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**”Try to relax” -  
A survey study in Sweden among native Swedes and  
Arabic immigrants concerning views on stuttering**

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## **ABSTRACT**

Studies performed in various countries have shown that negative attitudes and beliefs towards stuttering and People Who Stutter (PWS), which can lead to stigmatization, discrimination and social anxiety, are widespread across different societies.

It is important that clinicians are aware that patients can meet different attitudes in their daily life, affecting health care seeking behavior and self-image. These can also be affected by the cultural background. Combined with different views on disorders and individualist versus collectivist societal constructions, this has clinical impacts for the treatment.

For measuring these attitudes and beliefs, a questionnaire (POSHA-S) has been developed in the USA with the aim of being a worldwide instrument. We translated POSHA-S to Swedish and conducted a survey among native Swedes and immigrants with an Arabic background, as the latter group is one of the largest, and growing, minorities in Sweden.

We contacted schools around Sweden for the distribution of the survey. They received either a paper version or an online version of the questionnaire. We obtained answers from 42 native Swedes, seven Arabic immigrants and 13 respondents with a background in another country.

The results show that in an international comparison, native Swedes have a positive/accurate view on stuttering and PWS; notwithstanding, the attitudes towards the PWS abilities at the labor market were negative. The Arabic group holds a more negative/inaccurate view on certain items, specifically regarding the cause of stuttering and the traits attributed to PWS. The low number of Arabic respondents, however, prevents us from drawing general conclusions as the statistical power is too low.

### **Keywords**

Stuttering, attitudes, beliefs, culture, questionnaire

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## 1 INTRODUCTION

Beliefs and stereotypes, mostly negative ones, held towards stuttering and towards people who stutter (PWS) have been shown to exist in various countries (Abdalla & St Louis, 2012; Al-Khaledi, Lincoln, McCabe, Packman, & Alshatti, 2009; de Britto Pereira, Rossi, & Van Borsel, 2008). Being a subject to these stereotypes, beliefs and attitudes may affect the quality of life for a PWS as they can lead to stigmatization (Boyle, Blood, & Blood, 2009). Studies have shown that they can be discriminated against by their employers and they are at risk of developing depression and social phobia (Menziez, Onslow, Packman, & O'Brian, 2009). Furthermore, these stereotypes and attitudes are strongly affected by the society and the cultural group that one belongs to.

Today, the Swedish society is pluralistic and multicultural as defined by the Swedish constitution (Regeringskansliet, 1999). For the clinician treating the PWS it may be crucial to the quality of intervention to identify possible cultural differences between him/her and the patient. Among the largest groups of immigrants in Sweden are people originating in the Middle East (Statistiska Centralbyrån, 2013), and Swedish-Arabic children are the largest group of multilingual children being referred to speech therapy in Malmö (Salameh, e-mail communication, 2013-03-03). Cultural differences can affect both the health care seeking behavior and the degree of participation in treatment. The Swedish, or “western”, view on health care is to a large extent biomedical, thus rather dualistic than holistic. Swedish practitioners tend to stress the importance of genetics or biological processes as the origin of disorders and diseases. In contrast to this stands the holistic approach to health care, which emphasizes not only the physical aspect of disorders and diseases, but also the psychological and social ones (Morsy, 1981) and sometimes also supernatural reasons (Adib, 2004; Helman, 2001). This approach is not uncommon in the Middle East (Adib, 2004; Helman, 2001; Morsy, 1981). The view on what should constitute a *treatment* of a disorder or disease is also often influenced by an individual’s cultural background. For example, in the Arab world, faith constitutes an important part of the remedy for disease believed to be caused by e.g. an evil spirit; it is not known exactly how widespread these beliefs are, but a survey conducted in Kuwait among civil servants revealed that 56 % had seen a so-called Coranic faith-healer. For more than 1/3 of those this was the only help that they had sought (Adib, 2004). However, it is important to bear in mind that this can also be influenced by an individual’s level of education and social background and that both views may co-exist in both Sweden and the Middle Eastern countries.

These cultural differences are important as they affect how an individual behaves and what help he/she expects, and also how the health care practitioners interpret the patient. Therefore, a Speech – Language Pathologist (SLP) must be careful when meeting patients from another culture than his/her own and bear in mind cultural beliefs regarding stuttering in the patient. Stuttering therapy is to a large extent based on a close cooperation with the patient. When treating children, the speech therapist is also often working closely with the parents. Therefore, it is of great importance to know what attitudes and beliefs might influence their reasoning and behavior. Another aspect regarding cultural differences in behavior is the phenomenon known as acculturation; the influence of a host culture on an individual’s attitudes and behavior (Thomson & Hoffman-Goetz, 2009). Therefore, there is a need for studies carried out among people with a background in one culture, in this case Arabic, living in a society with a different majority culture. Some research has been done regarding the attitudes towards stuttering in Middle Eastern countries; nevertheless we believe it important to carry out a study on this matter among Arabic people living in Sweden.

It has also been shown that being a subject to discrimination and stereotypes can lead to less participating in the treatment (Boyle, et al., 2009). It is important to know if these individuals are likely to be stigmatized as a result of possibly negative attitudes and beliefs held by the society and culture in which they live.

It has been shown that it is feasible by intervention to change attitudes and beliefs about stuttering (Flynn & St Louis, 2011). Therefore, we consider it important to measure the attitudes and beliefs in Sweden. If it is found that beliefs about causes are not in line with what research has shown the last decades, and that attitudes and stereotypes are present, it would be of interest to work for a change in these attitudes. However, as with all interventions, it is important to survey what attitudes are held today, in order to achieve the most efficient outcome.

In USA, an instrument has been developed for measurement of these attitudes and beliefs that is intended to be translated and used around the world in order to standardize comparisons of studies conducted. Although the attitudes towards stuttering to some extent are universal, it has been shown that they also vary (St Louis, 2011). We have translated this instrument into Swedish to measure the attitudes and beliefs about stuttering in Sweden among native Swedes. To avoid errors due to language confusions for the Arabic respondents, we have also used an Arabic version previously used in Kuwait that we obtained from the developer of the questionnaire.

## **2 BACKGROUND**

### **2.1 Attitudes to PWS**

The impact that a non-fluent speech has on an individual's psychological well-being is not only related to the severity of the stuttering, although this factor has been shown to lower the Quality of Life (QoL) among PWS (Beilby, Byrnes, & Yaruss, 2012; Bleek et al., 2012). This impact seems partly to depend on an individual's coping style (Bleek, et al., 2012). An individual's coping style and how the stuttering is perceived by the individual is also influenced by the reactions, particularly negative ones, in the individual's environment (Murphy, Yaruss, & Quesal, 2007a). A number of studies have been conducted regarding this matter, unfortunately showing that the attitudes towards stuttering and PWS are negative and widespread among different populations, including highly educated individuals such as university professors (Dorsey & Guenther, 2000), teachers (Abdalla & St Louis, 2012) and even SLPs (Crichton-Smith, Wright, & Stackhouse, 2003). The beliefs and attitudes seem to exist no matter the age (Ezrati-Vinacour, Platzky, & Yairi, 2001), level of education (Dorsey & Guenther, 2000), culture, geographic location and profession. These negative attitudes can be such as "a stuttering individual cannot do any job they want" or "cannot make friends" (Abdalla & St Louis, 2012).

Not only do negative attitudes have a strong impact on the QoL on PWS, and affect how they experience their stuttering; they are also considered underlying factors to unacceptable behavior from the surrounding towards PWS. These behaviors range from stigmatization and bullying to victimization and actual discrimination (Crichton-Smith, 2002).

Goffman's definition of the concept of stigmatization is that it conveys a "spoiled identity" (Goffman, 1963). The idea behind stigmatization is that an individual may possess one characteristic that is different from the majority (e.g. stuttering), and if this characteristic is considered negative, it may overshadow all the other characteristics and traits in the person. Therefore, he or she is being seen as defect in *all* aspects due to this single characteristic. This is also labeled the "spread effect". Hence, being an object to these stereotypes can lead to a PWS

experiencing a confirmation of being negatively viewed as his or her fear seems to be well-founded (Menzies, et al., 2009). In the long term, it can lead to avoidance behavior and mental health disorders such as depression, social anxiety and social phobia (Iverach et al., 2011; Mulcahy, Hennessey, Beilby, & Byrnes, 2008; Yaruss, 1998).

This also has clinical impacts for the speech therapy, as studies have shown that participants undergoing behavioral treatment fail to benefit from the treatment if they have a mental health disorder (Menzies, et al., 2009); a catch 22. This has also been shown to be the case for patients participating in therapies adopting a more speech restructuring approach, i.e. fluency shaping techniques (Carey, O'Brian, Onslow, Packman, & Menzies, 2012) Furthermore, in presence of bullying the stuttering can be exacerbated (Murphy, Yaruss, & Quesal, 2007b), making it a matter not only of the person's well-being but also a clinical issue.

## **2.2 Beliefs about Stuttering and PWS**

Despite the evidence accumulated since the seventies that stuttering is multifactorial and mainly genetic (Rautakoski, Hannus, Simberg, Sandnabba, & Santtila, 2012), many people still believe that its causes are psychological. This has been shown in studies in various countries (Abdalla & St Louis, 2012; Ming, Jing, Wen, & Van Borsel, 2001; Van Borsel, Verniers, & Bouvry, 1999). In a study conducted among Arab school teachers in Kuwait, 35 % claimed that the PWS "have themselves to blame for the stuttering" (Abdalla & St Louis, 2012). In the same study, it was revealed that a common belief is that if the PWS takes a deep breath before speaking, or think about what she or he wants to say, it will help. Also, a study recently carried out among teachers in Mumbai, India, revealed that most teachers believed that a school-aged child can overcome its stuttering (Pachigar, Stansfield, & Goldbart, 2011). Furthermore, many people feel that they do not know what to do when someone stutters or think that it is best dealt with by ignoring it. There are also many negative beliefs about stuttering, including stereotypes such as PWS being shy, self-conscious, anxious people who lack confidence (Craig, Tran, & Craig, 2003). This can lead to adverse consequences for the individuals, as they may begin to believe these negative characteristics about their person to be true. Another consequence has clinical, and public health, implications as it has been shown that individuals suffering from stigmatization do not seek, or participate in, treatment to the same extent (Boyle, et al., 2009).

## **2.3 Stuttering Therapy**

There are a number of different stuttering therapies available. Two main currents can be found among these: The Fluency Shaping (FS) and the Stuttering Management (SM) treatments. The goal for the FS treatment is stutter-free speech, by teaching different techniques in order to achieve this. The SM treatment does not have as a primary goal stutter-free speech, but rather to minimize the tension and struggle when fluency disruptions occur and focusing more on feelings, attitudes and acceptance (Guitar, 2014). These two poles do not exclude each other; in fact, many therapies combine them in an integrated therapy (Prins & Ingham, 2009). For this thesis, the ideas embedded in the SM treatment are of most interest.

If fluent speech is obtained by avoiding some words or speaking less on the cost of what the person wants to express, this can have a strong negative impact on the self-image. Notwithstanding, focusing only on fluency techniques can result in a speech that is burdensome and difficult to adapt in an everyday conversation and thereby affect the communication effectiveness (Beilby, et al.,

2012). Therefore, many stuttering therapies stress the importance of communication effectiveness, implying that fluency techniques have to be combined with emotional support to accept the situations when these cannot be applied and/or when they fail. This emotional support is often provided today in therapy based on a cognitive approach (Beilby, et al., 2012; Menzies, et al., 2009). This implies that the client is supposed to work with adopting a more accepting approach to his/her stuttering. Many therapies embrace this idea and adapt it in a number of ways, such as Cognitive Behavioral Therapy (CBT) (Menzies, et al., 2009), Mindfulness (Boyle, 2011), Acceptance and Commitment Therapy (ACT) (Beilby, et al., 2012) among others. Most of them report positive outcomes on many domains; interestingly, not only the psychosocial functioning is enhanced but also the speech fluency (Beilby, et al., 2012).

However, as many of the patients have been victims to aforementioned bullying and/or discrimination related to their stuttering, it is a great challenge for them to take on the task of accepting it. Furthermore, a recent study has shown that patients with a mental health disorder, for instance social anxiety that can be a result of previous negative experiences, failed to maintain the benefits of treatment (Menzies, et al., 2009). Therefore, if therapists aim to help these patients, it is important to know the extent of negative attitudes that they are likely to meet every day.

### **2.3.1 Parents/Caregivers and Stuttering Therapy**

Few studies have focused on how the parents feel and react emotionally towards their child's stuttering. One study conducted recently in Australia with parents enrolled in a stuttering treatment program, or on a waiting list to such a program, revealed that parents indeed tend to be emotionally affected by it. The majority of the parents in the study considered the communication with their child affected and approximately one third did not know how to react to their child's stuttering (Langevin, Packman, & Onslow, 2010). Another intervention study, based on the stuttering therapy Palin PCI, showed that parental anxiety lowered when the fluency increased (Millard, Edwards, & Cook, 2009). They also comment that many experienced therapists have noticed this phenomenon but that there is need for more empirical evidence in future investigations.

In many stuttering treatments concerning young children, parents are the main actors with whom the speech therapist works (Onslow & Millard, 2012; Ratner, 2004; Yaruss, Coleman, & Hammer, 2006). If a stuttering child can be helped by a speech therapist, and his/her mood and attitudes are influencing the child, it seems natural that the parental environment is even more important and has a strong impact on a child's communication (Conture & Zebrowski, 1992). Some of these treatments are mainly operant-focused, such as the Lidcombe program, where the clinician trains the parents to praise fluent utterances and to mildly correct stuttered utterances, with the main focus on praise (Onslow, Menzies, & Packman, 2001; Ratner, 2004). The outcome of this intervention has been investigated, and the effects seem to be evident and often long-lasting (Miller & Guitar, 2009). In other treatment programs or methods, the clinician adapts a more cognitive approach where the first parts of the treatment are to reduce the parents' concern about stuttering and to change the family interaction strategies. In those cases the parents play a central role throughout the entire process; sometimes it even becomes unnecessary to treat the child itself. Studies have shown that such treatment methods as well often significantly improve the child's stuttering (Millard, Nicholas, & Cook, 2008; Yaruss, et al., 2006). If stuttering is not reduced after applying these first steps, focus moves on to the third part of the therapy, which is child strategies, i.e. stuttering modification of the speech (Onslow & Millard, 2012). Regardless of therapy approach, the acknowledgement of the child's stuttering is important since a common reaction to a child's stutter seems to be to ignore it. An accepting attitude towards the stuttering from the parents is almost always reported to reduce the child's tension and struggle connected with the disfluency (Ratner,

2004). Despite the research carried out on the subject, some internet sites continue to recommend that a child's stuttering should be ignored (Iannelli, 2008). Therefore, again it is important to know what beliefs are held about stuttering and about PWS as the child and the parents can be ambivalent regarding what source to listen to.

## **2.4 Culture and health care**

In the increasingly globalized and pluralistic society, the health care system must be prepared to receive patients from a wide range of countries and cultures, with diverse religious beliefs, customs and social structures. The awareness of the issues deriving from such differences, and the associated field of research, has been termed "cultural competence" (Betancourt, Green, Carrillo, & Ananeh-Firempong, 2003). For instance, it has been shown that minorities to a lesser extent seek and participate in treatment (Agodi, Barchitta, Agodi, Scuderi, & Sciacca, 2004). This may be due both to expectations and attitudes carried by the individual (Betancourt, et al., 2003) and to behaviors they are met with by health care staff (Cohen, 2003). Despite the term culture being widely used, there are various definitions, sometimes contradictory to one another (Jahoda, 2012). However, as described by Finn & Cordes, culture may be subdivided into explicit and implicit aspects (Finn & Cordes, 1997). In this thesis, the latter is most applicable, as it reflects behaviors and beliefs that may influence attitudes and views relevant to our aims. Even if the clinician herself/himself is sensible to the cultural background of its patients, treatment and assessment will take place within a health care system that is based on the majority culture. It is of great importance, therefore, that the clinician is aware of his or her own culture, as it can compose a bias in the valuation of a patient's response in the clinical context. For instance, the cultural background may influence the patient's objectives with seeking treatment, and how concrete or abstract expectations on the treatment are (Panos & Panos, 2000).

### **2.4.1 Culture and Stuttering Therapy**

Stuttering therapy takes, to a large extent, its starting point in the behaviors and attitudes of the patient, factors widely based on the individual's own culture. One of the early researchers in this field was Wendell Johnson, whose diagnosogenic theory became influential. In Johnson's view, parents' reactions to their children's speech and speech errors amplify problems and may lead to chronic stuttering (Gateley, 2003). Based on this theory, the idea emerged that differences in parenting practices can cause a stuttering behavior in the child. Stuttering was thus by some not expected to exist, or be less occurring, in cultures with a less demanding view on child rearing and with less expectations on children's language performance. However, the diagnosogenic theory has since been disproven in favor of a multifactorial model on the cause of stuttering, and the prevalence for stuttering is reported to be roughly the same in all cultures (Finn & Cordes, 1997). The most recent numbers presented regarding prevalence are around 0.72 % (Yairi & Ambrose, 2012).

Research on cultural aspects of the nature of stuttering and the affiliated thoughts and attitudes is far from sufficient to form a foundation for culturally sensitive practice. Also, as the clinician has to take into account differences in culture that otherwise may create obstacles for successful treatment, it is important not to rely on stereotypes or make assumptions based on prejudice. In all practice both extrinsic and intrinsic features of stuttering should be assessed individually. If the clinician is conscious of cultural differences, it will facilitate such assessment in the sense that it enables a correct interpretation of the patient's communicative style. One example is eye contact, which is avoided in many cases of stuttering (Atkins, 1988). If the patient has a cultural background in which



eye contact is seen as inappropriate, the therapist may misjudge the lack of eye contact as an intrinsic behavior connected to stuttering (Guitar, 2006).

The level of participation by the parents or family of a child who stutters may be affected by the expectations on treatment and their view on the therapist's or their own role in treatment. Indirect treatment can require modification of interaction patterns in families. Requesting families to change these patterns calls for sensitivity on the clinician's part, as some of the family's actions simply may be a reflection of their culture. Thus if the clinician is not aware of both his or her own culture and the one of the client, there is a risk of a misunderstanding regarding the aim of intervention. For the clinician to make fair considerations there must be research to provide proof for the existence of such differences. Finn and Cordes report that suggestions used to guide clinicians in their work with patients from diverse cultures are often based more or less on assumptions (Finn & Cordes, 1997). As pointed out by Guitar, all aspects of every patient's culture cannot be known (Guitar, 2014). The important factor is the knowledge that a patient's responses may be due to cultural background.

Although stereotypes and negative attitudes regarding PWS are common around the globe, some variation exists in the beliefs about the etiology of stuttering as well as the attributes ascribed to the PWS. For instance, Özdemir, St Louis and Topbaş found less positive attitudes in the Turkish city of Eskişehir compared to samples from other countries (Özdemir, St Louis, & Topbaş, 2011). While attitudes to stuttering in the Middle East has not been widely examined, public opinions about disabilities in general are frequently negative (Sharifzadeh, 2004). Also, surveys conducted among Arab parents in Kuwait showed widespread negative attitudes as well as faulty ideas on the cause of stuttering (Al-Khaledi, et al., 2009).

As a stigma is often attached to stuttering, it is of great value that the SLP has an idea of the attitudes the PWS confronts every day when treating and assessing the intrinsic aspects of stuttering. Indeed, environmental factors are a key part of what changes a dysfunction into a disability and/or a handicap as defined by the International Classification of Functioning, Disability and Health (ICF) (WHO, 2013). An instrument for self-evaluation of the impact of the stuttering, OASES, also includes an evaluation of the reactions from the surroundings from the PWS' own perspective (Yaruss & Quesal, 2006).

## **2.5 Public Opinion Survey of Human Attributes – Stuttering (POSHA-S)**

An instrument for measuring the public's attitudes toward PWS, and for measuring knowledge of stuttering such as causes and treatment, has been developed in the USA in the last decade. The aim of the researchers is for the survey to be used worldwide as a "standard" instrument so that comparisons across investigations around the world are meaningful (St Louis, 2012). During the development process, this aim was taken into account and therefore jargon and expressions were avoided for the translation process to go smoother. In 2011, the POSHA-S had been translated into 11 languages from different language families, such as Turkish, Arabic, French and Norwegian. Studies have been conducted in various countries and two pilot studies, both in English and other languages, have been carried out to control that a translation of the survey is possible and to change phrases that were difficult to translate. Both the pilot studies and the final version has been validated and tested for reliability (St Louis, 2011). During the pilot studies, it was found that the correlations between the same respondents (intrapersonal reliability) were about .8 and that the correlations among different respondents (interpersonal reliability) were close to .5. This was interpreted as strong common societal influences accounting for the .5 correlation (St Louis, 2011). It has also been shown that it is sensitive to differences and changes in attitudes (Flynn & St Louis, 2011).

The survey contains questions regarding the respondent's knowledge, beliefs and attitudes of stuttering and of PWS. It also contains questions about the respondent's origin, religion, education, income and age, making it possible for us to take those factors into account when analyzing the results. Furthermore, it contains questions about the respondents' attitudes towards life and other personal attributes such as mental illness, left-handedness, obesity and intelligence. These items are included for allowing a comparison between stuttering and other, possibly stigmatizing, conditions. Obesity and mental illness are supposed to be considered negative, left-handedness is supposed to be neutral and intelligence a positive attribute. For a more detailed description of the questionnaire and the reasons for including above-mentioned items, see St Louis (2012).

### **3 AIM OF STUDY**

The aim of the study was (a) to investigate the attitudes and beliefs towards stuttering and PWS among native Swedes and among people who have immigrated to Sweden from an Arabic speaking country, and (b) whether these attitudes and beliefs differed between the two groups examined.

Another, separate, aim of the study is to translate the POSHA-S to Swedish in order to contribute to the world data bank of standardized examination of attitudes and beliefs about stuttering and PWS.

Questions:

- What are the attitudes and beliefs towards stuttering and PWS among native Swedes?
- What are the attitudes and beliefs towards stuttering and PWS among Arabic speaking people living in Sweden?
- Do these attitudes and beliefs differ among the two groups?
- How do these groups compare to the international data bank?

### **4 METHOD**

Both authors of this thesis have participated actively in all parts of the process. The study has been approved by the Ethical Committee of the Department of Logopedics, Phoniatics and Audiology, Department of Clinical Sciences, Lund, Lund University.

#### **4.1 Swedish translation and adjustment of POSHA-S**

The Swedish version of the POSHA-S was translated by the authors of this thesis and used by permission from Kenneth O. St. Louis and Populore Publishing Company in Morgantown, West Virginia, USA. It was back translated into English by a native bilingual individual; a method previously used when translating POSHA-S into different languages (St Louis, 2011; Özdemir, et al., 2011), and thereafter we controlled that no information had been changed in a substantial way in the translation.

The instrument has been developed in the USA and might therefore be adjusted to the American society. Despite the fact that the Swedish and the American culture have many things in common, some adjustments of the questionnaire were necessary. For instance, the concept of "race" is in Sweden considered unscientific and not relevant; therefore we excluded that question entirely. Also, we adjusted the questions regarding the respondent's education to the Swedish school system.

## 4.2 Arabic translation and adjustment of POSHA-S

The Arabic translation of the POSHA-S is courtesy of Khalid Al-shdifat, with previous contributions by Laila Mallah, Fauzia Abdalla, and Maram Al-Khaledi. Some adjustments to the Kuwaiti society had been made (Abdalla & St Louis, 2012). Furthermore, some adjustments to the Swedish society were necessary. Therefore a native Arabic speaker was controlling both the original version in English, the Swedish version and the Arabic version in order to make any adjustments needed and to make sure that there were no important differences between the Arabic version and the Swedish version and that none of them differed in any substantial way from the original version.

## 4.3 Recruitment of participants

A study conducted by Özdemir et al. in 2011 showed that a probability sampling is superior to a convenience sampling if the aim of the project is to obtain a representative sample of a broad-based population. Özdemir et al. describe the difference between the two sampling methods as

“Convenience (or availability) samples are a type of nonprobability sampling typically consisting of persons either known by the investigators and/or readily available to the investigators”

whereas

“Probability sampling refers to a variety of schemes wherein, before the participants are selected, all the persons in a given population have an approximately equal probability of being chosen” (Özdemir, et al., 2011).

Therefore, convenience samplings tend to include people that are educated beyond average. In their study, schools were chosen randomly, the survey was distributed to pupils at the schools and the pupils were subsequently asked to bring them home and to have three adults fill them out (parents and a relative or neighbor). We followed the probability sampling procedure used by the Özdemir research group with small alterations in the procedure. In order to get as many respondents as possible for distribution of the paper version of POSHA-S we contacted all schools available at the municipal web pages in the municipalities of Malmö, Landskrona, Lund, Helsingborg, Kristianstad and Göteborg (n = 649). Eight of these schools answered positively; eventually three of them participated. We did not choose particular schools for special reasons, but contacted all the schools and those answering positively to participate were included in our study. The participating schools were located in areas and cities with different socioeconomic status, lowering the risk for selection bias on socioeconomic grounds. Also, instead of three surveys we distributed two surveys to each child as we considered it more likely to obtain returned, filled in surveys if the parents did not have to ask a third person to fill them in as well.

In two schools, a contact person from the school staff was responsible for distributing the surveys to the classes and subsequently collected them and returned them to us. At the third school we participated in a parent-teacher meeting where we handed out the surveys to the parents present at the meeting. Some parents filled in the questionnaires immediately and returned them to us. The principal at the school was assigned the task to collect the others and return them to us. Eventually, that school cancelled their participation and did not return any more questionnaires. Altogether, we distributed 1000 paper questionnaires.

This procedure did not render the number of respondents we had expected. Therefore, we created a web survey, believing that this would encourage more schools to participate as it would mean less work for them. Also, the logistics would not be an issue; thus we could contact schools in other parts of Sweden. We contacted all schools in the municipality of Stockholm available at the municipal web page (n=265). However, very few schools answered and none of them chose to participate.

We also contacted schools (n = 130) in randomly chosen cities around Sweden, in consistency with the probability sampling method, with the request for participation in our web survey. Eventually, one school in Borås and one school in Luleå answered positively and agreed to participate.

### 4.3.1 Participants

In all schools that participated in our study, the children with an Arabic background were given Arabic surveys to bring home and have their parents or another adult fill them out. The other children were given the Swedish version and followed the same procedure as the Arabic children. The respondents were divided into three groups depending on their mother tongue and country of birth: 1) native Swedes (born in Sweden and Swedish being their mother tongue), 2) Arabic immigrants (born outside Sweden and Arabic being their mother tongue) and 3) Immigrants born in other countries and with another mother tongue than Swedish or Arabic (Immigrants – other). The creation of the third group was due to the fact that the Arabic respondents had received the questionnaire in their mother tongue whereas this was not possible for immigrants from other countries because of the variety of linguistic backgrounds. Therefore, in this group there could be some errors originating in a misinterpretation of the questions.

## 4.4 Calculating the results

The part of the survey measuring the subscore “Self Reactions: To PWS” (i.e., *attitudes*) towards stuttering and PWS consists of the following items divided into component scores (in capital letters):

### HELPING

*If I were talking to a PWS, I would...*

- try to act like the person was talking normally (‘ignore’)
- fill in words when the person stutters (‘fill words’)
- tell the person to relax (‘relax’)
- tell a joke about stuttering (‘joke’)

*I believe that...*

- a PWS should try to hide her/his stuttering (‘hide’)
- stuttering should be helped by someone like me (‘me’).

### DISTANCE/SYMPATHY

*If I were talking to a PWS, I would...*

- feel comfortable (‘comfortable’)
- feel pity for the PWS (‘pity’)
- feel impatient and not want to wait (‘impatient’)

*If the following person stuttered I would feel worried*

- my doctor (‘doctor’)
- neighbor (‘neighbor’)

- sibling ('sibling')
- myself ('myself')
- *On a five-grade scale, from very negative/strongly disagree to very positive/strongly agree*
- my overall impression of a PWS ('impression')
- I would want to be a person who stutters ('want to stutter').

#### KNOWLEDGE

*For the item 'no persons known', tick a box for a description of the relation between you and any PWS you know, with several alternatives such as acquaintance, good friend, etc.,*

- I do not know anyone who stutters ('no person known')
- *On a five-grade scale, from none to a great deal*
- the amount I believe I know about stuttering ('amount known')
- *My knowledge of stuttering comes from...*
- personal experience ('personal')

#### SOURCE

*My knowledge about stuttering comes from...*

- TV or radio ('TV/radio')
- magazines or books ('print')
- Internet ('Internet')
- School ('school')
- Health care specialists ('specialist').

The questions measuring the subscore "Beliefs: About PWS" (i.e., *beliefs* and *knowledge*) about stuttering and PWS are the following items divided into component scores (in capital letters):

#### TRAITS

*A PWS...*

- has herself/himself to blame for stuttering ('blame')
- is nervous or easily excitable ('nervous')
- is shy ('shy').

#### HELP

*I believe stuttering should be helped by...*

- a Speech-Language Pathologist ('SLP')
- another person who stutters ('stutterers')
- a doctor ('doctor')

#### CAUSE

*I believe stuttering is caused by...*

- genetic inheritance ('genetics')
- learning or habits ('learning')
- a very frightening experience ('fright')
- an act of God ('act of God')
- a virus/disease ('virus/disease')
- ghosts or demons ('ghosts/demons')

#### POTENTIAL

*People Who Stutter...*

- can make friends ('friends')

- can lead a normal life ('normal life')
- can do any job they want ('any job')
- should have a job where they have to correctly understand and make important decisions ('judgment job').

The respondents were given the alternatives yes/no/don't know, except for the items 'impression', 'amount known' and 'want to stutter', where they were asked to mark a number on a five-step scale and 'no persons known', where they were asked to tick a box to mark any relation between themselves and PWS.

The score was hereafter transformed to a scale ranging from -100 (negative/inaccurate) to +100 (positive/accurate), where 0 is considered neutral. In some questions, marked with an asterisk in table 2, table 4, figure 2 and figure 3, the score was reversed. This conveyed that an affirmative answer to a question meant a lower score when the value was transformed into the scale in the final analyses. We will consistently name the results as "higher" or "lower". A higher score will thus always represent a more positive attitude or greater knowledge (more accurate answer) about stuttering and/or PWS. Noteworthy is that a high number of unsure answers lowers the score. For a more detailed description on how the scores are transformed, we refer the reader to the article "The Public Opinion Survey of Human Attributes-Stuttering (POSHA-S): Summary framework and empirical comparisons" (St Louis, 2011).

T-tests were performed pairwise, native Swedes vs. the Arabic group and native Swedes vs. Immigrants – other respectively. In order to minimize the risk of type I errors due to multiple comparison, a Bonferroni correction was applied (St Louis, 2012). For an item to be considered statistically significant, the corrected p-value was 0.00417. In our result analyses, we will identify the similarities and the differences between the three groups.

We will also compare our findings with the median from 172 samples (including ours) in the POSHA-S database from previous studies conducted in 27 countries and in 19 different languages with a total number of 7261 respondents. The median is used as using the mean would bring extreme scores to affect the average to a too large extent. The respondents from the paper version and from the web version were analyzed as one entity, as the developers have shown that they yield similar results (St Louis, 2012). The international data was made available to us by the developer of the questionnaire, Dr. Kenneth St Louis, Morgantown, USA, who also performed the statistical analyses.

An Overall Stuttering Score is also calculated from the mean of the two subscores "Beliefs: About PWS" (i.e., beliefs and knowledge) and "Self Reactions: To PWS" (i.e., attitudes) (St Louis, 2011).

## **5 RESULTS**

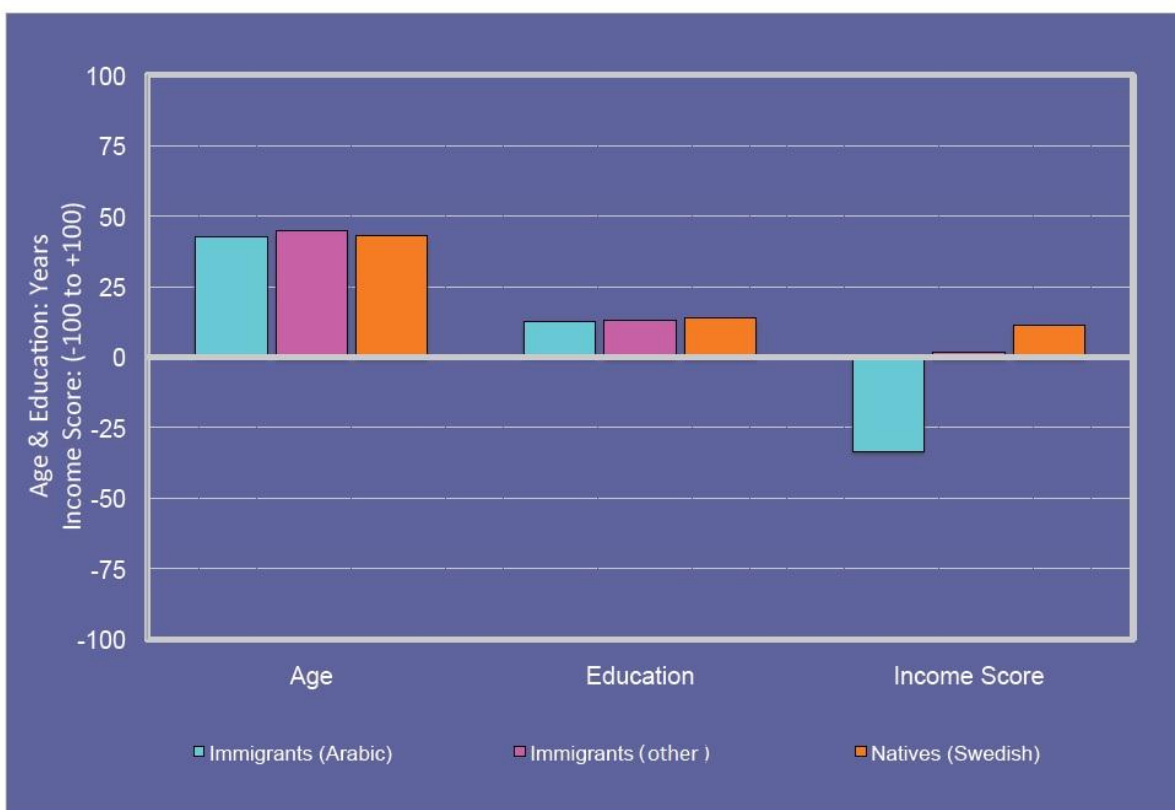
### **5.1 Respondent characteristics**

Altogether, we obtained 62 answers, of which 23 respondents filled in the online questionnaire and 39 respondents filled in the paper version of the questionnaire. 7 respondents filled in the Arabic questionnaire; all of them were paper versions. 13 respondents who filled in the Swedish version of the questionnaire had another first language than Swedish (11 of them answered on the paper version of POSHA-S and 2 of them filled in the online questionnaire) and 42 respondents were of Swedish origin. Among the respondents with Swedish as their first language, 21 filled in the paper version and 21 answered online (table 1).

**Table 1.** Distribution of respondents according to version (language and recruitment method).

Version	Swedish	Arabic
<b>Paper</b>	21 native Swedes 11 immigrant - others	7 Arabic immigrants
<b>Online</b>	21 native Swedes 2 immigrant – others	None

The respondents did not differ in any significant way in age and education among the different groups. The Arabic group of respondents considered their income lower than average whereas the group of immigrants – other considered their income as average. Native Swedes stated that they earned more than average (figure 1).



**Figure 1.** Demographic characteristics among the respondents.

## 5.2 Similarities and differences in attitudes towards PWS

The results on the items measuring attitudes towards stuttering and PWS reveal no significant differences between the groups, except for the item ‘neighbor’, where the Arabic group scored lower (i.e., they would be more worried) than the native Swedes, and the item ‘Internet’, where the Arabic group scored higher than the native Swedes. No significant differences were found between the native Swedish and the immigrants - other, nor between the Arabic group and the group immigrants - other.

### 5.2.1 Distribution of responses to the items

As can be seen in table 2, among the native Swedes, a majority of the respondents would try to act like the person was talking normally (97.6 %). More than half of the respondents (61.9 %) would feel comfortable/relaxed when talking to a PWS and a little less than half would feel pity for the person 45.2 %. 11.9% tell the person to “slow down” or “relax”. 9.5 % would fill in the person’s words and/or feel impatient. 2.4 % believed that the PWS should hide his/her stuttering whereas 97.6 % did not agree with this statement. No respondent answered that they would make a joke about stuttering. On the items asking the respondent if he/she would feel worry if his/her neighbor/doctor/sibling/or themselves stuttered, 31.0 % answered that they would feel worried for themselves and 16.7% did not know. 14.3% would worry if their sibling stuttered. The largest sources of knowledge about stuttering among Swedes were “Personal experience” (54.8%) and Magazines/Newspapers/Books (42.9%).

In the Arabic group, all of the respondents would try to act like nothing and 66.7 % would feel comfortable when talking to a PWS. 33.3 % would fill in the person’s words and 16.7 % would tell the person to “slow down” or “relax” and/or feel pity for the person. No respondent in this group would make a joke about stuttering and no one would feel impatient. Also, no one believed that a PWS should hide his/her stuttering but 28.6 % did not know. 28.6% would worry for themselves or their sibling if they stuttered. No one would feel worried if their doctor or neighbor stuttered, but 28.6% answered that they did not know. Television, radio or films were together with the Internet the main sources for knowledge about stuttering (85.7% and 83.3% respectively).

Among the Immigrant - others, a majority of the respondents would try to act like the person was talking normally (92.3 %), and/or feel pity for the person 61.5 %. Approximately one third would fill in the person’s word (38.5 %) and/or tell the person to “slow down” or “relax” (30.8 %). 23.1 % would not feel comfortable or relaxed when talking to a PWS and 15.4 % would make a joke about stuttering. A little less than half (46.2%) would worry for themselves if they stuttered. The percentage of respondents that would worry for their doctor/neighbor/sibling if they stuttered was 15.4%, 7.7% and 33.3% respectively. 90.9% of the respondents in this group reported personal experience as a source for knowledge about stuttering and 72.2% reported school as a source. .

**Table 2.** Attitudes towards stuttering and PWS. Percentages of Arabic immigrants, Immigrants - other and native Swedes who responded yes, no or don’t know to each item. All numbers are percentage unless otherwise indicated. P-values (\*Bonferroni correction applied) are calculated for comparison between the Arabic group and the native Swedish group. Significant differences are marked in italics.

Attitudes	Arabic group (n=7)			Immigrant - others (n=13)			Native Swedes (n=42)			p-value*
	Yes	Don’t know	No	Yes	Don’t know	No	Yes	Don’t know	No	
<b>If I were talking with a person who stutters, I would...</b>										
try to ignore it	100	0.0	0.0	92.3	0.0	7.7	97.6	2.4	0.0	0.70976
make a joke	0.0	16.7	83.3	15.4	0.0	84.6	0.0	2.4	97.6	0.10568
fill in the words	33.3	50.0	16.7	38.5	15.4	46.2	9.5	11.9	78.6	0.00444
feel impatient	0.0	0.0	100	7.7	0.0	92.3	9.5	9.5	81.0	0.28108
feel comfortable	66.7	16.7	16.7	53.8	23.1	23.1	61.9	14.3	23.8	0.75035
feel pity for the	16.7	16.7	66.7	61.5	7.7	30.8	45.2	9.5	45.2	0.23392
tell “relax”	16.7	16.7	66.7	30.8	23.1	46.2	11.9	14.3	73.8	0.70392
<b>People Who Stutter...</b>										
Should hide it	0.0	28.6	71.4	0.0	7.7	92.3	2.4	0.0	97.6	0.08996

**I believe stuttering should be helped by...**



people like me                    0.0 66.7 33.3 | 40.0        0.0 60.0 |    9.8 26.8 63.4 | 0.48391

**If the following people stuttered, I would be concerned or worried...**

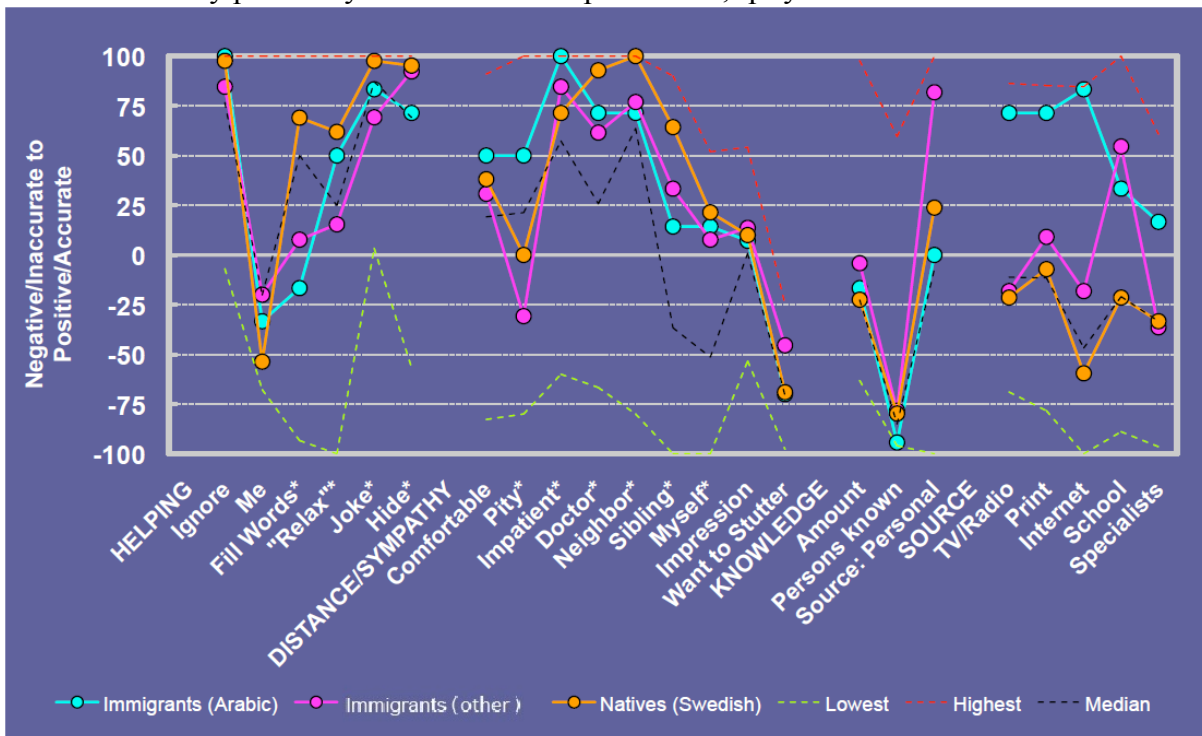
my doctor	0.0	28.6	71.4	15.4	7.7	76.9	2.4	2.4	95.2	0.15551
my neighbor	0.0	28.6	71.4	7.7	7.7	84.6	0.0	0.0	100	0.00021
my sibling	28.6	28.6	42.9	33.3	0.0	66.7	14.3	7.1	78.6	0.10956
Me	28.6	28.6	42.9	46.2	0.0	53.8	31.0	16.7	52.4	0.84642

**My knowledge about stuttering comes from...**

personal	42.9	14.3	42.9	90.9	0.0	9.1	54.8	14.3	31.0	0.52837
TV, radio or films	85.7	0.0	14.3	36.4	9.1	54.5	33.3	11.9	54.8	0.01546
magazines etc.	71.4	28.6	0.0	45.5	18.2	36.4	42.9	7.1	50.0	0.04294
Internet	83.3	16.7	0.0	36.4	9.1	54.5	14.3	11.9	73.8	0.00003
School	50.0	33.3	16.7	72.7	9.1	18.2	35.7	7.1	57.1	0.18721
health care staff	50.0	16.7	33.3	27.3	9.1	63.6	28.6	9.5	61.9	0.21484

**5.2.2 Positive/accurate vs. negative/inaccurate answers**

The group consisting of native Swedes scored accurately/positively on all items except for ‘me’ and ‘want to stutter’. The group consisting of Arabic immigrants scored accurately/positively on all items except for ‘me’, ‘fill in words’ and ‘want to stutter’. The third group, immigrants - other, scored accurately/positively on all items except for ‘me’, ‘pity’ and ‘want to stutter’.



**Figure 2.** Attitudes towards stuttering and PWS. The median represents the median of 172 samples from 27 countries.

**5.2.3 International comparisons**

In an international comparison the native Swedes scored higher than the median on all items except for ‘pity’ and ‘me’. The other items ranged from the 54<sup>th</sup> percentile (‘want to stutter’) to the 99<sup>th</sup> percentile (‘doctor’). The overall impression of stuttering and PWS among native Swedes was on the 64<sup>th</sup> percentile.

The Arabic group scored lower than the international median on ‘fill words’, ‘joke’, ‘hide’, ‘neighbor’ and ‘me’ and higher on the other items, ranging from 52<sup>nd</sup> percentile (‘want to stutter’) to the 98<sup>th</sup> percentile (‘impatient’). The overall impression of stuttering among Arabic immigrants was on the 58<sup>th</sup> percentile in an international comparison.

The group immigrants - other scored lower than the international median on ‘fill words’, ‘joke’, ‘relax’, ‘pity’ and ‘me’ and higher on the other items, ranging from the 51<sup>st</sup> percentile (‘neighbor’) and the 94<sup>th</sup> percentile (‘want to stutter’). An overall impression of stuttering and PWS was in an international comparison on the 73<sup>rd</sup> percentile in this group. For more detailed information regarding the percentiles on all separate items in the different groups, see Table 3.

**Table 3.** All numbers are percentiles in an international comparison with 172 samples from 27 countries.

<b>Attitudes: Helping</b>	<b>Try Ignore</b>	<b>Me</b>	<b>Fill in the Words*</b>	<b>Tell them to "Relax"*</b>	<b>Make a joke*</b>	<b>Should hide*</b>
Arabic group	94	24	10	67	27	49
Immigrants – other	61	46	19	34	8	87
Native Swedes	92	6	80	77	82	90
<b>Attitudes: Distance/Sympathy</b>	<b>Pity*</b>	<b>Impatient*</b>	<b>Comfortable</b>	<b>Impression of PWS</b>	<b>Want to Stutter</b>	
Arabic group	85	98	78	58	52	
Immigrants – other	9	89	53	73	94	
Native Swedes	25	70	64	64	54	
<b>Attitudes: Worry if</b>	<b>Doctor*</b>	<b>Neighbor*</b>	<b>Sibling*</b>	<b>Myself*</b>		
Arabic group	88	43	62	93		
Immigrants – other	73	51	77	90		
Native Swedes	99	90	95	96		
<b>Knowledge: Source</b>	<b>Personal</b>	<b>TV/Radio or films</b>	<b>Print</b>	<b>Internet</b>	<b>School</b>	<b>Health care staff</b>
Arabic group	51	99	99	99	72	91
Immigrants - other	98	42	78	70	87	56
Native Swedes	74	39	68	42	42	60

### 5.3 Similarities and differences in beliefs and knowledge about stuttering and PWS

The differences in beliefs and knowledge about stuttering were significant on several items between the native Swedish group and the Arabic group and had a very large effect size (mean effect size on significant differences: 1.353). No significant differences were found between the native Swedish and the immigrants - other, nor between the Arabic group and the group immigrants - other.

Native Swedes did not believe PWS to be particularly nervous or shy, although some people attributed these traits to PWS. These beliefs were more common in the Arabic group. Also, there were significant differences between the groups regarding beliefs about the causes of stuttering.

In the Arabic group it was more common to believe that stuttering was caused by a very frightening experience or an act of God than among the native Swedish group. Also, the source of information concerning stuttering was to a larger extent Internet among the Arabic group than among the native Swedes.

### 5.3.1 Distribution of responses to the items

In table 4 we can see that there were some differences between the groups on the items measuring familiarity with/knowledge about stuttering. In the group consisting of Arabic people there were more people who claimed that they did not know any PWS (42.9 %). Among the native Swedes, there were fewer people who did not know any PWS (7.1 %) and in the group consisting of immigrants from other countries 15.4 % claimed that they did not know anyone who stutters.

In the group of native Swedes a large majority did not claim that the PWS is to blame himself/herself for stuttering and they do believe that PWS can make friends (95.2 %) and lead normal lives (97.5 %). A majority (71.4 %) also believe that they can have any job they want, with some respondents being negative or unsure. More than half of the respondents answered that they do not know whether a PWS should have a job where they have to understand correctly and make important decisions; around one fourth answered positively to this statement. When asked about traits associated with stuttering, 14.3 % thought that PWS are shy or nervous. 82.9 % in this group believed an SLP to be suited to help with stuttering, and one fourth believed a doctor would be suited. Genetic inheritance was the most common item chosen as the cause of stuttering (38.1%). 1 out of 10 respondents believed that stuttering can be caused by learning or habits.

In the Arabic group, no one claimed that people who stutter have themselves to blame. In this group, a majority (66.7%) attribute nervousness and shyness to PWS. As with the Swedish group, a large majority believe that PWS can make friends and lead normal lives. Almost half did not know whether a PWS can have any job they want. Most of respondents (71.4%) were unsure on whether a PWS should have a job where they have to understand correctly and make important decisions and no one answered positively to this statement. One third of respondents in the Arabic group thought an SLP best suited to help stuttering, the remaining part of the group being unsure. Same pattern was found regarding genetics as a cause for stuttering and that stuttering is caused by an act of God; no one answered yes but a large majority (83.3%) was unsure about this. One third believed that learning/habits or a very frightening event could cause stuttering.

In the group immigrant – others 69.2 % did not believe that PWS have themselves to blame. 30.8 % believed PWS to be shy or nervous and 46.2 % did not know whether this was the case or not. 84.6 % believed that they could make friends and lead normal lives. 23.1 % did not believe that they can do any job they want. 46.2 % believed that they should have a job where they have to understand correctly and make important decisions. Concerning the origin of stuttering, 40.0 % identified genetic inheritance as a cause. 20.0 % believed the reason to be learning/habits and 40.0 % answered yes to the statement that it was due to a very frightening event. Around 1 out of 10 (11.1 %) believed it to be an act of God or due to ghosts, demons or spirits whereas 40.0 % believed the reason to be a virus or a disease.

**Table 4.** Beliefs about stuttering and PWS. Percentages of Arabic immigrants, Immigrants - other and native Swedes who responded yes, no or don't know to each item. All numbers are percentage unless otherwise indicated. P-values (\*Bonferroni correction applied) are calculated for comparison between the Arabic group and the native Swedish group. Significant differences are marked in italics.

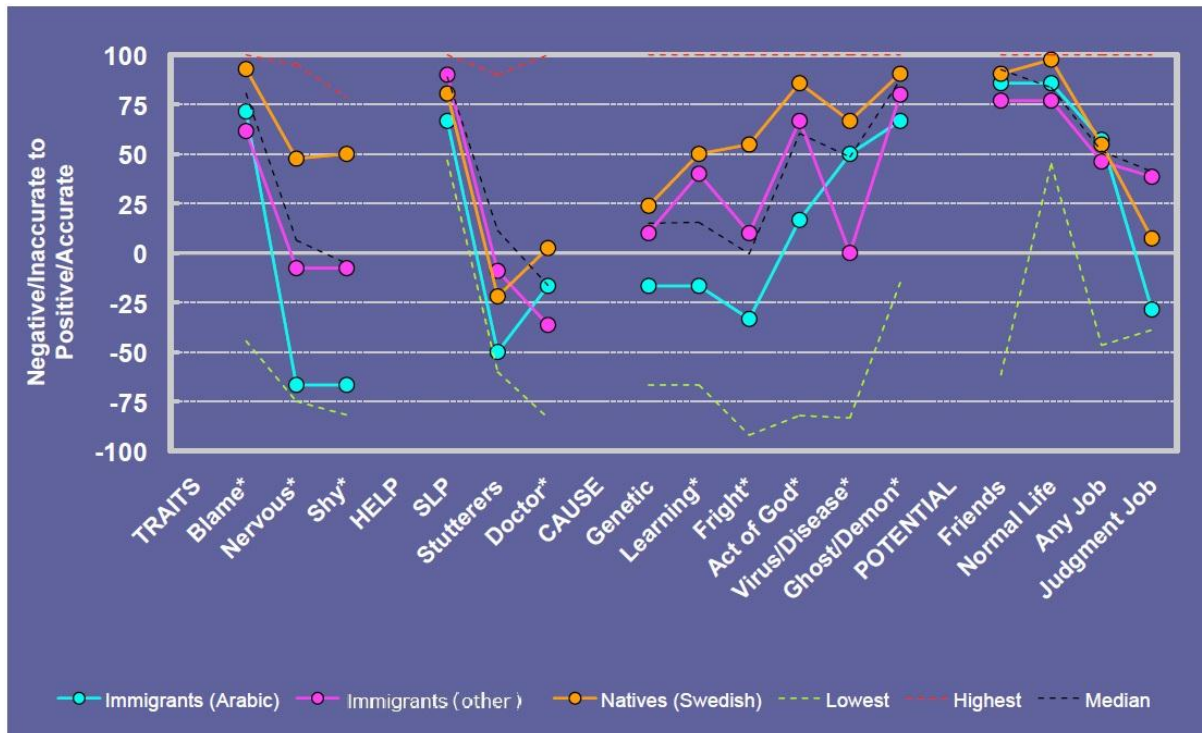
Beliefs and knowledge	Arabic Group (n=7)			Immigrants – other (n=13)			Native Swedes (n=42)			p-value*
	Yes	Don't know	No	Yes	Don't know	No	Yes	Don't know	No	
<b>People Who Stutter...</b>										
are to blame	0.0	28.6	71.4	7.7	23.1	69.2	2.4	2.4	95.2	0.15551
nervous/excitable	66.7	33.3	0.0	30.8	46.2	23.1	14.3	23.8	61.9	<i>0.00069</i>
are shy or fearful	66.7	33.3	0.0	30.8	46.2	23.1	14.3	21.4	64.3	<i>0.00055</i>
can make friends	85.7	14.3	0.0	84.6	7.7	7.7	95.2	0.0	4.8	0.78478
normal lives	85.7	14.3	0.0	84.6	7.7	7.7	97.6	2.4	0.0	0.14649
any job they want	57.1	42.9	0.0	69.2	7.7	23.1	71.4	11.9	16.7	0.93797
Judgment job	0.0	71.4	28.6	46.2	46.2	7.7	26.2	54.8	19.0	0.19205
<b>I believe stuttering should be helped by...</b>										
a SLP	66.7	33.3	0.0	90.0	10.0	0.0	82.9	14.6	2.4	0.50091
other PWS	16.7	16.7	66.7	27.3	36.4	36.4	24.4	29.3	46.3	0.43998
a medical doctor	33.3	50.0	16.7	63.6	9.1	27.3	29.3	39.0	31.7	0.58095
<b>I believe stuttering is caused by...</b>										
ghosts, demons etc	0.0	33.3	66.7	10.0	0.0	90.0	0.0	9.5	90.5	0.10318
genetic inheritance	0.0	83.3	16.7	40.0	30.0	30.0	38.1	47.6	14.3	0.17096
learning or habits	33.3	50.0	16.7	20.0	20.0	60.0	9.5	31.0	59.5	0.02975
a frightening event	33.3	66.7	0.0	40.0	10.0	50.0	7.1	31.0	61.9	<i>0.00216</i>
an act of God	0.0	83.3	16.7	11.1	11.1	77.8	2.4	9.5	88.1	<i>0.00042</i>
a virus or disease	16.7	16.7	66.7	40.0	20.0	40.0	2.4	28.6	69.0	0.50463
<b>I know a PWS</b>	57.1	0.0	42.9	84.6	0.0	15.4	92.9	0.0	7.1	

### 5.3.2 Positive/accurate vs. negative/inaccurate answers

Overall, the group consisting of native Swedes scored accurately/positively on all items except for 'stutterers'. Nonetheless, some items are in the lower range of the positive side of the scale, meaning that there still are people who believe that PWS are nervous or shy, and that they cannot do any job they want. Further, the item 'doctor' scored 0, implying that some people believe that a doctor is suited to help the stuttering.

The group consisting of Arabic immigrants scored accurately/positively on half the items and inaccurately/negatively on the other half, namely the items 'nervous', 'shy', 'stutterers', 'doctor', 'genetic', 'learning', 'fright' and 'judgment job'. Specifically, the beliefs considering PWS as being nervous and/or shy, and that they should not have a job where they have to understand correctly and make important decisions, are widespread.

The third group, immigrants from other countries, scored accurately/positively on the majority of the items but inaccurately/negatively on the items measuring ‘nervous’, ‘shy’, ‘stutterers’ and ‘doctor’. For more details, see figure 3.



**Figure 3.** Beliefs about stuttering and PWS. The median represents the median of 173 samples from 27 countries.

### 5.3.3 International comparisons

In an international comparison, the native Swedes scored higher than the median on most items but ‘SLP’, ‘Stutterers’, ‘Ghost/Demon’, ‘Friends’, ‘Judgment Job’ and ‘Amount known’. The group consisting of immigrants from other countries scored lower than the international median on all items except for ‘learning’ and ‘amount known’. The Arabic group scored lower than the international median on all items except for ‘any job’ and ‘amount known’.

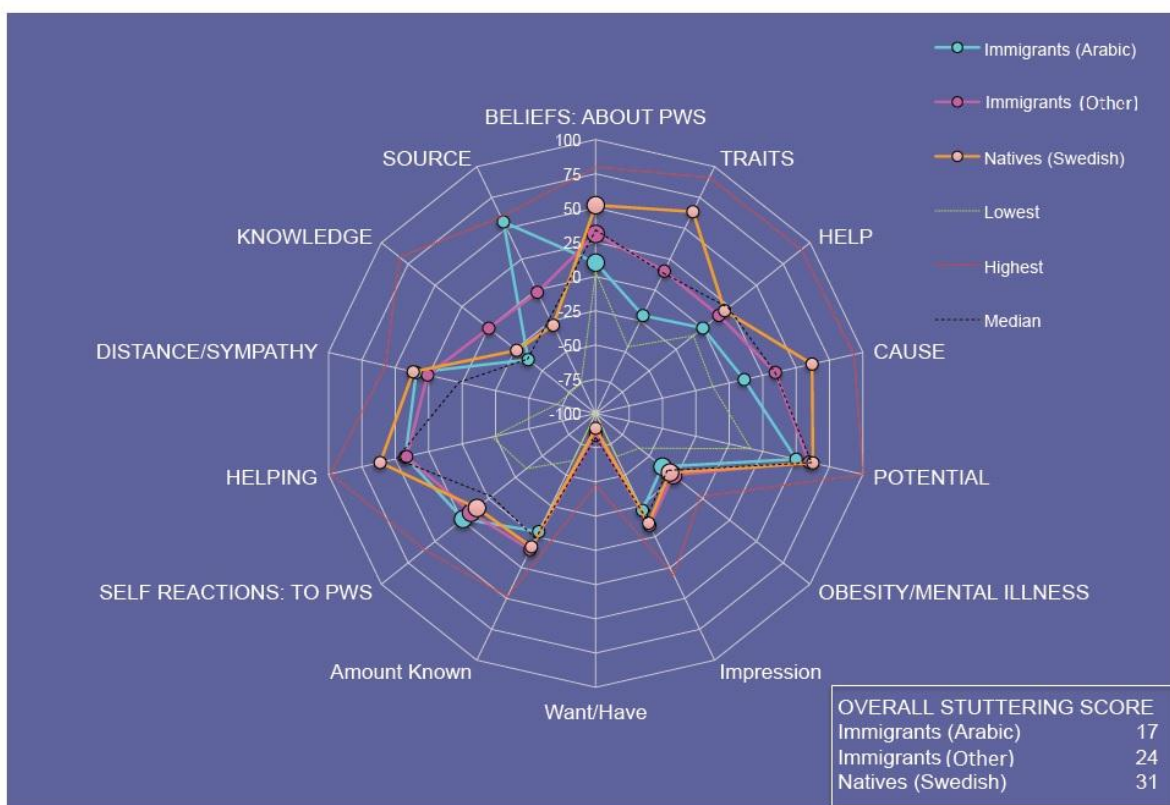
**Table 5.** Percentiles in an international comparison among 172 samples from 27 countries.

<b>Beliefs: Traits and Help</b>	<b>Blame*</b>	<b>Nervous*</b>	<b>Shy*</b>	<b>a SLP</b>	<b>Other PWS</b>	<b>a doctor*</b>
Arabic group	32	1	5	13	6	46
Immigrants – other	23	33	42	50	26	28
Native Swedes	69	88	95	28	16	71
<b>Beliefs: Cause</b>	<b>Ghost/Demon*</b>	<b>Genetic</b>	<b>Learning*</b>	<b>Fright*</b>	<b>Act of God*</b>	<b>Virus/Disease*</b>
Arabic group	17	14	10	21	15	38
Immigrants – other	25	38	72	48	50	3
Native Swedes	43	63	83	78	77	61
<b>Beliefs: Potential</b>	<b>Can make</b>	<b>Normal Life</b>	<b>Can do any Job</b>	<b>Judgment Job</b>	<b>Amount known</b>	

	Friends				about PWS
Arabic group	27	48	57	1	56
Immigrants - other	17	29	36	39	73
Native Swedes	39	77	51	5	45

## 5.4 Overall Stuttering Score

The Arabic respondents in our survey obtained an OSS of 17 with a SD of 13.78, reaching the 39<sup>th</sup> percentile in an international comparison. The immigrant – others scored 24 with a SD of 18.99, reaching the 59<sup>th</sup> percentile. The native Swedish group obtained altogether an OSS of 31 with a SD of 18.43, which is on the 78<sup>th</sup> percentile internationally. The component scores Impression, Want/Have and Amount known are related to attitudes and beliefs towards the attributes Obesity/Mental Illness. For more detailed information, see figure 4.



**Figure 4.** Overall Stuttering Score, compared to the international median, highest and lowest score.

## 6 DISCUSSION

### 6.1 Results discussion

Our results show that native Swedes in general are more positive in their attitudes and beliefs regarding stuttering and PWS than the international median. However, there are some items where Swedes are more negative or more inaccurate. For instance, they believe that they are suited to help someone who stutters and they tend to feel pity for a PWS. They also hold a more negative view on PWS' abilities to make friends and towards a PWS having a job where they have to correctly

understand and make important decisions at work (5<sup>th</sup> percentile), which we believe is alarming. Surprisingly, despite the fact that the native Swedes scored the lowest of all samples on the importance of practicing their religion (0<sup>th</sup> percentile), they also scored more inaccurately than the international median on believing that ghosts or demons could be a cause for stuttering. As previous studies have shown that a sample of between 20 and 40 respondents is enough to get a representative view of the attitudes held by the population (St Louis, 2012), and our sample size of native Swedes reaches the 50<sup>th</sup> percentile, we believe these results to be accurate. The fact that native Swedes are negative towards a PWS having a job where they have to make important decisions could lead to discrimination at work and more difficulties in pursuing a career. Also, we do not know whether the negative view upon the abilities of making friends mean that Swedes are negative towards being friends with a PWS. If this is the case, it is an issue that needs to be addressed as it can lead to exclusion and stigmatization. As Swedes hold a very positive/accurate view on most other items, it is surprising to see the negative attitudes on these items. Furthermore, compared to the international median, few Swedes know that a Speech - Language Pathologist is suited to help stuttering. Hopefully, this does not prevent any person from obtaining the help he/she needs; yet it is worth noting that the knowledge could be greater among the public regarding this issue as it could enhance the understanding of stuttering. Also, to the SLP treating the PWS, it may be of importance to know that these are questions worth being aware of in treatment, as the PWS may be affected by public attitudes.

There were some significant differences between the group consisting of native Swedes and the group consisting of Arabic immigrants with a very large effect size; however, the low number of respondents prevents us from drawing general conclusions. Overall, the group of Arabic respondents scored lower than the international median on most items. Also, there were fewer people claiming that they knew someone who stuttered in this group, which could indicate that it is less accepted.

The fact that the native Swedes would be less worried than the Arabic respondents if their neighbor, doctor or sibling stuttered could be a result of the cultural differences of the societies; Sweden, being a Western country, may be considered a more individualist society (Riemer & Shavitt, 2011) whereas the Arabic society can be considered more collectivist (Kahttab, Al - Manasra, Zaid, & Qutaishat, 2012). Another salient difference between the groups is the tendency to consider PWS as nervous or shy, where the Arabic group scored very low compared to the international median (1<sup>st</sup> and 5<sup>th</sup> percentile respectively) and the native Swedes scored very high (88<sup>th</sup> and 95<sup>th</sup> percentile respectively).

Despite significant differences between the groups regarding beliefs and knowledge about stuttering and PWS, there were no differences found in attitudes. Hence, more knowledge and more positive beliefs do not seem to lead to positive attitudes to an expected extent. Also, more people in the native Swedish group claimed to know a PWS than the respondents in the Arabic group. As contact with a person with a disability has been shown to enhance a positive attitude more than information and knowledge about the condition (Daruwalla & Darcy, 2005), we would again expect the native Swedes to be more positive in their attitudes towards stuttering and PWS.

It seems thus that it is not only a question of being aware of the causes behind a disorder for it to be accepted or more positively viewed. Perhaps the problem with the negative attitudes is a part of a structural discrimination. It could be for instance that the idea of perfection, which is highly valued in the Western societies (Krahé & Altwasser, 2006), does not leave any space for people who are considered deviant from the norm. Thus, these individuals might not be considered suitable for a job where they need to make important decisions. As we did not reach a sufficient number of respondents in the Arabic group (n = 7) it would be interesting if further studies with more

participants confirm these findings. There is also need for investigations that explore the underlying reasons.

## **6.2 Methods discussion**

### **6.2.1 Survey studies**

While a quantitative study will tell us what people are willing to let us know about their views, we do consider the risk that their answer does not tell us the truth about how they would act when talking to a PWS. That is, to some extent people might unwittingly make themselves look better. Also, looking into quantitative data might not give us the whole picture, as some aspects or nuances may simply be missed due to the limitations that a questionnaire inevitably presents. For instance, greater knowledge about a subject will lead to answers more to the extremes on scales (Harzing, Brown, Köster, & Zhao, 2012). The quantitative study may make us overlook this aspect.

One option for measuring attitudes toward stuttering would have been to perform a qualitative study rather than the quantitative one we chose. A qualitative study regarding attitudes may be performed in the form of interviews, as previously done by Kolmert, although her study was from the perspective of the PWS (Kolmert, 2012). This type of study may provide a deeper insight into the reasoning of the respondent, and gives an opportunity to follow his/her interpretation of given questions. The obvious disadvantage, the lower number of informants, makes a qualitative study less expedient for the study conducted by the authors of this thesis.

One reason for the low answering rate could be that people in general are not inclined to answer questionnaires due to the large number of survey studies they are asked to participate in. As an example, the rate of participating in the Public Health Survey conducted by the regional government in Skåne has been steadily decreasing over the last two decades (Rosvall, Grahn, Modén & Merlo, 2009).

### **6.2.2 POSHA-S**

The questionnaire that we have been using for our study, the POSHA-S, has been validated and reliability tested in several studies (St Louis, 2012). It has also been shown to be sensitive to changes in attitudes and beliefs in the same population (Flynn & St Louis, 2011).

Using an already constructed questionnaire for this survey, there was not much room for optimizing the design of the questionnaire to make it more attractive to the respondents.

In order to engage the respondent in a survey not directly connected to his/her own interests, the lack of interest should be made up for by constructing a questionnaire which is appealing in design and easy to fill in. A comprehensive battery of questions demanding more time from the participant may simply deter from participating. Even if a respondent is engaged in taking a poll or filling in a questionnaire, the design of the survey may also affect the level of effort and cognitive attention put into the answers (Downes-Le Guin, Baker, Mechling, & Ruyle, 2012). Another important issue is to be sensitive to the importance of how to introduce the study to the participants in order to motivate them to participate despite the extra work it conveys. If we would have put more focus on the fact that this is an internationally used questionnaire, it is possible that this would have generated more respondents as people might have been more inclined to participate knowing that they were contributing to an international database. Also, this could have made it easier for the respondents to understand and tolerate the fact that some of the questions were not entirely adapted to the Swedish culture.



Questions which are not directly connected to the aims of the survey may have to be included for other reasons. For instance, one may add questions to make the respondent understand what is expected from him/her, or to embed the target question between others if the aim is to be obscured to the respondent. However, if questions are included for which the purpose is not entirely clear; an abundance of questions may instead render the questionnaire a bit blunter as an instrument, as aforementioned aspects come into action. Indeed, one reason for the very low number of respondents may be the questionnaire itself. A contact at a school reported that some parents had contacted her with complaints of how the questions were constructed. Some found it difficult to answer while others did not agree with the questions themselves and did not want to answer. It is possible that other parents did not want to fill in the questionnaire for the same reason and therefore did not participate. Although POSHA-S aims to be culturally neutral and is constructed to be able to be used worldwide, it could be that it is not entirely adaptable to Swedish conditions.

### **6.2.3 International aspects**

Using an internationally acknowledged instrument for measuring attitudes has advantages such as the obvious one of not having to construct and validate a questionnaire in every new country the survey is to be conducted. Also, it may be of great value to build an accurate database of attitudes. Knowing what views on stuttering exist around the world can provide a helpful tool for assessing behavior in patients originating from other countries than the clinician's own. When these attitudes are measured in different countries, and repeated, hopefully it will show what measures can be taken to change negative attitudes and increase knowledge about stuttering among the population.

### **6.2.4 Cultural aspects**

POSHA-S has been developed in order to be used in all countries for worldwide comparisons. The developer has taken great care in avoiding words that are culturally specific; however, our experience during this study is that the entire questions are formulated in a way that cannot easily be translated to another language. If they are changed in order to fit in to the culture where the survey is being performed, they can no longer be said to measure the same thing as they have to be alternated in a substantial way. We believe that there is a need for more consideration of the pragmatic aspects regarding cultural differences. We had to take into account cultural issues not only when making comparisons between groups in Sweden, but also when translating the original POSHA-S and carefully adapting it to Swedish conditions. However, as we have put considerable effort into making our interpretation as close as possible to the original set of questions in the POSHA-S, this effort can have had as a result that it is not entirely adapted to Swedish conditions.

It is also possible, or even plausible, that the cultural background affects the respondent behavior. For instance, Harzing suggests that there are cultural differences in how inclined people are to fill in the extremes in the scales (Harzing, et al., 2012). Though the case presented by Harzing regards collectivist versus individualist cultures, and concerns marketing research, this provides an example of the problems associated with translating and using an established questionnaire in different countries that goes beyond the language issues. Cultural differences as an explanation for some differences in response style are also substantiated by studies indicating that acculturation influences the behavior of the respondents (Marín, Gamba, & Marín, 1992).

With the aim of collecting data from the Arabic-speaking minority in Sweden, we chose to also use an Arabic version of the POSHA-S. Thereby, both groups of respondents we were aiming for would

be able to perform in their native language. Although Arabic-speaking respondents in many cases would be bilingual and thus able to fill in the Swedish version, it is likely that the results give a more fair representation when both groups aimed for are presented with the questionnaire in their native language. Also, not all of our possible respondents speak Swedish fluently, making it necessary to distribute an Arabic version. Hopefully biases based on differences in language skills are thereby minimized in those cases where one language is stronger than the other.

### **6.2.5 Recruitment and design**

Many schools did not answer at all to our mails and many others declined participation in the study. A large number of the schools contacted reported a heavy work load due to already ongoing studies and did therefore not want to participate.

As a means of rendering the response frequency higher, we also created two web-based versions of the POSHA-S; one in Swedish and one in Arabic. However, some schools did not want to use their mail contact with the parents for purposes other than those regarding school matters and many schools did not respond at all. In the end, only four schools chose to participate. It could be that a web survey is not considered as important by the principals and other school staff contacted and it may therefore have been ignored.

Furthermore, a certain number of respondents failed to correctly fill in the survey, which also lowers our statistical power. In the paper version, some did not notice the questions on the last page whereas others made mistakes when filling in the survey (i.e. marking several alternatives on the same question and not at all at other questions). When a respondent marked several alternatives (i.e. both 4 and 5) we alternated between the highest and lowest in order to keep the mean unaffected. In the web survey, it was not possible to commit such errors.

When a respondent answered both “yes” and “no”, we chose to interpret this as “don’t know”. We also applied this procedure when a question was not answered at all. As we are looking at populations and not individuals, this practice should leave the mean unaffected (which is what we are looking at). The constructor of the POSHA-S has previously analyzed how the mean is affected by the respondents’ errors and concluded that it is not considered a source of error in the results (St Louis, e-mail communication, 2013-03-07). In the web survey, the design did not allow the respondent to fill in two answers at the same question, making it more likely to provide us with answers closer to the respondents’ real attitudes. Another advantage with the web survey is that it provides us with the answers directly in an excel file. When transferring the answers from the paper version to the computer there is always a risk for committing mistakes which could be a possible source of error.

We chose to perform a probability sampling, as studies have shown that these results are better suited to draw general conclusions from. This is due to the fact that convenience samplings tend to be based on populations that are higher educated, i.e. a selection bias is present (Özdemir, et al., 2011). Nonetheless, it is possible that our method resulted in a lower number of respondents, and therefore we cannot draw any general conclusions. A carefully selected convenience sampling in order to avoid selection bias would maybe have been preferable for the statistical power. Nevertheless, as we had to make two different versions of the survey, one paper version and one web version, this probably conveyed a selection bias as the two survey types differ in conditions. For instance, the paper version came with instructions in Arabic brought to the respondents by their child whereas the e-mail was likely to be sent out in Swedish. Although we had an information letter in Arabic in the web survey, the parents first had to be introduced to the survey by the school.

This could be an explanation to the complete absence of Arabic respondents in the web survey. Although respondents may answer similarly on the paper version and the web version of the questionnaire, a selection bias may be present as there is a need for access to computer for the web version. However, we decided to treat them as one group due to the need for statistical power. There were no Arabic immigrants responding to the web version, and we believe that most Swedes in the group targeted (parents to school children) have access to computer and internet communication, minimizing the risk for aforementioned selection bias. All groups were similar in age and level of education; differences in those factors could otherwise have been affecting the results.

As it would have been ethically troublesome we did not contact the parents directly but asked the children to bring the filled in surveys back to school. It is likely that many children forgot to give the parents the surveys, or to bring them back to school once filled in. Previous studies using this method did not report the percentage of surveys returned, therefore we cannot know if our very low respondent rate (around 3 %) is normal when applying this method. However, we believe that there are more efficient ways to collect answers. For this reason (and for the logistical problems if we wanted to conduct a survey outside Skåne), we chose to create a web based survey. The idea behind the web based survey is to get one step closer to the respondents by having the schools contact the parents directly instead of via the children.

## **7 CONCLUSION**

Overall, our results show that native Swedes in general are positive and hold accurate views towards stuttering and PWS in an international comparison. However, there are some issues that call for attention, particularly the fact that the native Swedish population is not very positive towards PWS having any job they want and/or holding a position where they have to correctly understand and make important decisions. Also, some people still believe that stuttering is a result of a frightening experience or learning or habits and that PWS are nervous and/or shy. Further, there are people that would not feel comfortable when talking to a PWS. Some would react by telling them to relax or fill in the words and/or would feel impatient and not want to wait. These issues need to be addressed in the Swedish society in order to improve the public awareness of stuttering. For instance, the consequences of a belief such as stuttering being caused by learning or habits can lead to stigmatization and exclusion of a child that stutters.

We also found differences between the different groups investigated, although the number of respondents is not large enough to draw general conclusions. The tendency, however, is that people with an Arabic background in Sweden seem to hold a more negative/inaccurate view upon stuttering and PWS. In this group, the beliefs that PWS are nervous or shy are more widespread and so are the beliefs regarding stuttering being caused by for instance an act of God, learning or habits, a very frightening experience etc. The attitudes towards stuttering also differ; the respondents in this group are more inclined to fill in words and/or tell the PWS to relax and some believe that a PWS should hide his/her stuttering. They would also be more worried if their doctor, neighbor or sibling stuttered. More positive reactions are that they would not at all feel impatient/not want to wait.

It is important to notice that the results from the different groups cannot be compared without bearing in mind cultural differences. This is valid for both how the respondents interpreted the questions in the questionnaire and for the underlying reasons guiding their feelings and behavior. Cultural differences matter not only in attitudes towards stuttering and PWS, but also the view upon society and diseases in general.

The statistical power is low as the response frequency was much lower than we calculated from the beginning. Therefore this is more to be considered a pilot project where we discuss pros and cons and what difficulties there can be when conducting a study based on a questionnaire.

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