anticipated for acts of enacted stigma**: i.e. prejudices, accused of cheating etc. Therefore, it is plausible that these anticipated acts of stigma serve as a barrier for Turkish HBV carriers to discuss the disease more openly with the practitioner. In contrast to shame is the anxiety of the respondents of what might happen in the future, which is arguably a factor with a greater impact on whether the patient will actively engage with practitioners during HBV consultations. This explanation is also supported by the fact that most respondents do not appear to possess a large amount of knowledge on chronic hepatitis B prognosis, indicating that they did not actively search for information. A final factor argued to be involved in the lack of participation is the fact that most respondents seek additional HBV confirmation abroad in Turkey and therefore do not actively participate in hepatitis B consultations in the Netherlands, which is also attributed to the language barrier they face in the Netherlands. However, it is highly likely they also lack active engagement during hepatitis B consultations in Turkey, since there was no evidence of a better understanding of the routes of disease transmission and disease prognosis, when comparing those who opted to consult a practitioner in Turkey and those who did not. Therefore, simply attributing this passive attitude of the respondents during consultations to the language barrier is not likely.

When analyzing what kind of coping strategies were employed when dealing with forms of stigma in the context of this study (both inter- and intra-personal forms of stigma), it is notable that despite a majority of the respondents stating that they are aware of the negative views in society, most respondents decided to disclose their chronic HBV status to others. However, disclosure is mostly restricted to close relatives. The motivation behind disclosing one's positive hepatitis B status to others is mainly to acquire support, advice and information about the disease (**seeking of instrumental support**) according to the majority of the respondents. Therefore it is mainly **problem-focused** in nature, opposed to the emotion focused coping strategies employed when looking for information. However, **elements of emotion-focused coping** are observed as well, (most) respondents stated that they decided only to disclose hepatitis B to those close to them, since they anticipated for negative responses of others towards hepatitis B. Thereby, the respondents clearly indicate a desire to **seek positive reinterpretation**, by preventing stress associated with enacted stigma. Also the decision of the respondents to restrict disclosure to those close to them was enhanced in most cases by the fact that respondents experienced forms of enacted stigma by more distant relatives (e.g. cousins, uncles). Experiencing enacted stigma in this sense raises the awareness of respondents for negative views/attitudes in society regarding hepatitis B. Withal, since around half of the respondents mentioned forms of **enacted stigma**, one would expect to encounter a substantial amount of **vicarious stigma**. However, only a few cases of vicarious stigma were reported, confirming that indeed not much is spoken about the disease within the community.

Also it has to be noted that a substantial number of the Turkish HBV carriers (both of The Hague and Rotterdam) stated that they did not believe the disease to pose any danger (via transmission) to others, however they insisted that they did take measures in order to prevent HBV transmission to others. Based on these contradictory statements it is therefore more likely to assume that a **substantial number of these respondents do not take steps to prevent HBV transmission**, but instead gave socially desired answers when asked if they took preventive measures. Also, a minority of the male respondents (Both the HBV carriers, The Hague, 2012 & HBV carriers, Rotterdam, 2004) admitted that they did not take measures to prevent the transmission of hepatitis B.

Psychosocial distress

When probing for psychological distress attributed to hepatitis B (and the associated stigma) amongst respondents (The Hague, 2012), psychological distress was only reported by the minority of the respondents in The Hague as a problem. In overall, some forms of frustration were currently reported by respondents, since they were not able to disclose the disease to anyone. Furthermore, upon hearing their diagnosis for the first time, stress in the forms of shock and frustration were reported. However, most respondents did not appear to experience distress currently. These findings are in stark contrast to the assessment of psychological distress amongst HBV carriers in Rotterdam, in the study conducted by Pars and colleagues (2007), where more psychological distress was reported amongst the respondents of Rotterdam compared to the respondents of The Hague. This difference in both samples is most likely attributed to the earlier statements of the majority of the respondents of The Hague that chronic hepatitis B is **not a dangerous disease**, whereas the respondents of Rotterdam (2004) were in overall less knowledgeable and more fearful of the potential consequences of the disease. A potential selection bias will be discussed in the sections limitation of the study.

The impact of coping behavioural responses on the social life and health of Turkish-Dutch chronic hepatitis B carriers

The last sub-research question aimed to determine what the impact of stigma is on the social life of Turkish HBV carriers. As already indicated, most respondents disclosed their HBV status to relatives, about half of these respondents experienced forms of enacted stigma, which led to forms of social interruptions. These social interruptions consisted mostly of forms of isolation imposed by relatives on the respondents, which ranged from eating separately to keeping distance. Consequently, most respondents who experienced discrimination are more wary of revealing their HBV-positive status to others, due to an increased level of **felt normative stigma**.

More importantly, a number of respondents adopted coping strategies ranging from not sharing cutlery, plates and glasses to respondents keeping their distance from others. These coping strategies indicate that **internalized stigma** is prevalent among a number of respondents, since **coping strategies** such as not sharing cutlery are clearly adopted based on **inaccurate knowledge** of the respondents and forms of **enacted stigma** by others.

Limitations of the study

Interpreters were not used during this study, due to budget constraints. Instead, most interviews (n=11) were conducted in the presence of close family members, therefore it is arguable that the respondents did not disclose acts of stigmatization of their direct relatives to the interviewer. However, most respondents appeared more comfortable during the interviews when other family members were present. Furthermore, in around half of the cases the family members assisted in making certain statements of the interviewees clearer. However, one respondent (without family around during the interviews) did report acts of stigmatization of close relatives; therefore it is arguably possible that more socially desired answers were given by these respondents when conducting the interview in the presence of family members. However, it has to be noted that there did not appear to be much difference in the answers given by the other respondents surrounded by family members and the other respondents without family members present during the interview, since in both cases similar acts of stigma were reported by the respondents. Also, in addition similar coping strategies were reported by respondents, confirming that the presence of family members had a limited influence on the interview.

Based on the results, it can be argued that a certain level of selection bias occurred during the course of the study, since most respondents in The Hague did not appear to suffer much psychological distress. Therefore, it is likely to assume that only those who did not suffer much distress came forward to discuss their disease with the interviewer and that those suffering of an increased level of distress did not come forward. Besides the apparent low level of psychological distress of the respondents, still a wide range of stigma was reported by the respondents. Withal, the low level of psychological distress of the interviewees did not appear to influence the main purpose of the study, which was aimed to assess the occurrence of hepatitis B related stigma within the Turkish community of The Hague.

Also it has to be taken into account; it is not possible to determine the exact selection criteria used to contact respondents in 2004 in Rotterdam. Therefore, it is more difficult to explain some notable differences between the respondents of The Hague and the respondents of Rotterdam, such as the higher level of psychological distress of the respondents of Rotterdam. Even though the selection criteria were not transparent, the correlation between knowledge and coping strategies of the respondents of Rotterdam was clear and therefore did not hinder correlations made within the study sample of Rotterdam.

Several key informants were approached for interviews, in order to gain an overview of the thoughts and beliefs of members of the Turkish-Dutch community regarding chronic disease and more particularly hepatitis B. Marshall (1996) argues that the formal role of the informant in the community should expose them to the kind of information sought by the researcher. However, the key informants approached during this study consisted mostly of practitioners (one of Turkish descent); the only non-practitioner interviewed was a Turkish social worker. Therefore, it can be argued that the view of some of the informants may be limited when it comes to insight in consequences of hepatitis B on the daily life of members of the Turkish community. Especially since some key informants reported that they did not believe that there were negative consequences attached to the disease, when Turkish HBV carriers discussed the disease openly with others. This idea is strengthened by the fact that one of these key informants stated that hepatitis B will not lead

to prejudices amongst members of the Turkish Dutch community and others stated that they did not really know the effects of the disease on the social life of Turkish HBV carriers.

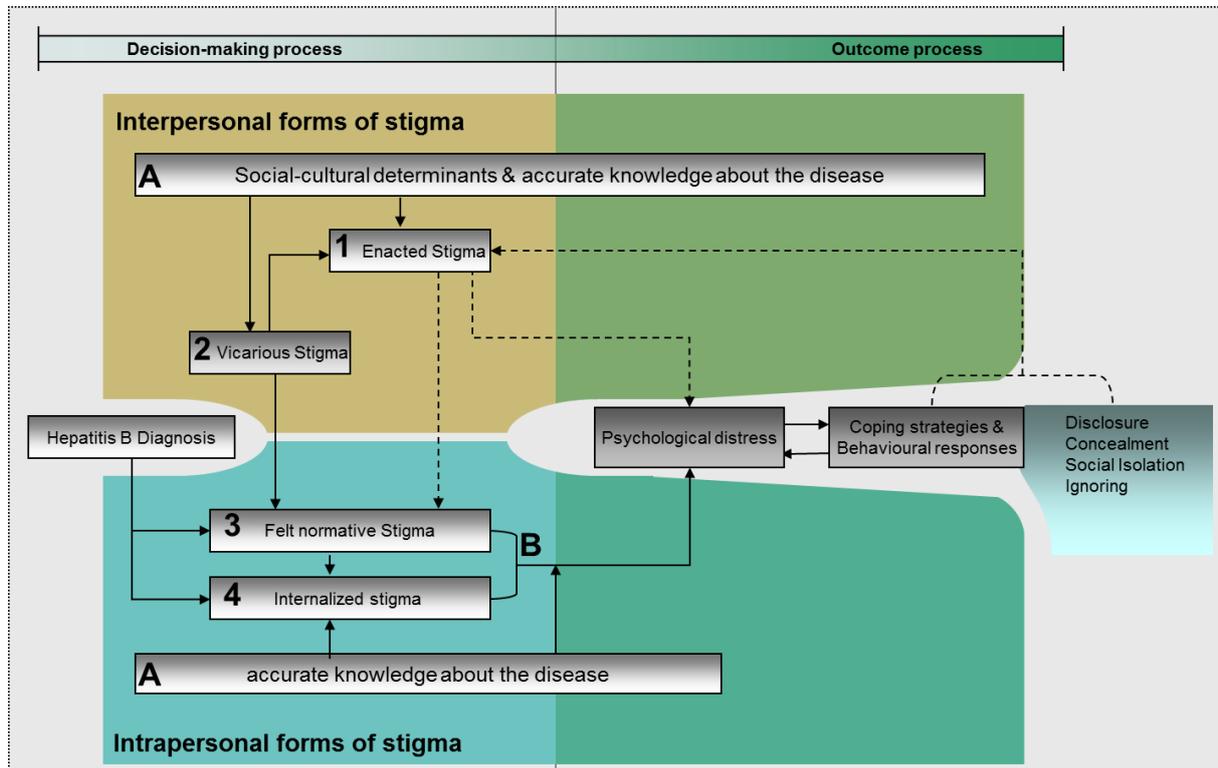
Another possible limitation of the study was the use of a generic stigma interview design, leaving little room to ask the respondents questions regarding the unique situation of chronic hepatitis B. For instance, in most cases chronic HBV is not visible to others, therefore enacted stigma only occurs when the respondent decides to reveal his/her hepatitis B status to others. The generic interview was adjusted in order to include this important aspect in the interview design. However, the interview design should be adapted for future use in order to indicate the education level of the interviewees, by doing so it is possible to correlate the amount of knowledge of the interviewees with their educational level. Especially since the data indicated that knowledge is an important driver behind the acts of stigma and the subsequent coping strategies and behavioral responses, it is important to indicate what kind of role educational level plays in relation to the amount of knowledge. Especially, since studies conducted amongst immigrants in the US have indicated educational level as an important factor in how hepatitis B is perceived by HBV carriers (Cotler et al. 2012; Ma et al. 2007).

Overall Conclusion

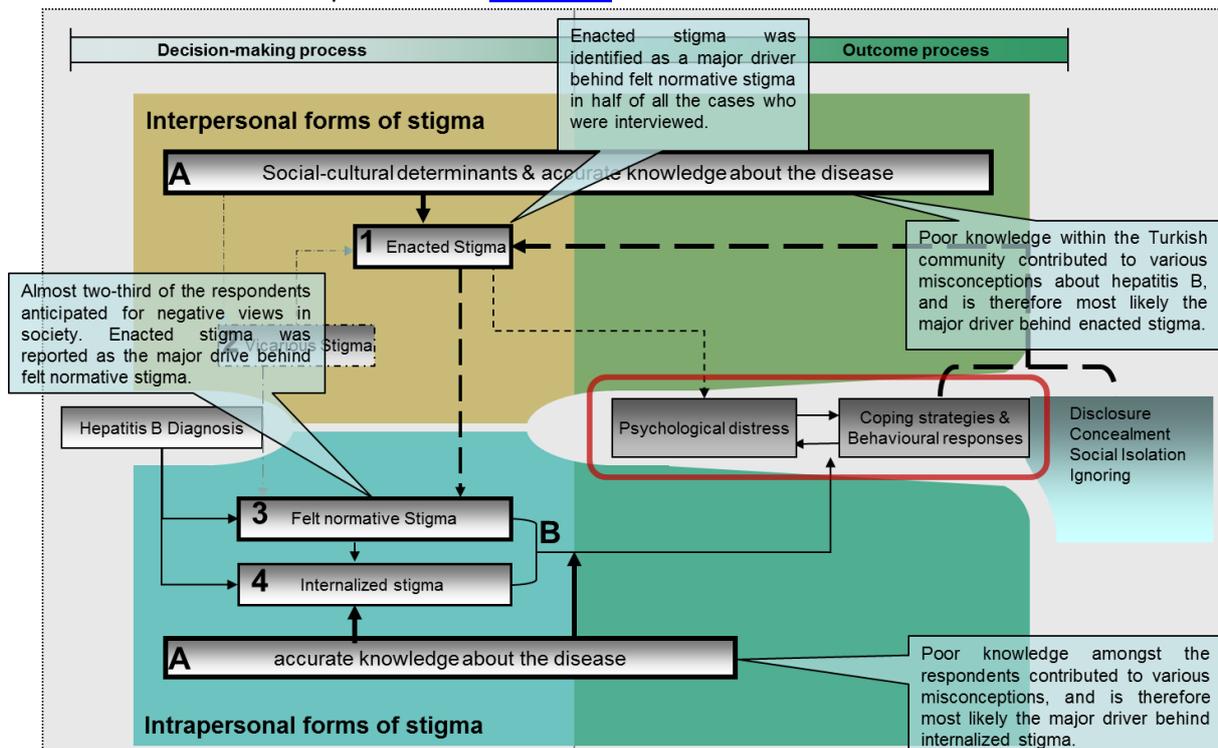
Hepatitis B and its associated stigma affect the social lives of first-generation Turkish HBV carriers, even in a low-endemic hepatitis B country as the Netherlands. A high number of respondents were affected by intrapersonal forms of stigma, especially after receiving their diagnosis. Even though Interpersonal stigma was observed to a lesser extent than intrapersonal forms of stigma; still around half of the respondents were affected by interpersonal forms of stigma. It is important to note that internalized stigma does persist to a certain extent when analyzing the coping strategies adopted by the chronic HBV carriers, these forms of internalized stigma are most likely caused by enacted stigma and poor knowledge. **1)** Poor knowledge about the disease is identified as the main driver behind forms of stigma, in both the Turkish-Dutch community and first generation Turkish immigrants diagnosed with chronic HBV. Also the respondents mainly rely on family members for information about the disease, making them more susceptible for stigma. **2)** In addition, poor knowledge contributes to most respondents not taking the appropriate measures to prevent disease transmission to others. **3)** Emotion-focused coping strategies are more prominently used by the respondents, since they mainly aim to reduce stress instead of actively engaging with the problem. This is evident in the general passive attitude of respondents when it comes to acquiring information about the disease and in their decision to limit disclosure to others, in anticipation of negative attitudes of others towards the respondents. **4)** The awareness of the passive attitude of Turkish HBV carriers during consultations should be increased amongst practitioners, since it can be misinterpreted as a lack of interest in the disease. Also, practitioners should rely less on distributing information brochures when a hepatitis B consultation falters, since a majority of the respondents indicated that they did not read the information brochure at all and fill in the gaps in their knowledge with their own assumptions (i.e. cleaning the toilet, keep cutlery separately etc.). Consequently, during hepatitis B consultations with Turkish HBV carriers more emphasis should be put on the hepatitis B transmission routes, which will make Turkish HBV carriers less vulnerable to forms of enacted stigma, since they will consequently not view these acts of stigma as valid. Also it would be prudent to assess hepatitis B-stigma in other (large) immigrant groups from intermediate or highly hepatitis B endemic countries to assess if similar psychosocial disruptions occur, in order to

determine if it is necessary to adapt hepatitis B consultations for more immigrant groups from intermediate or high endemic HBV countries.

Adapted framework according to the results and conclusion



Unaltered framework as represented in [chapter 2](#).



Adapted framework according to the data acquired during the interviews. Based on the interviews it was determined that (1) enacted stigma towards (chronic) hepatitis B carriers occurred prominently

within the Turkish community, whereas, **(2) vicarious stigma** was virtually non-existent. Therefore, enacted stigma is likely to play a prominent role as a driver behind **(3) felt normative stigma**. Most respondents (2/3) reported that they anticipated for enacted stigma, such as exclusion, prejudices, isolation etc. Most respondents stated that they experienced **distress** initially, but do not experience it currently. However, both **felt normative stigma** and (A) **inaccurate knowledge of the disease** did seem to play a salient role in what kind of **coping strategies** were adopted by the respondents. For instance, a wide range of false transmission routes were reported by the respondents, which ultimately resulted in the respondents claiming to take preventive measures in order to quell these false transmission routes. Also it was noted that when evaluating the coping strategies adopted by the patients it became clear that a portion of the chronic carriers did believe that sharing glasses, plates, cutlery were transmission routes, indicating that forms of **(4) internalized stigma** did persist, since stigma was perceived as valid by the patients. Furthermore, due to experiencing forms of enacted stigma, respondents became more reluctant to disclose their positive HBV status to others. Withal, respondents did not actively search for information about the disease themselves but rather expected others to give it to them.

References:

- Afsar, B., Elsurer, R., Eyiletem, T., Yilmaz, M. I. & Caglar, S. (2009). *Antibody response following hepatitis B vaccination in dialysis patients: Does depression and life quality matter?*. Vaccine Vol. 27 pp. 5865–5869
- Alizadeh, A. H. M., Ranjbar, M. & Yadollahzadeh, M. (2008). *Patient concerns regarding chronic hepatitis B and C infection*. Eastern Mediterranean Health Journal, Vol. 14, No. 5
- Andersson, G. & Willebrand, M. (2003). *What is coping? A critical review of the construct and its application in audiology*. International journal of audiology, Vol. 42
- Baaten, G. G. G., Sonder, G. J. B., Dukers, N. H. T. M., Coutinho, R. A. & Van der Hoek, J. A. R. (2007). *Population-Based Study on the Seroprevalence of Hepatitis A, B, and C Virus Infection in Amsterdam, 2004*. Journal of Medical Virology Vol. 79, pp. 1802–1810
- Berg, B. L. (2004). *Qualitative research methods for the social sciences*. Pearson Education 5th Edition ISBN 0-205-37905
- Carver, C. S., Kumari Wientraub, J. & Scheier, M. F. (1989). *Assessing coping strategies: A theoretically based approach*. Journal of personality and social psychology. Vol. 65 No. 2
- Chaudoir, S. R. & Fisher, J. D. (2010). *The disclosure processes model: Understanding disclosure decision-making and post-disclosure outcomes among people living with a concealable stigmatized identity*. Psychol Bull. Vol. 136 No. 2 pp. 236–256
- Cohen, D. & Crabtree, B. (2006). *Qualitative research guidelines project*. Published July 2006. <http://www.qualres.org/HomeSemi-3629.html>
- Cotler, S. J., Cotler, S., Xie, H., Luc, B. J., Layden, T. J. & Wong, S. S. (2012). *Characterizing hepatitis B stigma in Chinese immigrants*. Journal of Viral Hepatitis Vol. 19 pp. 147–152
- Crul, M. & Schneider, J. (2009). *Children of Turkish Immigrants in Germany and the Netherlands: The Impact of Differences in Vocational and Academic Tracking Systems*. Teachers College Record
- Custer, B., Sullivan, S. D., Hazlet, T. K., Iloeje, U., Veenstra, D. L., Kowdley, K. V. (2004). *Global epidemiology of hepatitis B virus*. Journal Clinical Gastroenterol. Vol. 38 No. 10 pp. S158-68.
- De Groot, R., Van Brakel, W. H. & De Vries, H. J. C. (2011). *Social implications of leprosy in the Netherlands - stigma among ex-leprosy patients in a non-endemic setting*. Lepr Rev Vol.82 pp. 168–177
- Dehesa-Violante, M. & Nunez-Nateras, R. (2007). *Epidemiology of Hepatitis Virus B and C*. Archives of Medical Research Vol. 38 pp. 606-611

ECDC. (2010). *Hepatitis B and C in the EU neighbourhood: prevalence, burden of disease and screening policies*. European Centre for Disease Prevention and Control Technical report

Eiser, C. (1990). *Psychological Effects of Chronic Disease*. Journal of Child Psychol. Psychiat. Vol. 31 No. 1 pp. 85-98

Esveld, MI (2001). *HBV prevention policy in the Netherlands*. Infectieziektenbulletin Vol. 12 pp. 313-316.

Ezzikouri, S., Chemin, I., Chafik, A., Wakrim, L., Nourlil, J., El Malki, A., Marchio, A., Dejean, A., Hassar, M., Trepo, C., Pineau, P. & Benjelloun, S. (2008). *Genotype determination in Moroccan hepatitis B chronic carriers*. Infection, Genetics and Evolution Vol. 8 pp. 306–312

Franciosi, M., Caccamo, L., De Simone, P., Pinna, A. D., Di Costanzo, G. G., Volpes, R., Scuderi, V., Strigano, P., Boccagni, P., Burra, P. & Nicolucci, A. (2012). *Development and Validation of a Questionnaire Evaluating the Impact of Hepatitis B Immune Globulin Prophylaxis on the Quality of Life of Liver Transplant Recipients*. Liver Transplantation, Vol. 18 No. 3

Guirgis, M., Nusair, F., Bu, Y. M., Yan, K. & Zekry, A. T. (2011). *Barriers Faced by Migrants in Accessing Healthcare for Viral Hepatitis Infection*. Accepted Article"; doi: 10.1111/j.1445-5994.2011.02647.x

Health Council of the Netherlands. (2009). *General vaccination against hepatitis B revisited*. The Hague: Health Council of the Netherlands; publication no. 2009/03.

Holzemer, W. L., Uys, L. R., Chirwa, M. L., Greeff, M., Makoe, L. N., Kohi, T. W., Dlamini, P. S., Stewart, A. L., Mullan, J., Phetlhu, R. D., Wantland, D. & Durrheim, K. (2007). *Validation of the HIV/AIDS Stigma Instrument—PLWA (HASI-P)* AIDS Care: Psychological and Socio-medical Aspects of AIDS/HIV Vol. 19 No.8 pp. 1002-1012

Houweling, H., Wittevrongel, C. F. W., Verweij, M. & Ruitenber, E. J. (2010). *Public vaccination programmes against hepatitis B in The Netherlands: Assessing whether a targeted or a universal approach is appropriate*. Vaccine vol. 28 pp. 7723–7730

ILEP. (2011). *Guidelines to reduce stigma*. The International Federation of Anti-Leprosy Associations (ILEP) and the Netherlands Leprosy Relief (NLR), London / Amsterdam, 2011

Jones, C. P. (2000). *Levels of racism: a theoretic framework and a gardener's tale*. American journal of public health vol. 90 No. 8

Koedijk, F. D. H., Van der Sande, M. A. B. & Hahne, S. J. M. (2010). *Declarations of acute hepatitis B in 2009 (aangifte acute hepatitis B in 2009)*. Infectieziekten bulletin Vol. 21 No. 10

LCI. (2011). *Guideline hepatitis B (Richtlijn hepatitis B)*. LCI/Cib/RIVM guideline infectious diseases. LCI may 2008, adapted October 2011

Lekganyane, R. & Du Plessis, G. (2011). *Dealing With HIV-Related Stigma: A Qualitative Study of Women Outpatients from the Chris Hani Baragwanath Hospital*. Journal of the Association of Nurses in AIDS Care Vol. 23 No. 2 pp. 1-8

Lim, C. K., Tan, J. T. M., Khoo, J. B. S., Ravichandran, A., Low, H. M., Chan, Y. C. & Ton, S. H. (2006). *Correlations of HBV Genotypes, Mutations Affecting HBeAg Expression and HBeAg/anti-HBe Status in HBV Carriers*. International Journal of Medical Sciences Vol. 3 pp. 14-20

Ma, G. X., Fang, C. Y., Shive, S. E., Toubbeh, J., Tan, Y. & Siu, P. (2007). *Risk Perceptions and Barriers to Hepatitis B Screening and Vaccination among Vietnamese Immigrants*. Journal of Immigrant Minority Health Vol.9 pp. 213–220

Marshall, M. N. (1996). *Sampling for qualitative research*. Family Practice Vol. 13 No. 6

Marshall, M. N. (1996). *The key informant technique*. Family Practice Vol. 13 No. 1

Matthews, G. & Robotin, M. (2008). *B Positive - all you wanted to know about hepatitis B: a guide for primary care providers*. ISBN: 978-1-920773-56-4

McCain, N. L. & Gramling, L. F. (1992). *Living with dying: coping with HIV disease*. Issues in Mental Health Nursing Vol. 13 pp.271-284

McMahon, B. J., Bulkow, L., Harpster, A., Snowball, M., Lanier, A., Sacco, F., Dunaway, E. & Williams, J. (2000). *Screening for Hepatocellular Carcinoma in Alaska Natives Infected With Chronic Hepatitis B: A 16-Year Population-Based Study*. Hepatology Vol. 32 No. 4

Mostert, M. C., Richardus, J. H., Van Leeuwen, P. & De Man, R. A. (2006). *New project for optimal referral of patients with chronic hepatitis B infection (Nieuw project voor optimale doorverwijzing van patiënten met een chronische hepatitis B-infectie)*. infectieziekten Bulletin Vol. 17 No. 10

Muraskin, W. (1988). *The Silent Epidemic: The Social, Ethical, and Medical Problems Surrounding the Fight against Hepatitis B*. Journal of Social History Vol. 22 No. 2 pp. 277-298

Ng, C. J., Low, W. Y., Wong, L. P., Sudin, M. R. & Mohamed, R. (2011). *Uncovering the experiences and needs of patients with chronic hepatitis B infection at diagnosis: a qualitative study*. Asia-Pacific Journal of Public Health Vol. 20 No. 10 pp. 1–9

Nowack, K. M. (1989). *Coping Style, Cognitive Hardiness, and Health Status*. Journal of Behavioral Medicine Vol. 12 No. 2

Op de Coul, E. L. M., Van Weert, J. W. M., Oomen, P. J., Smit, C., Van der Ploeg, C. P. B., Hahné, S. J. M., Notermans, D. W. & Van der Sande, M. A. B. (2010). *Prenatal screening for HIV, hepatitis B and*

syphilis in the Netherlands (Prenatale screening op hiv, hepatitis B en syfilis in Nederland effectief). Nederlands Tijdschrift Geneeskunde Vol. 154 No. 2175

Petrak, J. A., Doyle, A. M., Smith, A., Skinner, C. & Hedge, B. (2001). *Factors associated with self-disclosure of HIV serostatus to significant others.* British Journal of Health Psychology Vol. 6 pp. 69–79

Rahangdale, L., Banandur, P., Sreenivas, A., Turan, J. M., Washington, R. & Cohen, C. R. (2010). *Stigma as experienced by women accessing prevention of parent-to-child transmission of HIV services in Karnataka, India.* AIDS Care Vol. 22 No. 7 pp. 836-842

Reeves, S., Kuper, A. & Hodges, B. D. (2008). *Qualitative research methodologies: ethnography.* British Medical Journal Vol. 337 No. 1020

Richter, C., Ter Beest, G., Sancak, I., Aydinly, R., Bulbul, K., Leatemala-Tomata, F., De Leeuw, M., Waegemaekers, T., Swanink, C. & Roovers, E. (2012). *Hepatitis B prevalence in the Turkish population of Arnhem: implications for national screening policy?.* Epidemiol. Infect. Vol. 140 pp. 724–730

Scambler, G. (1993). *Epilepsy and quality of life research.* Journal of the Royal Society of Medicine Vol. 86

Scambler, G. (2009). *Health-related stigma.* Sociology of Health & Illness Vol. 31 No. 3

Scambler, G. (2011). *Epilepsy, stigma and quality of life.* Neurology Asia Vol. 16 pp s35 – s36

Smit B. (2002). *Atlas.ti for qualitative data analysis.* Perspectives in Education Vol. 20 No. 3

Spiegel, B. M. R., Bolus, R., Han, S., Tong, M., Esrailian, E., Talley, J., Tran, T., Smith, J., Karsan, H. A., Durazo, F., Bacon, B., Martin, P., Younossi, Z., Hwa-Ong, S. & Kanwal, F. (2007). *Development and Validation of a Disease-Targeted Quality of Life Instrument in Chronic Hepatitis B: The Hepatitis B Quality of Life Instrument, Version 1.0.* Hepatology Vol. 46 No. 1

Stevelink, S. A. M., Van Brakel, W. H. & Augustine, V. (2011). *Stigma and social participation in Southern India: Differences and commonalities among persons affected by leprosy and persons living with HIV/AIDS.* Psychology, Health & Medicine Vol. 16 No. 6 pp. 695-707

Steward, W. T., Herek, G. M., Ramakrishna, J., Bharat, S., Chandy, S., Wrubel, J. & Ekstrand, M. L. (2008). *HIV-Related Stigma: Adapting a Theoretical Framework for Use in India.* Social Science & Medicine Vol. 67 No. 8 pp. 1225–1235

Taylor, V. M., Shin-Ping, T., Woodall, E., Acorda, E., Chen, H., Choe, J., Li, L., Yasui, Y. & Hislop, G. T. (2006). *Hepatitis B Knowledge and Practices among Chinese Immigrants to the United States.* Asian Pacific Journal of Cancer Prevention Vol. 7

Taylor, V. M., Seng, P., Acorda, E., Sawn, L. & Li, L. (2009). *Hepatitis B knowledge and practices among Cambodian immigrants*. Journal Cancer Education Vol. 24 No. 2 pp. 100–104

Taylor-Powell, E. & Renner, M. (2003). *Analyzing qualitative data*. University of Wisconsin-Extension, Analyzing qualitative data (G3658-12)

Temple, B. & Young, A. (2004). *Qualitative research and translation dilemmas*. Qualitative Research Vol. 4 No. 2

Toy, M., Oguz Önder, F., Wörmann, T., Bozdayi, A. M., Schalm, S. W., Borsboom, G. J., van Rosmalen, J., Richardus, J. & Yurdaydin, C. (2011). *Age- and region-specific hepatitis B prevalence in Turkey estimated using generalized linear mixed models: a systematic review*. BMC Infectious Diseases Vol. 11

Van Brakel, W. H. (2005). *Measuring health-related stigma – a literature review*. Royal Tropical Institute / Leprosy Unit

Van Brakel, W. H., Anderson, A. M., Mutatkar, R. K., Bakirtzief, Z., Nicholls, P. G., Saju, M. S. & Das-Pattanayak, R. K. (2006). *The Participation Scale: Measuring a key concept in public health*. Journal of Disability and Rehabilitation Vol. 28 No. 4 pp. 193 – 203

Van Houdt, R., Bruisten, S. M., Speksnijder, A. G. C. L. & Prins, M. (2012). *Unexpectedly high proportion of drug users and men having sex with men who develop chronic hepatitis B infection*. Journal of Hepatology Vol. 57 pp. 529-533

Van Houdt, R., Koedijk, F. D. H., Bruisten, S. M., Op de Coul, E. L. M., Heijnen, M. L. A., Waldhober, Q., Veldhuijzen, I. K., Richardus, J. H., Schutten, M., Doornum, G. J. J., De Man, R. A., Hahné, S. J., Coutinho, R. A. & Boot, H. J. (2009). *Hepatitis B vaccination targeted at behavioural risk groups in the Netherlands: Does it work?*. Vaccine vol. 27 pp. 3530–3535

Van der Veen, Y. J. J., De Zwart, O., Voeten, H. A. C. M., Mackenbach, J. P. & Richardus, J. H. (2009). *Hepatitis B screening in the Turkish-Dutch population in Rotterdam, the Netherlands; qualitative assessment of socio-cultural determinants*. BMC Public Health Vol. 9 pp. 328

Van der Veen, Y. J. J., Voeten, H. A. C. M., De Zwart, O. & Richardus, J. H. (2010). *Awareness, knowledge and self-reported test rates regarding Hepatitis B in Turkish-Dutch: a survey*. BMC Public Health Vol. 10 pp. 512

Veldhuijzen, I. K., van Driel, H. F., Vos, D., de Zwart, O., van Doornum, G. J. J., de Man, R. A. & Richardus, J. H. (2009). *Viral hepatitis in a multi-ethnic neighborhood in the Netherlands: results of a community-based study in a low prevalence country*. International Journal of Infectious Diseases Vol. 13 pp. e9-e13

Veldhuijzen, I. K., Toy, M., Hahné, S. J. M., De Wit, G. A., Schalm, S. W., De Man, R. A. & Richardus, J. H. (2010). *Screening and Early Treatment of Migrants for Chronic Hepatitis B Virus Infection Is Cost-Effective*. *Gastroenterology* 138. pp. 522–530

Weiss, M. G. (2008). *Stigma and the Social Burden of Neglected Tropical Diseases*. *PLoS Neglected Tropical Diseases* Vol. 2 No. 5

Williamson, D. L., Choi, J., Charchuk, M., Rempel, G. R., Pitre, N., Breikreuz, R. & Eastlick Kushner, K. (2011). *Interpreter-facilitated cross-language interviews: a research note*. *Qualitative Research* Vol. 11 No. 4 pp. 381–394

WHO. (2002). *Global distribution of hepatitis A, B and C, 2001*. *The Weekly Epidemiological Record (WER)* Vol. 77 No. 45

Yang, H., Li, X., Stanton, B., Fang, X., Lin, D. & Naar-King, S. (2006). *Hiv-related knowledge, stigma, and willingness to disclose: a mediation analysis*. *AIDS Care* Vol. 18 No. 7 pp. 717-724

Appendices

Appendix A: Semi structured interview design Turkish HBV carriers (In Dutch)

- Doel onderzoek uitleggen -

- Sinds wanneer weet U dat U hepatitis B heeft? **(4)**
 - Hoe voelde U zich, toen het bij U bekend werd?
 - In welke mate heeft u de gebeurtenis als stressvol ervaren?
 - Voelt U zich een patiënt?
 - Is Uw leven veranderd sinds de diagnose?
 - Bent U erachter gekomen hoe U de ziekte heeft opgelopen?
- Hoe zou U hepatitis B omschrijven?
 - Waar denkt U dat de ziekte vandaan komt?
 - Hoe denkt U dat de ziekte zal verlopen?
 - Hoe belangrijk is HBV in u leven vergeleken met andere dingen?
 - Scale: niet belangrijk – gering belangrijk – belangrijk – erg belangrijk
- In welke mate vindt U het belangrijk dat U regelmatig gecontroleerd wordt?
 - Waarom wel/niet?
 - Heeft U een 2nd opinion gevraagd in Turkije?
 - Wat was daaruit gekomen?

Kennis & Maatregelen

- In welke mate heeft U informatie opgezocht over hepatitis B? **(2, 3)**
 - Hoe komt U aan deze informatie? (van anderen? arts? internet? boeken?)
 - In welke mate weet U op welke manieren hepatitis B overdraagbaar is? Zo ja, welke?
 - In welke mate weet U hoe U besmetting naar anderen toe kan voorkomen?
 - In welke mate vindt U dat U goed geïnformeerd bent door (de arts, folder, internet etc.)?
- In welke mate bent U wel eens bezorgd over de gevolgen van deze ziekte? **(4)**
 - Scale: geen probleem – gering probleem – middelgroot probleem – groot probleem
 - Heeft U wel eens klachten gehad die met de HBV infectie te maken hebben?
 - Wat zijn de gevolgen van de ziekte voor Uw leven?
 - In welke mate kunt alle dagelijkse dingen nog doen als voorheen?
- In welke mate bent U wel eens bezorgd dat U anderen kan besmetten? **(3, 4)**
 - Scale: geen probleem – gering probleem – middelgroot probleem – groot probleem (idem, niet compatibel)
 - Over welke manieren van besmetting maakt U zich vooral zorgen?
- Wat voor maatregelen heeft U genomen om besmetting van anderen te voorkomen? **(5, 6)**

Disclosure, Concealment

- Heeft U een beeld hoe erover hepatitis B wordt gedacht in de gemeenschap? **(2, 3)**
 - Zo nee, waarom denkt U dat het een niet veel besproken onderwerp is?
 - Voelt U zich daardoor onbegrepen?

- zo ja, Hoort U wel eens verhalen van anderen over hepatitis B?
- Waarover wordt zoal gesproken?
- In welke mate praat U met anderen over hepatitis B? **(4, 5, 6)**
 - Vindt U het gemakkelijk om erover te praten?
 - Scale: geen probleem – gering probleem – middelgroot probleem – groot probleem (idem)
 - *Zo nee*, Waarom heeft U besloten het niet met anderen te bespreken?
 - In welke mate bent U bang voor negatieve reacties van anderen?
 - Zo ja, waarom?
 - Vindt U het niet nodig om erover te praten?
 - Zo ja, waarom?
 - *Zo ja*, Met wie heeft U erover gesproken?
 - *Praat U met veel mensen erover?*
 - Spreekt U met Uw partner hoe u zich voelt?
 - Praat U erover met Uw familie?
 - # Praat U erover op Uw werk?
 - Hoe reageren anderen daarop?
 - Wordt U gesteund?
 - Helpen deze mensen met het omgaan met HBV?

Self-Esteem, Discrimination, Social Interactions

- Hoe voelt U zich nu? **(4, 5)**
 - Is dat veranderd sinds Uw diagnose?
 - Op wat voor een manier is dat veranderd?
- In welke mate voelt U zich wel eens onzeker doordat U hepatitis B heeft? **(4, 5)**
 - *Denkt U minder over Uzelf als gevolg van hepatitis B?*
 - **In Welke mate heeft HBV invloed gehad op Uw sociale leven?**
 - Heeft U moeite met omgaan met nieuwe mensen als gevolg van hepatitis B?
 - Scale: geen probleem – gering probleem – middelgroot probleem – groot probleem
- In welke mate voelt U zich beperkt door hepatitis B? **(4, 6)**
 - Waarin voelt U zich beperkt?
 - Waarom voelt U zich beperkt?
- In welke mate heeft U Uw leven aangepast/*moeten aanpassen*, sinds U weet dat U hepatitis B drager bent? **(4, 5)**
 - Op wat voor een manier(en) heeft U Uw leven aangepast?
 - In welke mate Bent U tevreden met deze aanpassingen?
- In welke mate kunt U nog dezelfde activiteiten doen als voorheen? **(4, 5, 6)**
 - Zo niet, waarom kunt U niet meer dezelfde activiteiten als voorheen doen?
 - Heeft U daar moeite mee?
 - Scale: geen probleem – gering probleem – middelgroot probleem – groot probleem

- In welke mate zijn er dingen veranderd in uw thuissituatie als gevolg van hepatitis B? Zo ja, welke? **(6)**
 - *Kunt U erover praten met Uw familieleden?*
 - *Hoe ging Uw familie ermee om toen ze het te horen kregen?*
 - *Kunt U voorbeelden geven over Uw ervaringen daarmee?*
 - *Heeft U thuis preventieve maatregelen genomen om besmetting van anderen te voorkomen?*
 - *Hoe reageert U familie daarop?*
 - *Praat U met hen erover?*
- # In welke mate zijn er dingen veranderd in uw werkomgeving als gevolg van hepatitis B? Zo ja, welke? **(6)**
 - # *Wordt U anders behandeld?*
 - # *Kunt U voorbeelden geven over Uw ervaringen daarmee?*
- Op wat voor manieren denkt U dat U leven kan worden verbeterd?
- Heeft hepatitis B nog andere gevolgen gehad voor Uw leven die U wilt noemen?

Appendix B: Semi structured interview design key informants (In Dutch)

- Doel onderzoek uitleggen -

Maatschappelijk Niveau - Algemeen

- Hoe wordt er tegen het concept ziekte in het algemeen aangekeken in de Turkse gemeenschap?
- Hoe wordt er tegen infectieziekten specifiek aangekeken in de Turkse gemeenschap?
 - Welke factoren spelen een rol in hoe er over infectieziekten wordt gedacht binnen de Turkse gemeenschap?
 - Wat is de rol van cultuur hierin? (*schaamtecultuur*)
 - Waarden en normen binnen de gemeenschap.
 - Wat is de rol van sociale structuren hierin?
 - Is er een verschil tussen typen infectieziekten SOA, Aids, Hepatitis, ...?
- Hoe wordt de Nederlandse gezondheidszorg gewaardeerd door de Turkse gemeenschap?
 - Heeft dit invloed op het zoeken naar medische zorg/hulp als het gaat om infectieziekten in Nederland?
 - In hoeverre denkt U dat dit een rol speelt in therapietrouw als het gaat om infectieziekten van Turkse patiënten in Nederland?

Maatschappelijk Niveau

- In welke mate wordt er over (chronische) hepatitis B gesproken in de Turkse gemeenschap? En hoe wordt er over gesproken onderling?
 - Waarover specifiek wordt gesproken?
 - Wat zijn redenen om er niet over te spreken?
 - In welke mate is er kennis is over hepatitis B binnen de Turkse gemeenschap?
- In welke mate is er specifieke voorlichting over hepatitis B binnen de Turkse gemeenschap? (??)
 - Bijvoorbeeld in buurtcentra
 - Door wie wordt die gegeven?
- Hoe wordt er tegen hepatitis B aangekeken in de Turkse gemeenschap?
 - (2, 3, 6)**
 - Waarmee wordt (chronische) hepatitis B in *verband gebracht/geassocieerd door Turken*?
 - Hoe uit zich dit?
- Wat is de rol van sociale en culturele factoren in de manier waarop tegen hepatitis B wordt aangekeken? **(2)**
 - Welke waarden en normen spelen een mogelijke rol?
 - Wat is de mogelijke invloed van deze waarden en normen op het beeld over hepatitis B binnen de gemeenschap?

Individueel Niveau

- Wat voor rol speelt (chronische) hepatitis B in het dagelijkse leven van Turkse mensen die de besmet zijn? **(4, 5, 6)**

Heeft dragerschap negatieve gevolgen?

- Hebben Turkse mensen, waar bij hepatitis B is vastgesteld, problemen met bewegen in en om het huis en bewegen rond de gemeenschap, als gevolg van hepatitis B? Zo ja, op welke manier(en)?
 - *Op welke manier verandert mogelijk hun relatie met familieleden? en met andere mensen in de Turkse gemeenschap?*
 - Kunnen dragers dezelfde rol vervullen als voor hun diagnose? **(4, 5, 6)**
 - Doorvraag: denk aan: werkloosheid, armoede, AOW?
 - Hoe gaan Turkse mensen met een (chronische) hepatitis B diagnose om met hun ziekte?
 - *Op wat voor een manier spreken ze daar met anderen over?*
 - *Op wat voor een manier beïnvloedt dit of ze medische hulp zoeken?*
 - *Wanneer zoeken ze wel medische hulp en wanneer niet?*
 - *Welke factoren zijn cruciaal voor het zoeken van medische hulp?*
- **(4, 5)**
- In welke mate worden deze mensen ondersteund daarin door hun familie/gemeenschap?
 - Welke factoren denkt U spelen een rol of Turkse mensen al dan niet gemakkelijk met anderen over hun dragerschap praten?
 - Spelen reacties van anderen (familie, leden van de gemeenschap) hierin een rol?
 - *op welke manier speelt kennis bij de draager over de ziekte hierin mogelijk een rol? En kennis bij de mensen in de omgeving van de draager?* **(6)**

Appendix C: Age distribution respondents

Age distribution respondents of The Hague			
age	male	female	Total
20-29	2	1	3
30-39	6	1	7
40-49	2	1	3
50-59	0	2	2
60-69	0	0	0

Age distribution respondents of Rotterdam			
age	male	female	Total
20-29	1	0	1
30-39	2	4	6
40-49	2	1	3
50-59	2	0	2
60-69	0	0	0

Appendix D: Points of interest when consulting Turkish-Dutch HBV carriers

Even though the objective of this study was to assess stigma and its causes, it became evident that the knowledge of the interviewed Turkish-Dutch chronic HBV carriers was alarmingly poor.

As already indicated in the discussion, in overall the interviewees were passive during hepatitis B consultations, even though their knowledge of hepatitis B was generally poor. Moreover, the interviewees filled in the blanks in their knowledge after consultations with their own interpretations of hepatitis B, opposed to asking questions about hepatitis B to practitioners. These interpretations led to various assumptions: **1)** hepatitis A, B & C being stages of the same disease, **2)** incorrect HBV transmission routes, subsequently the **3)** failure of most interviewees to make the connection between taking certain measures to prevent transmission and transmission routes.

