Does Experience Change Understanding? The Effects of Personal Experiences on Patients' Knowledge of Medical Terminology

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Abstract. This paper investigates the ways in which personal experience and native language status shape individual medical background knowledge. In this exploratory study, semi-structured in-depth interviews were conducted with native (NES, n = 10) and non-native English speaking (NNES, n = 7) participants. From the interviews it emerged that personal experiences or personal (emotional) involvement with any kind of medical condition have several effects on an individual's knowledge and perception of medical terminology. Three main effects were found: 1) Personal experience fosters the retention of medical terms; 2) personal experience can promote the development of deeper underlying knowledge structures for the medical terms in question; 3) personal experience can aid participants in becoming aware of the different meanings health professionals and lay people attach to one and the same medical term. These findings, however, only hold true for NES participants. NNES participants experience many difficulties in medical communication. Most of their problems relate to English proficiency, their respective native language and the unfamiliarity with Western medical practice.

Keywords: medical terminology, experience, knowledge, non-native English speakers, doctor-patient communication

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1. Introduction

Within the sciences, specialist terminology features as an extremely helpful tool enabling professionals to distil complex concepts in order to communicate more quickly and efficiently with each other (cf. Halliday & Martin 1993). Experts have "encapsulated" their field knowledge and developed more integrated knowledge structures by going through transitional phases in which their knowledge has been repeatedly reconstructed (Schmidt & Rikers 2007:1136). However, uninitiated people or novices of certain special fields often only possess superficial knowledge of these specialist terms and are consequently more susceptible to experience communication breakdowns (Chi et al. 1981; Schmidt & Rikers 2007).

Within health care settings, medical terminology plays a fundamental role in the communication of information between individuals but it also often inadvertently leads to miscommunication. Similar to non-experts and novices in academic settings, patients also lack the scaffolding upon which health professionals (experts) build their knowledge (Chi et al. 1981; Schmidt & Rikers 2007). Yet, patients and doctors do not only deviate from each with regard to their interpretation of medical terms but also differ with respect to which lexical items they actually perceive as medical terms (Bourhis et al. 1989; Hadlow & Pitts 1991). As a consequence, due to their mismatched understanding and skewed perception of medical terms patients are found to put successful communication in medical settings at risk (Koch-Weser et al. 2009; Lucero et al. 2007).

In this exploratory study I will take a closer look at how patients actually feel about the use of medical terms in consultations and how they judge their own knowledge and perception of medical terms. I hope to gain a clearer understanding of how medical terms impact on doctor-patient communication and how they can create miscommunication. Furthermore, by allowing participants to voice their own opinions I want to take a step closer to including the patients' perspective in health communication research (Epstein 2006).

2. Background

2.1. Patient knowledge of medical terms

In medical communication shared knowledge plays an essential role as doctors and patients struggle to follow one another without unnecessarily wasting consultation time or "talking at cross-purposes" as Tannen & Wallat (1987:213) emphasize. Especially for patients, medical terms offer seemingly endless opportunities for confusion, misunderstandings and most importantly miscommunication (e.g. Cooke et al. 2000; Hadlow & Pitts 1991; Lucero et al. 2007). Due to its mostly experiential nature, a patient's knowledge of medical concepts is restricted to superficialities and usually does not seem to penetrate beyond the surface (Prior 2003; Tannen & Wallat 1987). Consequently, it is highly plausible that patients will often use and interpret medical terms differently from doctors (Hadlow & Pitts 1991; Koch-Weser et al. 2009).

2.2. Non-native English speaking patients in English-medium consultations

The insight that patients struggle to comprehend terms correctly is far from new. For the past fifty years researchers have been aware of the fact that unfamiliar medical terms create communication difficulties (cf. Byrne & Edeani 1984; Hadlow & Pitts 1991; Samora et al. 1961). Unfortunately, the majority of studies have disregarded or even consciously excluded non-native English speaking (NNES) patients from their samples (e.g. Fields et al. 2008). With ever-increasing globalization traditionally English speaking countries such as Australia, the USA and Canada have grown more culturally and linguistically diverse. However, little is known about the problems that NNES patients face in medical encounters conducted in English.

The few studies that focused on NNES patients in English-medium consultations have highlighted language barriers such as the patients' ability to express their symptoms and to understand medical terms in the questions and explanations of medical professionals (Bolten et al. 2002; Cooke et al. 2000; Frank 2000). The importance of issues regarding cross-cultural communication in consultations has also been emphasised, for example in relation to the compliance to prescribed regimens but also regarding the patients' unfamiliarity with Western medical practices and concepts

such as patient autonomy in the discourse of breaking bad news (Bolten et al. 2002; Chater & Tsai 2008).

Despite these few innovative pioneer studies, the research on NNES patients in medical communication is still far from delivering a complete picture. Especially concerning medical terminology, more research is needed to uncover if and how the patients' different linguistic and cultural backgrounds influence their attitudes towards the use of medical terms in consultations. Further information on how they use and understand medical terms is also required.

2.3. The impact of technicalness on the interpretation of medical terms

Patient and doctors often deviate in their perception of which words should actually be classified as medical terms and which should not (Bourhis et al. 1989). Such divergences in the perceived technicalness of medical terms can further threaten the success of doctor-patient communication. The idea of "technicalness" was first proposed by Nation (2001) and Chung (2003) within the fields of foreign language vocabulary acquisition and English for academic/specific purposes. They developed a continuum of *technicalness* in which a specialist term no longer corresponds exclusively to a fixed category. Instead terms can change their position between the two extremes – lay and highly technical – on the continuum depending on who uses them. Essentially, the technicalness of a term defines how closely related it is to a certain specialty and how easily it can be used outside its home domain (Chung 2003:229).

Figure 1 illustrates how medical terms can move along the technicalness continuum. I have adopted Tannen & Wallat's (1987) example of the divergent understanding of the term *wheezing* as used by a doctor and the mother of a child suffering from cerebral palsy. The mother is alarmed by her sleeping child's noisy breathing which she refers to as *wheezing*, and which she associates with difficulty in breathing. This lay interpretation of *wheezing* stands in stark contrast to the technical definition that the doctor draws on. For her, *wheezing* is signified by high-pitched whistling sounds indicating some kind of narrowing or obstruction of the airways which in turn causes difficulty in breathing. Consequently, she cannot hear the child *wheezing* in the strict medical sense. This mismatch in interpretation leads to a communication breakdown which they never really resolve as the mother keeps insisting on the presence of a *wheezing* noise and the doctor denies it (Tannen & Wallat 1987).

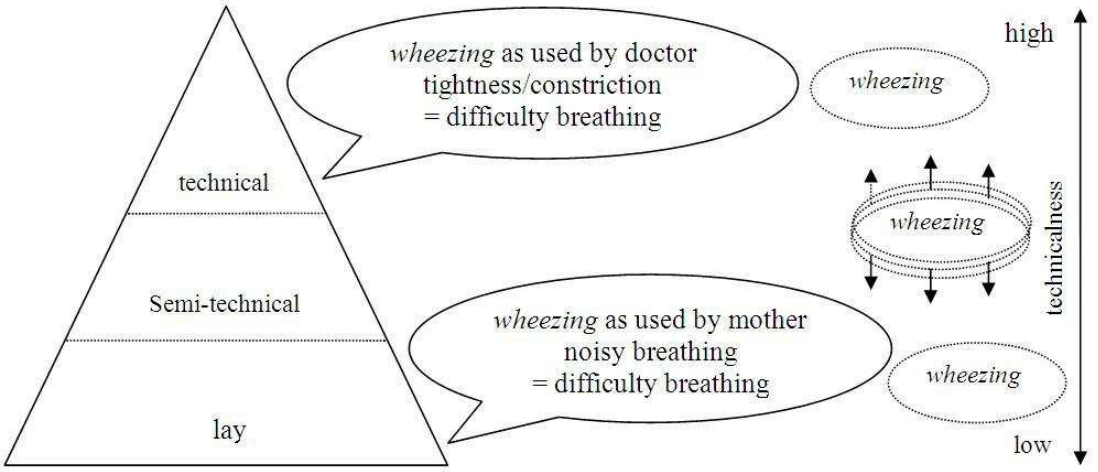

Figure 1. Continuum of technicalness adapted from Chung (2003) and Nation (2001); examples adopted from Tannen & Wallat (1987:214-215).

This example illustrates nicely how variable the meaning of a medical term can be. According to its position on the continuum a term can be interpreted from a lay (mother) or technical (doctor) perspective and thus one and the same term can take on different, even idiosyncratic, meanings. When compared to health professionals, patients rarely seem to converge in their understanding of any one given term (Boyle 1970; Lucero et al. 2007). But to the best of my knowledge no research exists on whether patients are aware of how much their interpretations of medical terms diverge from each other and from health professionals.

3. Research aims

The main focus of this exploratory study is to investigate the participants' attitudes towards the use of medical terms in medical situations. In particular, I want to answer questions regarding the relationship between patients' past experiences and the degree of their knowledge and understanding of medical terms. Moreover, I also want take a closer look at how personal involvement informs patients' awareness of diverging understanding and differences in perceived technicalness between them and health professionals. I will first attempt to ascertain how conscious patients actually are of such differences.

Following Epstein's (2006) call for the integration of the patients' perspective in health communication research, I draw from data gathered in semi-structured interviews in which native English speaking (NES) and NNES participants were prompted to talk about various aspects regarding their experiences as patients in Australia. I hope that by allowing the "patients" to talk, new light can be shed on the (potentially harmful) impact of medical terms on doctor-patient communication. Furthermore, given the lack of research on NNES patients, I will also give this previously neglected group the opportunity to express their opinions. From their remarks I hope to gain brief yet insightful glimpses into the effects that native language status has on consultations in general, and on their attitudes, use and understanding of medical terms in particular.

4. Methods

4.1. Procedure and Participants

In this paper I draw on part of the data that I collected in a larger exploratory pilot study. My overall aim in the pilot study was to generate new insights and reveal potential new areas for research regarding the experiences participants from different language backgrounds have in medical contexts in Australia. To this end I devised semi-structured interviews to cover a broad range of topics such as communication in medical consultations and talking about health problems with friends and families (see appendix for the complete list of interview questions).

The interviews were piloted with one NNES and one NES participant and minor adjustments were made concerning the wording of some questions. The study was approved by the Human Ethics Committee of an Australian University and participants were reminded throughout the interviews that they did not have to disclose any information that they felt uncomfortable discussing. I conducted the semi-structured interviews behind closed doors in the privacy of a department meeting room at a Sydney university. The room was light and airy with two large windows and furbished with several bookshelves, a large meeting table and chairs. The Interviewee sat across a table from me with an audio recorder positioned between us. All interviews were conducted in English. I tried to clarify all unclear or vague responses from the participants and followed up on their remarks to ensure saturation of each

topic. In order to avoid the interview becoming too probing, as far as personal medical details are concerned, I encouraged participants to remember specific moments in their medical history they felt comfortable sharing and simply let them tell me their stories.

Participant	Age	Male	Female	NES	NNES	Native language(s)	Years spent in Australia
1	18		X	X		Polish, English	18
2	18	X		X		English	18
3	18		X	X		English	4
4	18		X	X		English	18
5	19		X	X		English	19
6	19		X		X	Mandarin	2
7	20		X		X	Norwegian	0.75
8	21		X	X		English	21
9	22	X			X	Finnish	1.5
10	22	X			X	Spanish	0.58
11	23		X	X		Arabic, English	15
12	23		X	X		English	23
13	24		X		X	Mandarin	1.5
14	25		X		X	German	1.17
15	25		X		X	Khmer	8
16	32		X	X		English	32
17	36		X	X		Turkish, English	34
Total		3	14	10	7		

Table 1. Participant demographics (ordered by age)

Participants were drawn from an introductory course in Linguistics and received five percent course credit for their participation. Because of the exploratory nature of this study I let every willing student participate as this practice allowed me to generate as much new insight as possible. Nevertheless, given the limited scope of this study,

and in order to be able to address issues regarding NNES patients in medical encounters, a maximum number of ten NNES and NES participants were allowed to be interviewed. Overall seven NNES and ten NES (7 monolingual, 3 bilingual) participants volunteered to partake in the interviews. Table 1 provides demographic details of all participants. The interviews were designed to run for 30 minutes but ranged in length between 20 and 38 minutes. Despite the variety in age, all my participants were first year students of linguistics and I do not believe that at this point in their studies their language awareness was too far from that of the wider community.

4.2. Analysis

All interviews were audio-recorded. Initial analysis started immediately after each interview ended. I summarized the key points expressed by the participant and also recorded my own first impressions of the interview. Relevant sections of the audio-recordings were transcribed for further detailed analyses. Using open coding I reflected upon the transcribed data and my first comments (Strauss & Corbin 1998). Iterative reviews of the data allowed new insights to emerge. The multiple readings of the data prevented the mere picking out of interesting comments (Heigham & Croker 2009), but let themes surface gradually from the interview context.

5. Results

Because in this paper I focus on the role of medical terms in medical (mis-)communication, my analyses concentrated mainly on insights gained from data pertaining specifically to medical terms. This relates in particular to questions directly asking the participants for their opinion on the use and understanding of medical terms but also includes more indirect data gathered from the participants' narratives.

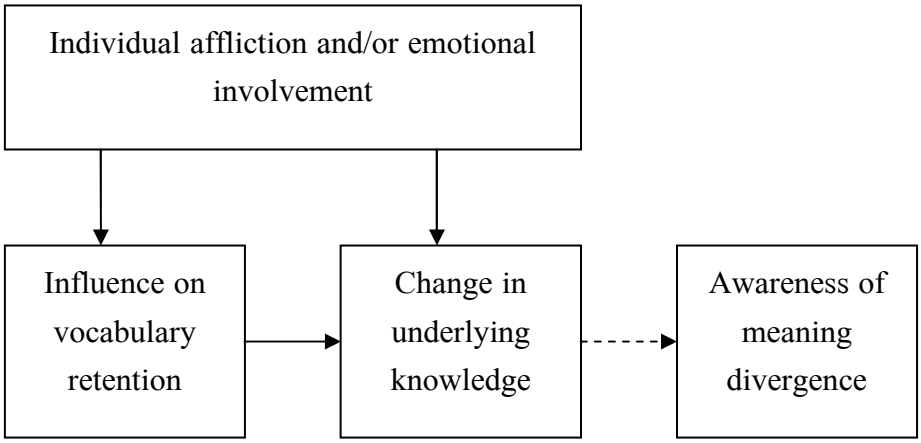

Figure 2. Influence of individual experience on the use and understanding of medical terms

Many of the participants reported similar experiences in their previous medical encounters. In their accounts, participants stressed the distinct personal connection to the medical terms they knew and frequently used. Personal involvement and experiences with any kind of medical condition (in-)directly influenced their knowledge and perception of medical terminology in three major ways: influence on vocabulary retention, change in underlying knowledge, and awareness of meaning divergence (see Figure 2).

Having been faced with a certain illness themselves, or while witnessing a family member or friend being affected by a particular condition, individuals retained most of those terms associated with the conditions in question. But beyond the mere increase in medical terminology vocabulary, some participants also reported broadening their understanding of these medical terms. They progressively acquired a more structured and more specific underlying knowledge base. Following this knowledge restructuring some individuals became more aware of the sheer amount of information that is condensed in just one medical term. Lastly, some participants grew more conscious about the divergences in the way they use and understand terms as compared to other "ignorant" lay people or well-informed doctors. This, in turn, also helped a few individuals to realize the fluctuating nature of a term's technicalness and the different meanings a term can take on depending on who uses it.

Since little is known about NNES patients in English-medium medical consultation, my analyses concentrated on their remarks with regard to medical communication in

general. But in order to be able to present a more complete picture of their medical experiences in Australia, I also explored the attitudes they expressed concerning the use and understanding of medical terms. Table 2 summarises the most common factors impacting upon NNES patients' ability to communicate in medical contexts. Major influences include problems regarding native language transfer and limited English proficiency.

Influence	Difficulty	Quote
Native language	(Im-)possibility of native language transfer	The [English medical] terms are really similar to the Spanish [lay] ones. (Participant 10) But in Chinese we just made up *lung* and *cancer* […] This is professional words. […] So for every Chinese we know what it is. (Participant 6)
English proficiency	Lack knowledge of medical terms	First it's hard to understand what they.. what they say to me what my problem yeah. And um I just guessing, in yeah.. generally guessing what they say. (Participant 15)
	Lack of natural exposure to and/or specific instruction in medical terms	Because we don't understand this. We never learned before the special terms so we are not able to use it but if I learnt I will try to use it. (Participant 13)

Table 2. Influences on NNES participant's abilities to communicate in medical contexts

Depending on their native language, some participants reported positive effects in understanding and using medical terms but others also mentioned negative consequences, for example in cases where English medical terms could not be easily transferred from the participant's native language or vice versa. NNES participants talked about limited English proficiency most often in connection to their lack of knowledge of medical terms. Most of them said that limited exposure to medical terms in naturally occurring conversations, as well as the absence of special instruction,

caused their lack of knowledge of medical terms. For NNES participants from non-Western backgrounds an unfamiliarity with certain features of the Western medical system was another source of difficulty in medical communication.

In the next three sections I will present detailed examples of the influence of individual experience on the use and understanding of medical terms. In the fourth section I will illustrate in more detail the most common influences on NNES participants' abilities to communicate in medical contexts. To avoid confusion as to which participant groups the results refer to I want to highlight that all results provided in sections 5.1 to 5.2 relate to NES and NNES participants, those in section 5.3 only relate to NES participants and those in section 5.4 pertain only to NNES participants.

5.1. Influence on vocabulary retention

The findings from the interviews suggest that personal experience or involvement with any kind of affliction, but particularly those of a chronic or recurring nature, leads to better retention of relevant medical terms among patients. Unlike doctors, who need to acquire a huge range of medical terms in order to cover all eventualities, patients learn medical terms on a strictly individual basis. As participant 10 phrased it:

> You learn [the terms] as you cross with them. (Participant 10)

Table 3 provides some of the complex medical terms retained by interview participants. The examples further illustrate that personal affliction and also emotional involvement in someone else's condition influence the retention of medical terms. Participants reported incorporating the newly acquired term in their active as well as passive vocabulary. They reported, for example, using terms in conversation with their families and friends or on follow-up visits to the doctor and thus consolidated the new acquisition. Being able to access medical terms in their passive vocabulary made participants feel less threatened or scared by subsequent encounters with previously unfamiliar terms:

> If a terminology comes up that I've heard before I definitely feel more secure and comfortable with the situation. (Participant 16)

Term	Quote
Roseola infantum	Even once she [her infant daughter] had an a virus. Uhm which the doctor told me the name and I was like "what?". And it's called *roseola infantum* (laughs). So that means she.. she was having red spots around… uh.. one one line around her her.. um stomach and uh and one around her neck. Yeah so it looked really strange and I.. I thought it must be itchy or something. (Participant 14)
Dysmenorhea	Well I had at one stage well *dysmenorrhea* which is like really bad period pains and I like I read that from somewhere. So I found out what that meant as a medical terms from like a book. (Participant 11)
Ovarian teratoma	My cousin for example. I found out that she has *ovarian teratoma* or something like that. […] It's like a cancer or something and it's got teeth and hair. (Participant 2)

Table 3. Medical term retention

5.2. Changes in underlying knowledge

Many participants expressed their desire to expand their background knowledge of personally relevant medical terms beyond mere surface structures. They spoke about taking active steps to steadily accrue more specific and underlying information about their condition, its prognosis and available treatment options.

> It is like a process of building your knowledge and stuff. So you find out the basics and then you get into more specific information. (Participant 1)

Furthermore, participants voiced their belief that suffering from more long-lasting or recurrent conditions generally entailed an increase in background knowledge:

> I think in [a] case [of chronic illness] the patient is going to have a progression of mind. (Participant 10)

Participants mentioned two pathways they usually followed in trying to acquire a more thorough background knowledge of terms that they were personally interested

in. They would either ask their doctor (see Table 4) or relatives or friends with a medical background like nurses or pharmacists. But many participants did not want to show their weaknesses or felt too embarrassed or too shy to speak to another individual or ask their doctor:

> Sometimes I don't want to ask in case it sounds dumb. (Participant 4)

So many individuals turned to self-study using medical books, encyclopaedias or the Internet, as participant 4 pointed out:

> Yeah cause I had bad skin so I went to her and um told her and she said "Oh it might be *polycystic ovarian syndrome*" but yeah I think I was a bit embarrassed at the time that's also why I didn't ask her. That's why I looked it up later on *wikipedia*. (Participant 4)

Table 4 provides nice examples of successful knowledge expansion. Participant 16 explains how her doctor's explanation helped her built a deeper underlying knowledge structure for her illness. She later commented on how she still falls back on this information when she needs to explain her condition to family or friends.

An interesting result concerning the quality of underlying knowledge was uncovered in participants' reports on deliberate and direct instruction in medical terms, for example, in health class in school. Removed from immediately "medical" environments and without any real personal involvement, medical terms and underlying concepts lost their significance. With passing time participants could recall attending certain health-related classes but were unable to define or even mention any of the medical terms covered in such classes.

> MRI I only knew because I had actually research um for uh um multiple sclerosis in a… for TAFE assignment last year. And that was when I heard of. Like I've heard of MRI but never sort of really understood it … So I knew basically that an MRI was just "yup okay it's obviously some sort of body-scanning process" um but didn't understand the whole thing. (Participant 16)

Participant 3, originally from the United Kingdom, talked about a project on cardiovascular disease she had done in a health class during year 11 or 12 (so no longer

than one or two years ago) but could not recall any terms other than *cardiovascular*. Her underlying knowledge was equally diminished as all she could remember was that her project had been concerned with "stuff to do with the heart".

Term	Quote
Amoxicillin	I'm.. allergic to uh certain kind of anti.. antibiotics so um I have to say the drug's name otherwise terrible things could happen […] I was once administered *amoxicillin* and I got quite strong allergic uh symptoms. So uh I really learnt the name of that component.. by um you know painful experience […] I used to think of them um like antibiotics as an entire group of medicines but.. uh when um I noticed um how different um the effects of two different antibiotics can be to my body than yeah then uh like started thinking antibiotics as a group of um very different kinds of medicines which have a similar purpose. (Participant 9)
Endometriosis	Yeah when I've… when I was first diagnosed with *endometriosis* um He sort of said "yeah it is *endometriosis*" and I'm like "yeah okay. What it is?" Like I had no idea um and he's "and what you've never heard of it before?" I said "I've heard of the word *endometriosis*" but had absolutely no idea. So he was able to just break it down by sort of, you know, explaining, "okay, well *endometriosis* is where yeah you know your monthly cycle comes along and instead of the blood flowing through the fallopian tubes it is actually sucked backed into the fallopian tubes and causes blood cysts." That's a lot more clearer than just saying *endometriosis*.(Participant 16)

Table 4. Change in knowledge structure

5.3. Awareness of meaning divergences

Halliday & Martin (1993) have argued that specialist terminology allows professionals to refer to complex concepts by using single technical terms. In medical com-

munication staff rely on medical terminology to communicate complicated facts quickly and efficiently, but most patients only have a superficial understanding of the medical terms (Prior 2003). Some of the participants in this study talked about becoming more aware of discrepancies in the meaning of terms as used by professionals or patients. For example, participant 12 expressed her belief that medical terms contained more precise information for doctors than lay words. She also felt that doctors used so many terms because it would be difficult for them to find a lay word that incorporated the same facts:

> That [medical] word immediately corresponds to the.. the right concept whereas if you're explaining it in simple words you might not get the whole idea. [...] maybe they just, especially GPs, they see so many people a day that it sort of becomes second nature to say things in the terms that they have learned rather than try and translate them through their brains into simple words. (Participant 12)

In some cases the awareness of meaning divergences also triggered a shift in the perceived technicalness of medical terms. The following quote from participant 5 illustrates this shift in perception nicely:

> Because the term *migraine* is thrown around a lot and people… some people who get *headaches* say they have *migraines* and they are totally different. […] So… sometimes if I tell people I have *migraine* I tell them a bit more about the symptoms because… Like if I call in… if I get a *migraine* I have to call in sick for work, like I feel I need to describe what I get… because it's not just a headache. (Participant 5)

Because she has been personally afflicted by migraines since puberty, she has accumulated a deeper underlying knowledge and now interprets *migraine* from a more technical perspective. She realized that her understanding differs from that of most people (without medical backgrounds) who interpret *migraine* to be a synonym for *headache*. Thus she felt obliged to explain herself in detail in an attempt to reconcile her technical interpretation with the more superficial lay understanding of *migraine*.

Some of the participants reported trying to monitor their use of terms when they were not absolutely certain of what the particular term actually referred to when used

by a professional. Individuals stated that, although they thought they knew the meaning of certain terms like *nausea* or *femur*, they would refrain from using them in order to prevent accidental mix-ups or not to cause unnecessary confusion. It is particularly interesting that some individuals, like participant 17, even admitted that their own perception and comprehension of certain terms had once been incorrect or incomplete:

> Like a knee reconstruction: you know what it means but you don't know what it means. You know a knee needs to be replaced oh but is your whole knee gonna be… (Participant 17)

These participants were conscious of how their former inadequate understanding has changed over time in conjunction with their personal experiences. Through their individual involvement they came to recognize how differently medical term can be interpreted from technical and lay standpoints:

> So when you go to the doctor with um you know I don't know with a cold or a flu. He might go "yeah it's nothing. You don't need any antibiotics. Off you go." You know "rest and fluids" kind of stuff. And people might not exp.. you know, understand it. Because I didn't know that there is a viral and a bacterial kind of flu and that one is treated with antibiotics and one is not. (Participant 17)

Participants also described how increased familiarity and use of medical term caused shifts in perception and understanding. These changes in turn made certain terms become less intimidating for them and their families and friends:

> And even with the endometriosis at first.. it was a big issue like "what's that? We [the participant's family] don't understand it" when I used that word it seemed a big medical term for them even though it's quite simple compared to other medical terms. (Participant 16)

5.4. New insight from NNES participants

The communication problems addressed by NNES participants in the interviews largely converge with the language and cultural barriers identified in the few previous studies on NNES patients (Bolten et al. 2002; Cooke et al. 2000; Frank 2000).

Following from the NNES participants' own remarks, their capability to efficiently communicate in an English-medium medical setting was highly influenced by their English proficiency. Participants from Asian backgrounds also encountered difficulties regarding their unfamiliarity with the Western medical system. In addition to the results of earlier studies, participants reported that their success in English medical communication was also affected by their native language background. In the following four subsections I will provide more detailed examples concerning English proficiency, unfamiliarity with Western medicine, and pertaining to the participants' native language. Lastly, I will address outcomes regarding the NNES participant's awareness of meaning divergence.

5.4.1. English proficiency and medical communication

NNES participants identified English proficiency as the greatest source of difficulty in medical communication. They frequently complained about their limited exposure to medical terms in everyday and educational settings and how this lack affected their own knowledge of medical terms negatively:

> Because we don't understand this.. um we never learned before the special terms so we are not able to use it but if I learnt I will try to use it. (Participant 13)

> Those [NES] people have been to an English doctor since they were little and uh they have gotten exposure to that [terms] more than I have. […] you don't really use [terms] in everyday life so I think when you hear some difficult vocabulary, even if you look up the meaning, if you don't use that one you will forget the meaning. (Participant 9)

In comparison, most NES participants reported they were familiar with many medical terms even though some of them, like participant 4, did not know what they signified:

> No new words. I know what they are. I have heard of the word before I just don't know what it is. (Participant 4)

Limited knowledge of plain English vocabulary was also cited as a common source for difficulty in communication with medical professionals. Many NNES participants, for example, participants 7, 13 and 15, reported that they often relied on non-verbal communication. They stated they used facial gestures to signify pain and pointed to the injured body parts to explain their symptoms. Participant 13 confessed to having trouble explaining her symptoms in plain English because the "normal [English] vocabulary [was] missing". Participant 15 admitted that in their explanations health professional would often use words she did not know and which caused her a lot of confusion and required guesswork from her:

> […] it's hard to understand what [the doctors].. what they say to me what my problem yeah. And um I just guessing, in yeah.. generally guessing what they say. (Participant 15)

When asked if and how they intended to improve their communication skills in medical contexts, NNES participant unanimously stated that they had to improve their English language skills overall. They proposed various techniques for deliberate and incidental acquisition of medical terms. Some of their ideas were similar to those of the NES, for example they suggested asking relatives and friends, or looking up unfamiliar terms online or in mono- or bilingual English dictionaries. The concept of deliberate study, however, diverges from NES participants, who hardly ever mentioned conscious study.

About half of the NNES participants believed that their overall performance in medical communication would be enhanced through deliberate study of medical terms regardless of whether they were personally relevant for them. But not all NNES participant believed that this kind of general and impersonal study of medical terms would be helpful. For example, participant 7 cited personal necessity as her reason for not wanting to deliberately study medical terms:

> That would be kind of like unnecessary. There is a lot of medical terms… and I wouldn't know which one I would be using later. (Participant 7)

Participant 14 maintained that "[she] would not sit down with a medical handbook and just study the terms […]." She believed in natural acquisition and stated that she

would study relevant terms if they were relevant to her personal health. Participant 6 adopted a particularly interesting individual strategy in an effort to ameliorate her performance in medical communication. Before every scheduled visit to her doctor, she would google her symptoms in Mandarin first, and then study the pronunciation of the corresponding English medical terms:

> Before I come to see them [the doctor] I will prepare […] I will search some professional words for me to understand them […] because of the pronunciation and uh […] if I learn this word then I'll know. (Participant 6)

5.4.2. Western medical system and medical communication

In their investigation of compliance issues relating to prescription medicine, Bolten et al. (2002) concentrated on two ethnic groups: Chinese and Arabic patients and their doctors. Concerning the Chinese group they discovered that patients often only knew a little about the medical system in Australia and that many Chinese patients harboured negative feelings regarding the efficiency and side effects of Western medicine.

In the present study, unfamiliarity or surprise with the Australian healthcare system was expressed by two of the three NNES participant with Asian backgrounds only. While participant 13 did not express a dislike of or confusion about Western medicine or medical systems, the comments made by the second Chinese participants (participant 6) mirrored the results obtained by Bolten et al. (2002). Participant 6 often voiced her doubts about Western medicine and also stated her puzzlement with the different medical structures in Australia:

> Basically […] I don't know Australia's medical environment… such as where to go [for what treatment].
>
> We don't have health cover in China.
>
> Chinese traditional medicine would help me um… more healthy.

> [Western medicine] just to relief pain… such like Panadol. But Chinese traditional medicine can make you more healthy […] give you health base. (Participant 6)

Participant 15, originally from Cambodia, was previously unaware of the difference in medical practice that exists between her home country and Australia. She expressed her surprise at the high amount of patient autonomy she experienced in the Australian medical context. She explained that she struggled with this new freedom at first and had to adapt to it slowly because she was so used to a system in which everyone "believe[s that] what the doctor do is right".

5.4.3. Native language and medical communication

Depending on their mother tongue NNES participants reported benefits and also disadvantages relating to their understanding of English medical terms. For example, the close connection between Romance languages and Latin-based English medical terms made it very easy for participant 10, a native speaker of Spanish, to transfer lay Spanish medical vocabulary to the English medical discourse. He felt his native language put him at an advantage, at least as long as he was familiar with the medical term in Spanish:

> The [English medical] terms are really similar to the Spanish [lay] ones. So um it doesn't really change [...] medical terms sound more natural to me [...] and possibly it is easier for me. (Participant 10)

The disadvantages experienced by speakers of other (non-romance) languages stand in stark contrast to these benefits. For example, participant 6, a native speaker of Mandarin, commented on the differences in the inherent transparency of English and Mandarin medical terms:

> But in Chinese we just made up *lung* and *cancer* […] This is professional words. […] Two simple words put together. Most Chinese professional words are like this. (Participant 6)

She stressed the fact that, in her mother tongue, more complex medical terms are created by combining well-known simple words to form the new medical term. The meaning of the newly created term could then be inferred from the meaning of its

parts, "so for every Chinese we know what it is". Participant 14, a native speaker of German, voiced her irritation at the unexpected differences between German medical terms and their English equivalents (see also Table 3):

> And it's called *roseola infantum* (laughs). […] It was just.. in Germany it would have been called *Drei-Tages-Fieber* [three-day fever]… So very different name, very different name. (Participant 14)

But, contrary to the examples just given, some participant did not feel their native language had any influence at all on their ability to communicate in medical settings. Participant 9, for example, argued that his native language (Finnish) did not impact on his ability to communicate at all since in both English and Finnish medical discourses "doctors use jargon people don't understand".

5.4.4. NNES participant and awareness of meaning divergence

Regrettably, new insights regarding the NNES participants' awareness of meaning difference or shifting technicalness were scarce. A few of the NNES participants were aware of a potential for meaning divergence of medical terms. For example, participant 7 expressed that "penicillin […] might mean a much broader thing for a doctor"; while participant 9 became aware of the underlying meaning of *antibiotics* after suffering from an allergic reaction (see Table 4). Unfortunately, some of the NNES participants had difficulties simply understanding the question about meaning differences, even after I rephrased the question several times and gave them various examples. Consequently, I could not collect any relevant data from them.

6. Discussion

6.1. Personal experience and retention of medical terminology

Data gathered in the interviews revealed that participants acquire most medical terms only as they become personally relevant to them. Participants encountered and used medical terms in a variety of contexts, e.g. in conversations with doctors but also when talking with families and friends, or when researching terms online. They thus had many opportunities to pick up terms and try to expand on their knowledge. However, it seems that only perceived individual necessity and/or personal experiences resulted in retention and the wish to expand their knowledge of the term in question.

The huge variety of medical terms retained by the participants provides strong evidence for the influence of perceived personal need on the retention of medical terms. A lot of the terms that were discussed by the participants were uncommon, highly technical and most importantly highly idiosyncratic, for example *myoclonic crisis* (participant 10) or *mycoplasma pneumonia* (participant 17). It is crucial to stress that such terms were only remembered because of the decidedly individual significance they have for each participant. Only when a condition became personally relevant to them, did participants start to seek the vocabulary necessary to discuss the condition, prognosis and treatment. In the words of participant 2:

> Unless it was directly related to me.. and I knew something was wrong with me I think that's when [the terms] starts to stick in my head. But if it was happening to someone else and they were describing to me "look I've got this condition blah blah blah" I don't think I can then go to someone else and say "look he's got this specific disorder" but if it's directly related to me I am confident [in using the term]. (Participant 2)

But sentimental feelings and emotional bonds with a sick loved one can also foster the retention of medical terms. Again quoting participant 2:

> If I feel sorry for them it's gonna stick in your head. Like someone has *breast cancer* or someone died from *emphysema*. (Participant 2)

So although individuals may use terms in everyday conversation with their family or peers, it seems unlikely that their counterparts will actually recall any of these terms unless they feel they had at least some kind of significance or triggered an emotional response in them.

6.2. Personal experience and changes in knowledge structures

Prior (2003) has stressed that patients' medical knowledge is based only on experience and is thus greatly limited. But although their knowledge is "only" experiential, the interview data shows that increases in personal experiences can still initiate the restructuring of underlying medical knowledge. Especially participants with long-standing or recurring conditions have developed deeper underlying knowledge

structures for the condition in question. These participants started to leave the superficial surface level of knowledge behind as they find out more and more about their condition. The new information they obtained and their new experience helped in the reconstruction of their underlying knowledge for a particular term and related concepts; similar to the development of specialist expertise in academic settings (cf. Chi et al. 1981; Schmidt & Rikers 2007). The second example in Table 4, for instance, illustrates nicely how participants 16 restructured her underlying knowledge. As she recounts the physiological information originally provided by her doctor it becomes clear that in the time that has passed since she has been diagnosed this information has become part of her own knowledge.

The influence of personal involvement can be used to explain the low retention rates and the lack of underlying knowledge reported for medical terms that were taught in educational settings. It appears that under such circumstances medical terms usually do not hold any immediate personal relevance for the participants. Thus participants 3 and 16 (cf. section 5.2) might not have felt the need to really study these term thoroughly, and that could be the reason why they forgot them soon after. But regardless of the role that personal involvement takes in educational environments it should be noted that direct instruction appears to lead to a fundamentally different sort of qualitative knowledge than experiential learning. This difference is particularly striking when comparing participant 16's comments regarding the MRI (study) and her endometriosis (experience).

6.3. Personal experience and awareness of meaning divergence (NES participants)

Differences in the meaning attached to a medical term frequently cause miscommunication between doctors and their patients (Hadlow & Pitts 1991; Tannen & Wallat 1987). It has been proposed that such meaning divergences can occur because the technicalness of a term and, in turn, its meaning can shift depending on who uses it (Chung 2003; Nation 2001). Thus if patients and doctors were more aware of the potentially different interpretation of medical terms they could take greater care when using such terms and thus reduce the likelihood of miscommunication.

Despite the great impact that personal experience had on vocabulary retention and the restructuring of medical knowledge, experience did not seem to create awareness for meaning divergence among all interview participants. When asked directly

'When you use a medical term, do you think it means the same to your doctor as it does to you?' the majority of NES participants felt a shared understanding to be unlikely. However, it seemed as though only a few of the participants who had already retained medical terms and gained access to deeper underlying knowledge structures also noticed differences in the interpretation of medical terms. These participants expressed their beliefs feely and without being asked directly. With respect to meaning divergence, personal experience appears to have a more narrow and individual impact. The realisation that one particular term can shift in technicalness and meaning may in fact be confined only this particular term or concepts. Even participants who have developed an awareness of meaning divergence for one term were found to fail to transfer this knowledge to other terms or medical situations. For example, participant 11 was aware of the meaning discrepancies often connected with the term *antibiotics*:

> I think [antibiotics] is a medical [term] but is has just been so overused that is has become like… what it's actual purposes is compared to like … I think people just think "oh I need an antibiotic" but it's not used for everything that people think it's used for. (Participant 11)

Yet her reasoning for being upset when her doctor declined to prescribe her antibiotics does not show any such insight:

> Well I think it was like I had a cold or flu or something and I thought that it was a flu because a cold usually would like go a lot quicker. And I go "can I have antibiotics?" and he was like "just wait for a few days. See if it gets worse". But I know like because obviously from having it so often... many times when I was… before that I knew that I needed something that was stronger than what I could just get over the counter. (Participant 11)

However, once meaning divergence has been experienced for a particular term, participants used this knowledge as a general strategy in the prevention of miscommunication. In some case, if they were not absolutely sure about how a professional would interpret a certain term they tried to avoid using it entirely.

6.4. New insights on NNES participants

The interviews allowed participants to express their opinions and give concrete details concerning their most pressing difficulties. Judging from their remarks it appears that NNES participants may, in general, feel more pressured in medical situations than their NES counterparts because of their limited English proficiency. NNES participants may refrain from asking their doctor for more specific explanations simply because they do not want to admit that not only do they lack relevant medical knowledge but also fundamental English vocabulary. Other factors, like unfamiliarity with Western medical practice or different cultural attitudes, such as seeing the doctor as an unfailing authority never to be questioned, may also cause some NNES participants to avoid asking questions.

Regarding relevant underlying knowledge NNES participants seem more prone to experience far greater difficulties. NES participants have been exposed to medical terms all their lives simply by being a NES growing up in an English-speaking environment. In contrast, NNES participants have probably never heard of or seen many common English medical terms. Therefore, NES participants might have unconsciously stored a lot of terms in their passive vocabulary while NNES participants have not had similar opportunities for encountering medical terms used in English-medium medical consultations.

Unfortunately, not a lot of data could be collected from NNES participants regarding their awareness of meaning divergence. Results from some of the NNES participants seemed to converge with the NES participants. A few of them reported a single instance in which they noticed a difference in meaning attached to terms by doctors and themselves. Concerning the remaining NNES participants, it seems that their ability to acknowledge meaning divergences is strongly connected to their English proficiency. Some of them did not even recognize medical terms let alone have any relevant background knowledge related to the term's meaning:

> First time I got an *appendix*. And I don't know what is that mean (laughs) and they just told me after the operation. […] Yeah took it and hey just told me that I had gotten an appendix and they already took it out. […] no clues what is was and I go back and checks the

> dictionary. […] I don't think it was a medical term […] just a word to me, just something I'd never heard. (Participant 15)

As a consequence, these NNES participants may remain unaware of the crucial information encoded in medical terms as used by doctors and unmindful about the high potential for meaning divergence, unless they try to educate themselves using books or online resources.

7. Conclusion

The findings presented in this paper are based on a small sample of participants so it is hard to draw firm conclusions on general patients' behaviour and knowledge. However, new insights emerged from the participants' responses and larger scale investigations following up on those patterns seem warranted. It has been revealed that personal experience or emotional involvement greatly impact upon the retention of medical terms and the structure of knowledge underlying these medical terms. Furthermore, it was found that in some cases personal experience could even lead to awareness of meaning divergence of particular, individual medical terms. Unfortunately, this realisation does not seem to be transferred to other terms easily.

Because the participants' awareness tends to be based on individual involvement and experiences, their knowledge and use of medical terms remains idiosyncratic and is never likely to be as coherent as that of doctors or other trained health professionals. But there is one positive conclusion to be drawn from the fact that participants' awareness of the shifting meaning of terms is highly individually marked, and thus far from universal: if some of the participants were capable of carefully monitoring their use of terms and assessing the meaning of terms as they are used by laypeople and professionals around them, perhaps it would not require much patient education to persuade them to take a cautious approach to terms encountered in any medical situation. In this way, patients may avoid miscommunication since they would no longer take terms at face value, which would ensure that both they and their doctor have the same concepts in mind when referring to a certain term.

The fact that patients seem to use medical terms frequently in discussion with their family and friends also supports the demand made by Epstein (2006) that health communication research should not end with the patient leaving the doctor's surgery.

More research is necessary to unveil how patient behaviour as whole, i.e. beyond the constraints of doctor-patient communication, affects the use, comprehension and perceived technicalness of medical terms and thereby the (medical) communication skills of patients. Findings gathered in more thorough examinations of the origin, extent and consequences of meaning divergence could be utilized in patient education and doctor training in order to raise more awareness regarding potential miscommunication triggered by mismatches in the meaning of medical terms. In this study in particular, participants appeared to underestimate, or even be entirely unaware of, the grave consequences of the issue at hand. Nonetheless, patients and doctors, as well as other health professionals, need to be cautioned not to give in to the false sense of security that accompanies the easy belief that their counterpart will interpret terms in exactly the same way they do.

This study also revealed that participants' development from retention to changes in knowledge structure, and eventually to awareness of meaning divergences, was heavily dependent on their native language status and level of English proficiency. The new insights regarding the problems faced by NNES participants in English medium consultations reveal just how much strain is actually put on the communicative value of such medical consultations and on the doctor-patient relationship in general.

More research on NNES patients involved in English-medium consultations is warranted in order to examine their communicative difficulties more closely. Subsequent investigations could also take the research beyond the limited scope of this paper, which was mostly interested in the effects of personal experience on the knowledge and understanding of medical terms. Findings from future studies will hopefully provide useful guidance for the development and implementation of cross-cultural communication training programs for health professionals. Finally, migrant English classes could provide an excellent platform to raise awareness of the great potential for miscommunication and meaning divergence in medical communication and encourage NNES patients to try and expand their medical vocabulary knowledge by asking questions.

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Appendix. Questions used in the semi-structured interviews

1. Did you ever experience difficulty in communicating with either your "regular" doctor or another GP or specialist you have seen? If yes, could you please describe these problems in more detail and also tell me how they were resolved?
2. Did you ever have communication problems caused by the use of medical terms? Did the doctor provide any explanations for the medical terms?

3. Did you ask anyone else to explain medical terms to you after you saw the doctor?
4. Have you ever looked up the meaning of a medical term in a dictionary or on the internet?
5. Do you think you have adequate vocabulary to tell your doctor exactly what is wrong with you?

    5.1. NNES: Do you think you only have problems understanding medical terms in the Australian context because English is not your native language? Do you think native speakers of English (NSE) have similar problems?

    5.2. NES: Do you have problems understanding medical terminology? Do you think non-native speakers have greater problems understanding medical terms than native speakers?

6. Think of a medical condition of a personal or non-personal nature that you feel comfortable discussing.

    6.1. What words do you use to describe your symptoms or affected body parts areas?

    6.2. What words do you use to talk about the "technical aspects" of this condition, e.g. treatment, medication etc.

7. When you use a medical term, do you think it means the same to your doctor as it does to you?
8. Regarding patient-doctor communication, how do you judge the amount of terms used, and what do you think in general about the use of medical terminology by doctors?
9. What kind of language do you prefer your doctor to use and why?
10. Do you think better of a doctor that uses more plain English or more technical terms?

    10.1. Judging specific characteristics of doctors in connection to the terms they use:

Do you associate professional medical expertise with the use of lay or of technical terminology?

Do you associate empathy with patients with the use of lay or of technical terminology?

11. Can you think of a word or words that you have come across in everyday life that you would consider to be a medical term?