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Transcultural pediatrics: Compliance and outcome of PKU patients from families with an immigration background*

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Transkulturelle Pädiatrie: Compliance und Therapieerfolg bei PKU-Patienten aus Migrantenfamilien

Zusammenfassung. Für Zuwanderer bedeutet das Leben in einem Land mit anderen Lebensstilen und Orientierungen eine vielfältige Herausforderung. Ein hoher Anteil der Patienten (30–50%) mit Stoffwechselerkrankungen, stammt aus Migrantenfamilien aus der Türkei und dem Mittleren Osten. Die Phenylketonurie ist eine Stoffwechselerkrankung, bei der die im natürlichen Verlauf entstehende geistige Behinderung durch Früherkennung und konsequente Diättherapie verhindert werden kann. Wir berichten von 7 Kindern mit Phenylketonurie, die aus 3 türkischen Familien stammen, die besondere Probleme in der Akzeptanz der Diagnose und der Durchführung der Diät hatten. Die durchwegs außerhalb der empfohlenen Werte liegenden Phenylalaninspiegel im Blut der betroffenen Kinder und die unterdurchschnittlichen IQ-Werte weisen auf die Risiken hin, die trotz standardisiertem medizinischen Angebot durch sprachliche, psychologische und kulturelle Kommunikationsbarrieren entstehen. Zur Förderung von Prävention und Compliance bei Kindern aus Migrantenfamilien schlagen wir vor: a) Einsatz von professionellen Dolmetschern bei Sprachbarrieren, b) Einsatz von soziokulturell und sprachlich kundigen Sozialarbeitern, die Familien sachkundig begleiten, und c) Einführung von Behandlungsverträgen, die Grenzen der Rechte und Pflichten sowohl der Patienten als auch der Betreuer festlegen. Aus juridischer Sicht liegt die Informationspflicht des Patienten beim Krankenhaus, und der Einsatz von professionellen Übersetzern bei Patienten, die der Landessprache nicht kundig sind, ist verpflichtend.

Summary. Living in a foreign country with a different lifestyle and a different orientation is a many-faceted challenge for immigrants. A considerable percentage (30–50%) of patients with metabolic disease come from immigrant families from Turkey and the Middle East. Phenylketonuria is one example of metabolic disease in which severe mental retardation can be entirely prevented by early detection via newborn screening and consistent dietary treatment. We report 7 phenylketonuria patients from 3 Turkish families who had considerable difficulty in coping with the diagnosis and adherence to the diet. Blood phenylalanine levels beyond recommended limits and IQ values below average, clearly demonstrate the risks arising from language as well as psychological and cultural communication barriers, despite standardized follow-up care structures and the observance of continuity by medical caregivers.

To propose a basis for systematic improvement in the care of patients from immigrant families we suggest that: a) the services of professional interpreters be used in case of language barriers; b) social workers with appropriate sociocultural and language competence should accompany the family in a professional manner; c) it would be meaningful to introduce treatment contracts that clearly establish the limits of the client's rights and duties as well as those of the care-givers. From the viewpoint of legislation, providing medical information is duty of the hospital and the use of translators is mandatory in patients from foreign countries and with foreign languages.

Key words: Hyperphenylalaninemia, prevention, mental retardation, immigrants, compliance.

Introduction

In the second half of the last century, Central Europe started to receive a large number of immigrants from the

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south-eastern part of Europe, from Turkey, North Africa and the Middle East. The growing proportion of the aged in the European population will further promote this process of immigration in the coming decades [1].

Living in a different country with a different lifestyle and a different orientation is a many-faceted challenge for immigrants. Particularly in health care, the meeting of individuals from different nations, languages, levels of education, knowledge of medicine, medical institutions, social strata, socialisation and other significant influences gives rise to verbal and non-verbal communication barriers [2]. Analyses of such communication barriers constitute an important tool in medical and systematic quality control [3, 5]. Central European countries, including German speaking countries (without particular history of colonies) find it particulary difficult to deal with strategies to overcome these communication barriers with immigrants.

In areas of industrial concentration, a large proportion of the patients in health care facilities and hospitals speak a foreign language. Many of them have no or meagre knowledge of the language of their host country and therefore find it difficult to utilise its health facilities [3-6].

This problem is particularly relevant in cases of genetic metabolic diseases which can be treated by specific diet therapies, because the observance of dietary rules usually influences the entire familial and social environment of the child affected by the disease. Additionally, these diseases are especially common among children from families that have migrated from Turkey, the Middle East, and northern Africa (Morocco). Thirty to 50% of patients with inborn metabolic diseases who undergo treatment in Austrian and German paediatric clinics come from Turkish immigrant families [7].

Phenylketonuria (PKU) is a representative example of treatable metabolic disease. Severe mental retardation is a part of the natural course of the classical form of the disease, but can be completely prevented by early identification through newborn screening and consistent treatment with a phenylalanine (Phe) -restricted diet [8, 9]. As a rule, in treated PKU patients, control of blood Phe levels is directly correlated with their adherence to the prescribed diet, psycho-mental development and IQ. The diet must be maintained until adolescence, and ideally should be observed throughout the individual's life in order to avoid late onset neurological complications [8, 9].

Since the introduction of newborn screening in Austria in the late 1960ies, more than 250 patients with classical PKU have been identified, including 12 patients (4.8%) from 8 Turkish immigrant families. Compliance and diet is a difficult issue in every family with a PKU child [10] but particular problems exist in families with immigrant background and poor sociocultural integration [7]. Preliminary data concerning the long-term follow-up of PKU patients from Turkish immigrant families have shown that despite identical medical care, the diet compliance (based on blood Phe levels) and outcome (based on IQ values) is poorer than that among Austrian children [7].

Here we report 7 PKU patients from 3 Turkish families who had considerable difficulty in coping with the diagnosis and adherence to the diet. The aim of this study was to propose a basis for: a) systematic analysis of the factors responsible for the ineffectiveness of the efforts made by medical caregivers, and b) systematic improvement of the care of patients from immigrant families.

Patients and methods

Patients

Seven patients with PKU (current age, 4–23 years) from three families with a Turkish immigrant background are presented. In all cases the diagnosis was made in the course of newborn screening and medical care was provided in the Department of Paediatrics, University of Vienna.

Treatment

After confirmation of diagnosis, the patients are routinely admitted to the hospital in order to initiate dietary treatment and instruct the parents about the principles of the diet. The diet is calculated on the basis of the Phe content of foodstuffs, and protein substitution through a Phe-free amino acid mixture. The diet is carefully adjusted to the child's blood Phe levels and physical growth. Blood Phe levels are measured in blood samples which are taken regularly (the samples may even be taken by the child's parents through a prick in the child's finger-tip). The diet is calculated by the dietitian assistant during the first year; in the second year the parents usually start to calculate the diet on their own under the supervision of the dietician.

The cost of the Phe-free amino acid mixture is borne by the health insurance. In addition, parents receive a two-fold children's allowance per affected child. The Phe-free amino acid mixture is ordered per medical prescription and delivered by regular mail.

Compliance was defined as adherence to the diet [11], and was objectively assessed by the median blood Phe levels at 1, 2, 5, 6, 10, 11–15 and 16–20 years of life. Limits of blood Phe levels are given in Table 2 and set according to the German recommendations 1997 [9].

Outcome was assessed by general items of psycho-mental development and by determination of IQ. Both of these parameters are routinely examined in PKU patients at the age of 1.5, 3, 6, and 12 years. In case the IQ test result was not available, the degree of mental retardation was estimated according to the definitions of ICD 10 [12].

Socioeconomic status and factors influencing compliance

A professional translator (native Turkish speaker) collected the following information in a structured interview during a routine outpatient control examination. The aim of the interview was explained to the parents and their consent was obtained:

a) The family's socioeconomic status, including profession, education, provenance, living space, income per year, and persons sharing the condominium (Table 1);
b) Self-assessment of language skills (1 = little, 2 = poor, 3 = fair, 4 = good) and self-assessment of the parent's textual understanding of the doctor's instructions (measured as % of the given information), and knowledge of the disease (given as % of correct answers out of 16 questions) (Table 2).

Case reports

Family 1 consists of 4 children, all of whom were born in Austria. The third and fourth children suffer from PKU; the first and second children are healthy.

Table 1. Socioeconomic traits of 3 families with children affected from phenylketonuria

Family	Year of birth M/F	Education Mother/ Father	Profession Mother/ Father	Immigrated to Austria	Provenance	Living space (m^2)	Income Euro/Year	Persons sharing condominium
F1	1962/1956	Elementary/ University	Housewife/ shop assistent	1980	M/F: Turkish City	30	800–2000	6
F2	1971/1968	O-level/ University	Housewife/ skilled worker	1986	M: Turkish immigrant family in Germany F: Rural area in Turkey	96	800–2000	7 (including grandparents)
F3	1957/1957	Elementary/ Elementary	Housewife/ unskilled worker	1970	M/F: Turkish Rural area	58	800–2000	8

M mother; *F* father.

Both parents speak enough German to be able to communicate in daily life. The majority of the consultations with doctors and the dietician took place in the presence of a professional translator. The diet plans were worked out together with the mother and German-speaking relatives.

To the external eye the family appears to be a modern urban family of Turkish origin. Socioeconomic factors are detailed in Table 1. The parents rated their language skills as poor (mother) or fair (father). Textual understanding was 50% of the given instructions, and objective assessment of disease-specific knowledge revealed 60% correct answers.

Patient 1: Female, third child of family 1, first child in this family with PKU. Initially the parents did not believe the diagnosis. On vacation in Turkey the parents asked for a second opinion in a Turkish metabolic centre. Although the diagnosis was re-confirmed, the parents remained sceptical and tended to reject the "doctor's opinion". Blood samples were taken regularly per instructions and the mother came regularly for the outpatient control examinations in the hospital. The child's blood Phe levels were fairly above the recommended limits during the first year of life, and far beyond the recommended values later on (Table 2). At the age of 9 years the girl's IQ is 85 (ICD 10: borderline intelligence [12]); she attends a special programme in a primary school for mentally disabled children.

Several one-week stays in the hospital to optimise the child's diet and to further instruct the mother in the preparation of the diet did not improve long-term compliance. Even during the hospital stays the child's blood Phe levels were only marginally improved. In the hospital ward the child's mother was frequently observed to offer her child foodstuffs that did not conform to the prescribed diet. The parents repeatedly refused to admit the mother and the child to the psychosomatic ward for a longer period of time in order to work out efficient therapeutic strategies. The child's poor blood Phe levels were discussed several times with the parents, who were repeatedly cautioned about the late sequelae of the condition.

Table 2. Blood phenylalanine levels in 7 patients with phenylketonuria from 3 families with poor compliance in dietary treatment

Family	Patient/ year of birth	Median blood Phe level						
		1 y	2 y	5 y	6 y	10 y	11–15	16–≤ 20
1	P 1/1995	6.2	16.7	28.9	26.4	–	–	–
	P 2/1998	5.3	18.9	19.9	20	–	–	–
2	P 3/1991	3.0	10.0	14.8	18	18.2	16.5	–
	P 4/1999	1.5	8.5	13	–	–	–	–
3	P 5/1981	8	15	><	><	><	><	><
	P 6/1984	><	><	6	11	16.5	23	24
	P 7/1990	1.5	7.8	17.2	5.2	19.5	15.4	–
Phe levels German recommendations [9] until 1997 from 1998		≤ 6 mg/dL 0.7–4 mg/dL					< 10 mg/dL 0.7–15 mg/dL	< 20 mg/dL 0.7–20 mg/dL
Phe levels French practic		≤ 6 mg/dL			< 25 mg/dL			

>< no treatment.

Patient 2: Male, fourth child of family 1, second child with PKU in this family. The patient also suffers from Down's syndrome. The child's blood Phe levels were well under control during the first year of his life, but rose far beyond the prescribed limits after this time because of poor observance of the diet (Table 2). At the age of 4 years the boy is able to walk without aid, but is unable to speak or follows simple commands. His movements are stereotyped, his behaviour is calm, and his estimated developmental age less than 2 years. He attends a kindergarten for mentally handicapped children. It is difficult to state whether and to what extent the child's retardation is due to poor dietary control of PKU or the natural course of Down's syndrome.

Interventions by Youth Welfare Office proved to be ineffective.

Family 2 consists of three children, all of whom were born in Austria. The first and third children suffer from PKU; the second child is healthy.

The father's German language skills are poor whereas the mother speaks fluent German. Both parents were present at nearly all medical consultations. Many professional translators were also present at the consultations because of the father's limited understanding of the German language. Other Turkish-speaking fathers of patients and Turkish hospital personnel also provided assistance by way of translation. However, the child's mother never translated for her husband. The diet plans were worked out together with the child's mother.

To the external eye the family appears to be conservative. Socioeconomic factors are detailed in Table 1. The parents rated their language skills as fair (mother) or poor (father). Their textual understanding was 75% of the given instructions, and the objective assessment of their disease-specific knowledge revealed 85% correct answers.

Patient 3: Male, first child of family 2, first child in this family with PKU. Following an initial hospital stay immediately after the diagnosis had been established, the parents seemed to be conscientious in their observance of the diet rules. During the first year of life, blood samples were taken regularly as per instructions, and the child's Phe levels were well within the recommended limits. However, after this time the parents came to the hospital for blood samples only after being urged several times to do so. The child's blood Phe levels indicate poor observance of the diet (Table 2). At the age of 12 years the boy's IQ is 61 (ICD-10: mild mental retardation [12]). He is aggressive and extremely hyperactive and attends a school for mentally retarded children.

Several one-week stays in the hospital led to significant improvement of blood Phe levels and the mother proved to be well informed about the diet. However, long-term compliance at home was not improved, as shown by the prompt deterioration of the child's Phe levels after discharge. The parents repeatedly refused to admit the mother and the child to the psychosomatic ward for a longer period of time in order to work out efficient therapeutic strategies. The child's poor blood Phe levels were discussed several times with the parents, who were informed of the causal relationship between poor diet control and the boy's retarded intellectual performance and behaviour disturbance. The Youth Welfare Office was asked to intervene several times and the parents were repeatedly cautioned about financial sanctions by way of cancellation of their two-fold child allowance for the diseased child. However, all of these measures were ineffective and did not bring about a satisfactory change in the situation.

Patient 4: Male, third child of family 2 and second child with PKU in this family. Following an initial hospital stay immediately after the diagnosis had been established, the mother became keenly aware of the mistake she had made with her first child and wished to avoid the errors a second time. Blood Phe levels were usually within the recommended limits during the first year of life. However, after this time the child's blood Phe levels rose beyond the recommended limits, as in the case of his brother (Table 2). The mother asserts she followed all the instructions given to her. At the age of 4 years the child is able to walk without aid, follow simple commands, and speaks less than 10 words. His behaviour is hyperactive and aggressive, and his estimated developmental age less than 2 years. He stays at home with his family and receives occupational therapy.

Family 3 consists of 7 children, all of whom were born in Austria; the first, third and fifth child (all females) suffer from PKU. The second and fourth (females) and the sixth and seventh (males) are not affected by PKU.

The child's father speaks broken German; the mother speaks no German. The conversations took place mainly with the father. Diet plans were worked out with the father in the presence of the mother. With the third child, most of the consultations with the doctors and the dietician were held in the presence of a translator. The diet plans were worked out together with the mother.

To the external eye the family appears to be conservative and of rural origin. Socioeconomic factors are detailed in Table 1. The parents rated their language skills as little (mother) or poor (father). The parents' textual understanding of the given instructions was 50%, while the objective assessment of their disease-specific knowledge revealed 55% correct answers.

Patient 5: Female, first child of family 3, first child with PKU in this family. Dietary treatment was started at the age of 5 months, as the parents accepted medical care only after several interventions from the Youth Welfare Office and the Turkish consulate. At the age of 5 months, the child's head circumference was in the 10th percentile, she was hypotonic, unable to roll over, but able to grasp, and her attitude was friendly. On diet the child's high pre-treatment blood Phe levels (30–40 mg/dL) decreased to the recommended limits within a few days. During the following months the mother prepared the diet at home according to the dietician's instructions and attended the outpatient control appointments. The child's blood Phe levels were within or slightly above the recommended limits. However, the parents' adherence to the diet recommendations deteriorated continuously during the second year of the girl's life, as reflected by her high blood Phe levels (Table 2) and by the parents' irregular attendance of the control appointments. At the end of the second year, when the second child (not affected by PKU) was born, the girl was brought to her grandmother in Turkey and received no treatment there. The parents reported that she was doing well and obviously they did not recognize her retarded development. At the age of 17 years she was brought back to Austria. At the age of 22 years her estimated IQ is between 35 and 49 (ICD10: moderate mental retardation [12]). She is able to walk without aid, speaks a few words, and can communicate her basic needs. She is unable to read or write. Her behaviour is calm. She stays at home with her family.

Patient 6: Female, third child of family 3, second child with PKU in this family. After PKU had been diagnosed during the very first weeks of the child's life, she was brought to relatives in Turkey and remained there without treatment. At the age of 4 years she was hardly able to walk, did not speak a word, had stereotyped movements, and no eye contact. When the parents recognized their child's abnormal development, they decided to introduce dietary treatment. Prior to introduc-

tion of the treatment they had been informed of the irreversible brain damage that had occurred during the untreated period. Following the diet after the child was admitted to the ward, her high pre-treatment blood Phe levels (> 30 mg/dL) decreased to recommended values. However, after the child returned home her blood Phe levels promptly increased far beyond the recommended values (Table 2). At the age of 5 years she became increasingly auto aggressive. As her parents were unable to take care of her, she was admitted to a nursing home for handicapped children. The facilities in the nursing home were such that the strictly calculated diet could not be followed; here the child was given a low-protein diet without exact calculation of her Phe intake, but supplemented with a Phe-free amino acid mixture. At the age of 17 years her estimated IQ was about 20 (ICD 10: severe to profound mental retardation). She was in a wheelchair, unable to speak, could follow simple commands to a moderate degree, and was incontinent. Her behaviour was hyperactive and auto aggressive. Neurological investigation and brain MRI revealed spastic paraparesis, occipitoparietal demyelisation and diffuse brain atrophy. Her behaviour is under careful observation and efforts are being made to keep her blood Phe levels below 20 mg/dL.

Patient 7: Female, fifth child of family 3, third child with PKU in this family. Since it was known from the past that the parents were unable to cope with the demands of a strictly calculated diet, the child was given a low-protein diet without exact calculation of the Phe intake, but supplemented with a Phe-free amino acid mixture from the very beginning. The parents agreed to hospital admission in order to optimize the diet. The mother's observance of the diet at home was considerably improved. Within the first year of life the girl's blood Phe levels were within recommended limits. Later on her blood Phe levels were higher than the recommended level but rarely in the untreated range (Table 2). At the age of 13 years her IQ is 57 (ICD 10: mild mental retardation [12]). She attends the 3rd performance group of an upper elementary school, is able to sustain herself, do simple domestic work and semi-skilled manual labour.

Discussion

The three PKU families presented here clearly demonstrate the risks arising from language, psychological and cultural communication barriers despite standardized follow-up care structures and the observance of continuity by the dietician, treating physician and psychologist.

Language barriers alone constitute an elementary factor in the medical care of immigrants [2, 5]. In the cases presented here, the language of communication with the parents was German. In two of the three families, at least one parent spoke fair German. Patients 5 and 6 are historic cases. Conversations that were held with the parents of these two children took place 20 years ago; whether and to what extent translators were consulted cannot be established today. In the last few years, professional translators have been used in all cases to overcome language barriers. Nevertheless, in the structured interview it was found that the subjects' self-assessed textual understanding of the instructions was incomplete.

Apart from language barriers, a number of complex socio-cultural and socio-economic factors hinder communication between the medical system in charge of treating the patient and the patients and their families [2–5,13–17]. In the cases presented here, factors from the following areas are worthy of note: *Coping strategy* (particularly family 1: not willing to believe the diagnosis and suppression of its potential consequences), and *disease concept* (particularly family 3: the parents became aware of the presence and the necessity to treat the disease only when they noticed their child's abnormal development). Also *education and values* (all families: learning disabilities are not considered a burden and are no convincing motive for compliance), as well as the *socioeconomic situation* seem to have an important impact. Another factor are the different *roles of the father* (head of the family and in charge of the family) *and the mother* (responsible for bringing up the children) in a patriarchal family structure [15, 17]. In family 2 the child's mother spoke much better German than did the child's father. However, in the absence of a professional interpreter other patients in the ward or acquaintances who had accompanied the couple were asked to translate for the father. It appears that the child's mother lacked the authority to implement the dietary regulations. In family 3, initially most conversations were conducted only with the father and even the diet plans were elaborated with him while the mother, unable to speak German, did not attend the outpatient control appointments. Only with their third PKU child the roles had changed and the mother attended most control examinations without her husband.

All three families demonstrate the ineffectuality of our current care structures. Compliance and adherence mean that a specific type of behaviour (which has been discussed during the therapy) is maintained [11]. The case reports presented here show that internal (e.g. education, ability to regulate actions) and external (e.g. socioeconomic status, lack of understanding of the family members) risk factors may hinder the success of treatment. The more the success of treatment depends on the patient and his/her family, the more the treatment team becomes a counselling team dependent on the patient's cooperative abilities. This tendency is reversed only at the point when the situation becomes dangerous for the child or for others. Failing to provide a medical measure needed by a child may be a form of child abuse. In this report, in particular in cases 5 and 6, the line of demarcation to child abuse is ambiguous. Generally, in the middle-class oriented cooperation model of the doctor and the client, the doctor's misjudgement of the family's ability to cooperate may impose unwarranted demands on the parents.

The excessive demands of medical caregivers during communication with immigrant patients also constitute an important factor in patient compliance and treatment outcome. As shown in the case of family 3, a learning process took place not only in the parents (who eventually accepted the purpose of the diet), but also among the medical care givers who finally found a way to communicate with the family and treat the third affected child.

It would be quite easy to locate German-speaking families with similar problems. However, in many instances immigrants have a higher risk profile than the native population [3–5, 14, 16–18]. Therefore, the problems in this risk group may well serve as a model to explain the causes and the processes by which a risk factor causes damage. The use of strategies to avoid or prevent these risk factors would benefit all patients.

Our concept of humanity in medicine includes certain major tasks in the communal setting [16–19]:

- Making the best possible medical care available;
- Prevention of health damage due to inappropriate behaviour or denial of help;
- The ability of the patient / the patient's family members to take care of the child's health concerns.

For transcultural paediatrics this means that the best possible medical care is not always achieved in the actual social setting [16–19]. Nevertheless,

- Culture-specific viewpoints must be investigated, considered and taken into account at all levels of medical action and thought ("*transcultural mainstreaming*").
- The limitations of our rigid institutional care structures must dissolve. Medical care must be able to implement the indicated measures in actual life.
- The borders of transcultural communication are reached when the physical or psychological integrity of a child is threatened. In conflict situations, intercultural communication would be desirable.

On the other hand, immigrants are also called upon to make active efforts to understand the medical issues relevant to their situation: A treatment contract between the receiver and the giver of medical (paediatric) services must achieve a balance between the demands of a medical speciality and the immigrants' necessities and options, between self-determination and legal incapacitation. This process may be difficult for the doctor (who is trained neither in ethnology nor in social work) in times of limited financial resources. Even if language barriers are overcome with the assistance of professional translators and interpreters, psychological and cultural communication barriers will persist. The use of a competent guide and home care could lead to better management and improve the focus on the client's individual needs. However, this is not a standard procedure. The failures experienced by the care team have caused the team to become subjectively involved in the matter, thus creating an obvious bias and exercising a negative influence on the patient's behaviour.

The following conclusions may be drawn from this report:

- Migrants have a high risk profile in highly developed health care systems.
- Communication barriers represent a main risk factor which is tackled relatively easily by the use of professional translators in case of language barriers and of social workers with appropriate sociocultural and language competences.
- It would be meaningful to introduce treatment contracts that clearly establish the limits of the client's rights and duties as well as those of the care-givers.

Appendix

From the viewpoint of legislation, both the commitment to inform the client and the question of liability must be taken into account. According to the law concerning the *Duty to Inform*, the medical staff of a hospital is obliged to inform the patient in a way that the patient understands what they are saying (§ 17a of the Vienna Hospital Law, 1995). Legally the burden of proof for providing medical information rests with the hospital. In cases of non-German-speaking patients, the use of an interpreter/translator is mandatory. The legal basis for the regulation of any claims to damage in the event of inappropriate treatment due to communication errors on the part of the interpreter are contained in § 1299 of the Austrian Civil Code ABGB (§ 1299, Allgemeines Bürgerliches Gesetzbuch ABGB). In other words, a doctor who uses the services of a foreign-language nurse to communicate with a patient and is aware of the nurse's lack of training as a professional translator/interpreter, is liable for the consequences of inappropriate diagnoses or therapeutic decisions arising from poor communication.

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