

Sociocultural Context of Pain Management in Oncology and Palliative Nursing Care

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Abstract—Pain management is a question of quality of life and an indicator for nursing quality. Chronic pain which is predominant in oncology and palliative nursing situations is perceived today as a multifactorial, individual emotional experience with specific characteristics including the sociocultural dimension when dealing with migrant patients. This dimension of chronic pain is of major importance in professional nursing of migrant patients in hospices or palliative care units. Objectives of the study are: 1. To find out more about the sociocultural views on pain and nursing care, on customs and nursing practices connected with pain of both Turkish Muslim and German Christian women, 2. To improve individual and family oriented nursing practice with view to sociocultural needs of patients in severe pain in palliative care.

In a qualitative-explorative comparative study 4 groups of women, Turkish Muslims immigrants (4 from the first generation, 5 from the second generation) and German Christian women of two generations (5 of each age group) of the same age groups as the Turkish women and with similar educational backgrounds were interviewed (semi-structured ethnographic interviews using Spradley, 1979) on their perceptions and experiences of pain and nursing care within their families.

For both target groups the presentation will demonstrate the following results in detail: Utterance of pain as well as “private” and “public” pain vary within different societies and cultures. Permitted forms of pain utterance are learned in childhood and determine attitudes and expectations in adulthood. Language, especially when metaphors and symbols are used, plays a major role for misunderstandings. The sociocultural context of illness may include specific beliefs that are important to the patients and yet seem more than far-fetched from a biomedical perspective. Pain can be an influential factor in family relationships where respect or hierarchies do not allow the direct utterance of individual needs. Specific resources are often, although not exclusively, linked to religious convictions and are significantly helpful in reducing pain.

The discussion will evaluate the results of the study with view to the relevant literature and present nursing interventions and instruments beyond medication that are helpful when dealing with patients from various socio-cultural backgrounds in painful end-of-life situations.

Keywords—Pain management, migrants, sociocultural context, palliative care.

I. INTRODUCTION

THE following is a most essential statement for this essay: “Pain can have the character of a message which has to be read.” [1]. The management of chronic pain is a central and crucial task in oncology and palliative nursing care which requires specific competences and a great deal of knowledge especially when dealing with migrant patients if high quality

care is to be achieved in end of life situations. Characteristics of chronic pain are

- cognitive-emotional impairments (e.g. thoughts, feelings, moods)
- behavioral impairments (e.g. demonstrations of pain, movement reduction)
- physiological-organic impairments (e.g. loss of mobility)
- social impairments (e.g. isolation)
- a tendency of the pain spreading all over the body
- permanent pain without pain-free intervals
- and sometimes: a considerable number of unsuccessful attempts of pain management [2]

With migrant patients, these factors have to be complemented by the most important sociocultural dimension. It comprises the following five aspects described in Section IV:

- a. sociocultural meaning of pain
- b. utterance of pain
- c. language
- d. sociocultural context of illness
- e. pain as an influential factor in family relationships

If this dimension is disregarded pain relief measures may fail.

II. RESEARCH SITUATION

Internationally there has been little research on the specific situation of migrant patients with chronic pain [3]-[10] and even less systematic research especially for palliative care.

The importance of such research is highlighted by the following finding of various studies: self-evaluation of pain suffered by migrant patients varies greatly from evaluation of others [11], [3]. Often doctors and nurses regard the pain as less intense than it is actually felt by the patients themselves. It seems that the level of education on the side of the patients as well as culture-bound views of the professionals play an important part in pain assessment. Without knowledge in anatomy and physiology, pain descriptions often remain unclear and patients of higher education are often ascribed a more adequate form of pain utterance than patients of lower education. At the same time some cultures are regarded as oversensitive [11].

“Adequate” here means that feelings of pain and utterances of pain are of the same emotional quality so that professionals can draw conclusions from the pain utterance as to the pain intensity.

St. Hill et al. [11] compared the pain utterance of women from different ethnic groups in the US. Their results can be divided into 3 sub-groups:

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1. ethnic groups who accept pain stoically and who complain *little to too little* (e.g. Vietnamese, Korea, Afro-American, Japanese or Chinese women, women from the West Indian Islands, from Ethiopia),
2. ethnic groups who are *expressive to very expressive* of pain (e.g. Russian, Puerto-Rican or Egyptian women).
3. the third group comprises women from ethnic groups who, depending on the situation, may be *either very expressive or very stoic* (e.g. women from Haiti, Mexico or Arab countries).

This kind of statement can be found in a number of studies [10], [12]-[15]. But in contrast to this, there are other findings according to which the variable ethnicity is of little to no meaning [8]. The explanation given is that ethnic differences may be reduced if the sample shows similar variables such as education, duration of pain, and professional status [8]. However: what exactly is *little/too little* and what is *expressive/very expressive*? Without communicating this explicitly, researchers and/or the professionals take their own culture of expressing pain as the norm when ascribing „*very expressive*“ or „*stoic*“ to patients' expressions of pain. This leads to the critical question whether there can be a norm at all. For now this problem can only be touched upon. Pain utterances termed as „*very expressive*“ as well as those seen as „*stoic*“ lead to a deficit in pain management. Insufficient therapy of chronic pain, however, especially in the end-of -life phase often requires the total attention of a patient with destructive effects on his/her wellbeing. It can lead into a vicious circle where pain, fear and depression enhance each other [1].

Helman [16] proposes the very helpful differentiation between „private“ and „public pain“ which means that the subjective pain (the „private“ one) will become „public“ only through pain utterance, i.e. a signal to others. If and when private pain may become public depends on various sociocultural factors which, however, to date have not been examined systematically. The decision to make private pain public, on the other hand, depends on the meaning of pain to the patient and on the consequences expected. Feelings of pain and utterance of pain are primarily psychological phenomena which are not directly connected to the intensity of the pain impulse [1].

III. METHODOLOGY

In a qualitative-explorative comparative study 4 groups of women, Turkish Muslim immigrants (4 from the first generation, 5 from the second generation) and German Christian women of two generations (5 of each age group) of the same age groups as the Turkish women and with similar educational backgrounds were interviewed (semi structured ethnographic interviews [17]) on their perceptions and experiences of pain and nursing care within their families. Informed consent was obtained before each interview. Interviews were conducted in Turkish (with the help of an interpreter) and in German. They were audiotaped and transcribed verbatim. Each informant had the right to refuse or withdraw at any time. The result was a "thick description" [18].

IV. RESULTS

A. Sociocultural Meaning of Pain

There are no recipes of how a migrant patient in severe pain should be treated. For individual pain management, however, knowledge about the sociocultural meaning of pain is of great importance. It acquaints the nurse with the most differing perspectives on pain which then can be compared to the patient's individual situation.

Prerequisite for adequate dealings with different views on pain is, first of all to consider one's own understanding of pain (What does pain mean in personal terms? Which pain experience is a judgement based upon? Is there pain that should simply be tolerated – without any therapy? Which attitude is held towards terms such as “Morbus Bosporus” or, Mediterranean syndrome?) Another prerequisite is being open for foreign values and norms.

B. Utterance of Pain

Permitted forms of pain utterance are learned in childhood and determine attitudes and expectations in adulthood [16]. In principal, the threshold of pain, the point at which an impulse triggers feelings of pain, is universal while pain tolerance and, therefore also pain utterance depend on one's sociocultural background [19].

St. Hill et al. [11] found the following sociocultural valuations for pain:

In the negative: pain utterances were regarded as signs of weakness, impatience, molestation, weakness of character, disruption of social harmony, deficiency in coping with life as it is, earthly suffering before returning to god after death or even something that will annoy the professionals. So, there are many reasons for not showing pain or for showing it very late only and for playing pain down which we mainly found in our Turkish interviewees.

In the positive: pain utterances lead to care from the family and from professionals to valuing life's positive aspects such as goodness and joy or pain is seen as caused by god and therefore valuable.

The more the pain presentation corresponds to the expectations of the environment of how pain is communicated adequately the bigger is the attention the patient receives [16].

C. Language

Language, especially when metaphors and symbols are used, plays a major role in misunderstandings.

Turkish women of the first generation or immigrants may speak of snails that wander through their body or of itchy ants which move inside them or of dwarfs who hurt the body from inside. – In Turkish there is the term “mürüvvet”, which means “joy”. One type of joy for old parents is to share the life of their children and grandchildren and to see that their marriages are happy. If “mürüvvet” fails, pain may be the result. In a particular case the daughter wanted to divorce her husband and her old father reacted with complaining about pain [4]. Therefore, in the pain assessment, patients should be asked open questions to allow them to present their pain in pictures, to report on their family situation or to talk about

their state using proverbs, myths or fairytales [4], [20].

Professional interpreters may be needed to cope with language barriers. Using family members may overtax them and cause shame or role conflicts [9]. Moreover, lay interpreters may easily make linguistic mistakes.

D. The Sociocultural Context of Illness

While Germans self-evidently believe in germs, inheritance, environmental factors or damaging behavior as causing illness, other cultures and also our Turkish sample regard magic, curses or punishment as reasons for illness. Here illness is seen as the consequence of breaking a taboo or rule. This is punished by god with pain, illness or death. Illness, especially a final one, symbolizes a crises and threat both for the patient and his family. The taboo system offers an order and explanation for the diffuse fear of being totally helpless and out of control [21]. To relieve the pain helpers are needed who can annul the breaking of the taboo by using magic-religious devices, dealing with demons and the "evil eye" etc. Therefore, migrant patients often contact leaders of their own religion, use amulets and sacrifices in various forms. Magic items in their bed or on the body should, therefore, be tolerated and their meaning understood and respected [22].

E. Pain as an Influential Factor in Family Relationships

Close family relationships are typical of many migrant families. Often the family is the only safe resource and the patient is part of a network which is collective in character (Turkish families) and not individually oriented (like German families). Depending on the individual or social character of a family's orientation, patients may communicate difficult wishes via pain. In other words, pain may signal family problems. Glier & Erim [4] for example describe a Turkish father on his deathbed who was in pain because his daughter wanted to divorce her husband. – Patients may be very strict in, thus showing a regressive and appellative attitude [5]. Also if a patient is left alone in the palliative situation, fear, depression, sadness or despair may raise his/her pain level very considerably.

V. DISCUSSION

A. Nursing Interventions

The most important nursing interventions are broad assessments including migration experiences, social status, family situation, and rules such as who makes decisions in a family.

Broad pain assessment should include enhancing and relieving factors. This applies also to patients who do not mention pain as pain utterance may not be the norm to them. In principal, the following should be observed:

Pain in all patients must be recognized in any circumstances as a subjective experience to be respected [8]

Patients need to be observed well and continuously, pain assessments should be carried out and documented at individual intervals

Pain rating scales should be used (numerical, visual, and faces pain rating scales). The Wong-Baker faces pain rating

scale for example is available in several languages [23].

Stuppy [24] developed an 8-step faces pain rating scale which was tested with adults between 55-87 years and showed high rater validity with the Verbal Rating Scale, and the Visual Analogous Scale. Faces pain rating scales have been proven to overcome language and educational barriers [25].

- (Non-)verbal observational aspects:
 - o Phonetic aspects (unclear utterances, moaning, loud breathing)
 - o Mimic aspects (clenching one's teeth, screwing up one's eyes, nervous twitches)
 - o Behavioral aspects (swinging, unusual posture, strain, reduced mobility, insomnia, lack of appetite, irritability, social withdrawal),
 - o Physical aspects (heightened muscle tension, moderated breathing, hyperemization of body parts, vomiting, sweating, trembling) [25]
- The documentation should also contain psychosocial and spiritual aspects as well as side-effects of pain medication.
- Preventive medicine should be given, e.g. before dressing a wound or rearranging patient's position etc.
- Supplementary therapies should be offered: e.g. TENS (Gate Control Theory), pain-defocusing for example through distraction, positive self-instruction (simple clear sentences), relaxation technics (Progressive Muscle Relaxation by Jacobson).
- Patients should be counselled and educated to prevent false assumptions about pain and to promote adequate coping strategies (e.g. learning movements for pain reduction) [25].
- Counselling should be offered also for non-medical problems.
- Medicine alone is not enough as it does not cater for the psychological needs of the patients.

Education can reduce fears and, thus, pain; consolations and affection have an analgesic effect. The patient needs human support at the end of his life most as well as security and warmth i.e. emotional dedication by the professional helpers [1].

B. Finding and Using Resources

Individual and sociocultural resources are important for a change of attitude towards one's pain, when necessary. Resources comprise strengthening the belief of self-efficacy [5]. Beliefs of exclusively external forms of control reduce the patient's options to actively act against the pain. He/she needs to be shown how more controllability can be achieved. As beliefs are not easily changed this process takes patience. Art therapy may enable the patient to paint pain pictures. These can bring together temporally distant traumatic experiences on an aesthetic level and thus may point out traumatological interrelations which can then be worked with.

Coping strategies are often based on religious beliefs, making them a good starting point for conversations [8]. Whatever the patient regards as helpful should be used. For example, dreams and imaginations of pilgrimages may reduce pain.

Blechner [16] suggests avoiding thinking of the pain and instead concentrating on something beautiful and working on the patient's inner guiding sentences by rewording them, e.g.: "I am thinking of the many lovely years with my children".

C. Relationship between Patients and Professionals

Aulbert [1] rightly points out that caring for dying patients means a confrontation with science's limits. This may be interpreted as personal failure by doctors and nurses, especially in the palliative care of migrant patients because of language and sociocultural barriers which in turn lead to uncertainty and fear on the part of the patient. It may help to be conscious of this aspect and to work on one's own professionalism through team sessions and further education.

It would be most desirable if migrant patients were to receive the best possible support when in pain at the end of their lives.

REFERENCES

- [1] E. Aulbert, „Psychische Grundlagen von Schmerzempfinden, Schmerzäußerung und Schmerztherapie,“ in *Lehrbuch der Palliativmedizin*, 3rd ed., E. Aulbert, F. Nauck, and L. Radbruch, Eds., Stuttgart: Schattauer, 2007, pp. 246-254.
- [2] B. Kröner-Herwig, „Chronischer Schmerz – eine Gegenstandsbestimmung,“ in *Psychologische Schmerztherapie*, 5th ed., H. D. Basler, C. Franz, B. Kröner-Herwig, and H. P. Rehfisch, and H. Seemann, Eds. Berlin: Springer, 1999, pp. 3-16.
- [3] C. R. Green, R. C. Tait and R. M. Gallagher, "The unequal burden of pain: confronting racial and ethnic disparities in pain," in *Pain Medicine*, vol. 4 no. 3, pp. 277-294, 2003.
- [4] B. Glier, Y. Erim, „Schmerz bei Migranten aus der Türkei,“ in *Schmerzpsychotherapie*, 7th ed., B. Kröner-Herwig, J. Frettlöh, R. Klinger, and P. Nilges, Eds. Berlin: Springer, 2011, pp. 244-258.
- [5] J. I. Kizilhan, „Interkulturelle Aspekte bei der Behandlung somatoformer Störungen,“ *Psychotherapeut*, vol. 4, pp. 281-288, 2009.
- [6] M. Sleptsova, B. Wössmer, and W. Langewitz, „Migranten empfinden Schmerzen anders,“ in *Schweiz Med Forum*, vol. 9, no. 7, pp. 319-321, 2009.
- [7] R. R. Edwards, M. Moric, B. Husfeldt, A. Buvanendran, and O. Ivankovich, "Ethnic Similarities and Differences in the Chronic Pain Experience: A Comparison of African American, Hispanic, and White Patients," in *Pain Medicine*, vol. 6, no. 1, pp. 88-98, 2005.
- [8] M. Verwey, „Schmerzpatientinnen und -patienten mit Migrationshintergrund aus der Perspektive von medizinischen und paramedizinischen Fachkräften,“ in *Curare*, vol. 27, no. 3, pp. 225-238, 2004.
- [9] A. Kilcher and R. Spiess, „Die hausärztliche Betreuung von Migranten/-innen mit chronischen Schmerzen,“ in *Schweizerische Ärztezeitung*, vol. 84, no. 10, pp. 452-460, 2003.
- [10] T. R. Allison D.P.M. Symmons, T. Brammah, P. Haynes, A. Rogers, M., and I. Roxby, "Musculoskeletal pain is more generalised among people from ethnic minorities than among white people in Greater Manchester," in *Ann Rheum Dis*, vol. 61, pp. 151-156, 2002.
- [11] P. St.Hill, J. Lipson, and A. I. Meleis (Eds.), *Caring for women cross culturally*. Philadelphia: Davis Comp, 2003.
- [12] C. L. Edwards, R. Fillingim, and F. Keefe, "Race, ethnicity and pain," in *Pain*, vol. 94, pp. 133-137, 2001.
- [13] C. Campbell, R. Fillingim, and R. R. Edwards, "Ethnic differences in responses to multiple experimental pain stimuli," in *Pain*, vol. 113, pp. 20-26, 2005.
- [14] A. Cano, A. Mayo and M. Ventimiglia, "Coping, pain severity, interference. And disability: the potential mediating and moderating roles of race and education," in *The Journal of Pain*, vol. 7, Jul, pp. 459-468, 2006.
- [15] I. Kavuk, C. Weimar, B.T. Kim, G. Gueneyli, and M. Araz, "One-year prevalence and socio-cultural aspects of chronic headache in Turkish immigrants and German natives," in *Cephalalgia*, vol. 26, pp. 1177-1181, 2006.
- [16] C. G. Helman, *Culture, Health and Illness*, 5th ed., London: Hodder, 2007.
- [17] J. Spradley, *The ethnographic interview*. Fort Worth: Harcourt Brace Jovanovich, 1979.
- [18] C. Geertz, *The Interpretation of Cultures*. Selected Essays, New York: Basic Books, Inc., Publishers, p. 70, 1973.
- [19] C. Hüper and R. Kerkow-Weil, „Schmerz im Migrationskontext,“ in *Transkulturelle Kompetenz* 2nd ed., Domenig D., Bern: Huber, 2007, pp. 541-558.
- [20] G. Blechner, „Kultursensible Schmerztherapie,“ in *Dr. med. Mabuse*, vol. 135 (Jan/Feb.), pp. 56-59, 2002.
- [21] U. Kaiser, „Sedna, die Meeresgöttin der Inuit - von Tabuverletzung und der Reise des Schamanen,“ in *Krank warum?* 2nd ed., F. B. Keller Ostfildern, Ed. 1996, pp. 286-290.
- [22] A. Zielke-Nadkarni, *Individualpflege als Herausforderung in multikulturellen Pflegesituationen*. Bern: Huber, 2003.
- [23] D. L. Wong, M. Hockenberry-Eaton, D. Wilson, M. L. Winkelstein, and P. Schwartz, *Wong's essentials of pediatric nursing*. 6th ed., St. Louis: Mosby, 2001, p. 1301 (<http://www.nacmedicalcenter.com/en-US/aboutUs/hospitalNews/newsAndArticles/Documents/9c590a7e6d584a05a45cb51c2f042e3eFaces1.jpg>) (10.5.2015)
- [24] D. Stuppy, "Research briefs. The Faces Pain Scale: reliability and validity with mature adults," in *Applied Nursing Research*, vol. 11, May, no. 2, pp. 84-89, 1998.
- [25] DNQP (Deutsches Netzwerk für Qualitätsentwicklung in der Pflege) (Ed.), *Expertenstandard Schmerzmanagement in der Pflege. Schriftenreihe des DNQP*. Hochschule Osnabrück: Osnabrück, 2005.