Theory in Action – A regular opportunity to explore core concepts of our discipline using actual patient interviews and interactions as triggers for discussion. Presented by Dr Anne Wright and Professor Bruce Sparks from the Department of Family Medicine, University of the Witwatersrand.

No 2. "Die bloed slaan kop toe": patients' and doctors' explanatory models...

The patient's story ...

A few years ago I spent some time at a psychiatric hospital doing research into the way patients and their families understood the illness which had resulted in hospitalisation. Patients and family members, all residents of the "coloured areas" of Johannesburg, were interviewed both during admission and for a year post discharge. Jenny was an unmarried 23 year old woman employed as a clerk at a photocopying company. This was her second admission. She and her boyfriend had been together for 6 years and they had a 4 year old daughter. She and her boyfriend didn't stay together but each lived with their own family. Jenny had left school as a consequence of the pregnancy. Within days of the birth of her baby, Jenny had her first psychiatric admission.. Shortly before the current admission, Jenny's mother had taken her 4 year old granddaughter on a holiday to Cape Town. Jenny was taken to the psychiatric hospital by family members and her boyfriend who complained that she was very restless, insomniac, screamed at night and refused food. She was hospitalised for 3 weeks and on discharge given the diagnosis of "query" schizophrenia. When asked by the doctor shortly before discharge why she thought she had come into the hospital she said her admission was due to a number of stresses: separation from her child; relationship problems with her boyfriend; stress at work and an impending cataract operation. She said: "they (her family) thought I had a nervous breakdown... I was worried about my job. My child has gone to Cape Town with my mother. I was crying over the child. I think that was the points (sic) why they brought me here because I wasn't sleeping". When I interviewed Jenny's parents and her sister at their home they also felt that various stresses, both current and past, lay at the root of Jenny's illness: her alcoholic father and the many years of verbal and physical abuse at his hands; her own demanding, "gruwelike" personality; her pregnancy and having to leave school; and also the more current stresses associated with her boyfriend, work and the impending cataract operation. Her sister concluded: "Sy dink te veel" and her mother similarly noted: "It's her nerves". Her father also alluded to the birth but seemed to imply there had been a medical problem: "she was only like this after the birth of her child.... so that is what I want to know, what do the doctors reckon is the cause of it.."

In interviews with me during her hospitalisation, Jenny elaborated on the various stresses she was experiencing in her life and seemed to feel that all these worries had led to her breakdown. As she recovered she began to gain perspective on the problem areas: she realised her baby would return soon; her boss had phoned to say her job was waiting for her; a new understanding was being reached with her boyfriend and a date was set for the cataract operation. It all seemed very understandable. However in a short talk with me just before her discharge she mentioned that she had been "bleeding" for a few weeks. She was very happy about this, interpreted it as a "good thing" and seemed not convinced when I suggested that she speak to the doctor about it. I didn't pursue this at the time but when I interviewed her at home a few weeks later she said that the treatment at the hospital had helped her because *"the problem was that the blood dried up in my head"*. She said they gave her an injection and then *"it all came out"*. I asked her what she thought had made her better and she said: *"the blood"*. I asked her to explain this and she said that when she was on the "the tablets" (contraceptive pill), she used to bleed for one week but now that she receives the injection she bleeds for three weeks and she think this "is a good sign". (She had been given Depo Provera on admission). She also felt that the hospital medication had helped her because it had made her sleep and had stopped unpleasant dreams. At the time Jenny was not able to explain more about the significance of her "bleeding" and I didn't return to the subject in subsequent interviews. However on reading the transcripts much later, I noted that her sister, in describing the first admission, recalled that when her father had asked to see the newborn baby, Jenny had refused saying: "*Nee daddy, ander vrou het met vuilgoed hier gekom en al die vuilgoed what nou onder uitkom is nou uit*" ("No, daddy, another woman with dirtiness (dirty

things) came here and all the dirtiness that comes out underneath is now out"). Her sister commented:"then we knew that Jenny was getting sick".....and she was admitted to hospital very shortly after this.

At the time I didn't understand the references to "blood" and "vuilgoed". However in conversation with other women during the research the significance became apparent. It was clear that there existed strongly held community beliefs about the relationship between menstruation, the head, bewitchment, pollution, mental illness, contraception and pregnancy.[1] For example, Margaret, a 32 year old woman having her third post partum admission believed - with her family - that the explanation of her illness lay in bewitchment. In an interview with me at her home, the patient stated that a sign of her bewitchment at the age of 17 years was the absence of her periods and the blood "going to her head" at the time of her first psychiatric admission: *"Toe is die bloed kop toe, toe is ek amper dood. Toe het die dokter daar 'n injection vir my gegee dat die bloed uitkom. Daarvoor het ek gelewe"*. ("Then the blood went to the head, then I was almost dead. Then the doctor there gave me an injection so that the blood came out. That is why I lived..") Similarly, the mother of a 36 year old woman, now having her 4th psychiatric admission, explained that the "root" cause of her daughter's illness occurred after the birth of her first child when she was *"given an injection and the blood was blocked .. toe loop die bloed kop toe"*. She noted that after the birth of her own children she was not given "the injection" *"en so kom daai vuil bloed uit"*. And the mother of another patient said: *"Daars niks verkeerd met haar. Dis net dat sy nie haar periods kry nie en dit slaan kop toe... die bloed gaan na die kop en dit maak haar 'n bietjie mallerig..."* ("There's nothing wrong with her. It's just that she doesn't get her periods and that goes to the head.. the blood goes to the head and makes her a little mad"). The words "vuil" and "vuilmense" were commonly used to refer to bewitchment.

It should be noted that during the hospital consultations there was no reference at all by the patients to blood, childbirth, witchcraft. The psychiatric diagnoses were postpartum psychosis and schizophrenia. The doctor attending these patients said he had never heard the expression "die bloed slaan kop toe" or similar ideas.

So what is the significance of all this for the family practitioner?

The Discussion ...

Jenny's story contains many points of significance for family doctors, for example, life events and mental illness; cultural beliefs; family and illness; hospital vs community based care and so on but the aspect I would like to focus on is that of explanation and the notion of explanatory models. One notes that Jenny's story (admittedly abridged) contains several explanations for her "illness" and included in the explanations are ideas about cause, symptoms, and treatment, for example:

- a "nervous breakdown" manifesting in sleeplessness, restlessness, and screaming and resulting from too much "thinking" about current stressful situation. The family (and Jenny) proposed that she calm down, sort out her affairs, take a nerve tonic and also medication for sleeping.
- beliefs concerning menstruation, birth and bewitchment manifested in amenorrhea, and strange behaviour, the treatment being menorraghia brought about by a Depo Provera injection.
- possibly a medical problem associated with birth since that event marked the start of her illness.
- psychosis, maybe schizophrenia, a diagnosis based on current symptoms, history and response to medication with the treatment being continuing medication and attention to life event issues.

It is all too easy to dismiss these disjointed, fragmentary and often bizarre sounding explanations (except the doctor's!) as misguided, false, or superstitious ideas -" it's just cultural!" - in any event not to be taken seriously and definitely not worth wasting time pursuing. A different perspective is to understand them as attempts to give meaning to an episode of illness and to view them as part of the illness narrative which was discussed in the previous issue[2]. Kleinman's[3] concept of "explanatory models" provides a useful framework for exploring these meaning-making attempts by both patients and their families and also their practitioners. Explanatory models are held by both lay people and health care professionals and are defined as: "the notions about an episode of sickness and its treatment that are employed by all those engaged in the clinical process ... they guide choices among available therapies and therapists and cast personal and social meaning on the experience of sickness". In other words for every episode of illness, not only will the doctor (or other healer) have some kind of explanation for the problem but so will the patient and others involved in the illness episode. These explanations attempt to address five major issues for *each episode:*[1]

(a) etiology

(b) time and mode of onset of symptoms

(c) pathophysiology

(d) course of sickness

(e) treatment

The explanatory models of doctors will usually include reference, however tentative and unvoiced, to all five issues, while the explanatory models of patients and families will only refer to those issues which have salience for them at the time. Thus while Jenny's doctor had some hypotheses or even just hunches about the cause, onset, course and management of the illness, Jenny and her family only focused on those aspects which particularly concerned them. For Jenny it was the healing "good" bleeding , for her family it was getting her "nerves" right.

Other aspects of lay explanatory models are also evident from Jenny's story. Firstly, while lay explanations draw upon general health beliefs and cultural concepts, the explanation is unique to the patient /family member and the particular episode of illness. For example, while all the ideas contained in lay explanations of Jenny's illness were well known and commonly used in the community to explain mental illness - "nerves", "vuilgoed", "blood going to the head", "dink te veel" and so on - only fragments of these ideas were used in the explanation of this particular episode. Thus while other women clearly made the link between "die bloed slaan kop toe" and bewitchment, for Jenny bewitchment was not an essential part of her story and remained on the fringes of her thinking. Ideas are borrowed and tailored to fit specific circumstances and problem areas.

Secondly, and following from this, lay explanatory models unlike the scientific thinking underlying practitioner models, are often rudimentary, lacking in coherence, poorly articulated, contradictory in parts, with many gaps and omissions. Thus, for example, Jenny couldn't give me (or wasn't prepared to disclose to me) a fully worked out explanation of how the "blood had dried up in her head" or the exact details of how the dried blood problem related to her strange behaviour before admission.

Thirdly, while practitioners may often not share their explanatory model with the patient - "the patient won't understand", "it's not necessary", "there's no time" - patients are also often very reluctant to volunteer their explanations to practitioners "or when they do, repeat them as short, single-phrase explanations because they are embarrassed about revealing their beliefs ... they fear being ridiculed, criticised or intimidated because their beliefs appear nonsensical from the professional medical view point"[4]. For example, Jenny's doctor gave her no information at all about his understanding of her illness. In order to assess her mental status and "readiness for discharge", he inadvertently elicited part of her explanatory model (about her worries) but didn't pursue it further other than noting that "she's getting insight". As with all the families, fuller explanations involving bewitchment, family relations, preferred "medicines" and a whole host of "cultural beliefs" were only elicited within the patient's home in a relaxed conversation.

But Jenny got better anyway, so why worry about explanatory models? Can they have any value beyond being interesting examples of quaint folklore and populist myth? And if significant, how can these explanations be elicited?

There can be no doubt that the sharing and understanding - to whatever degree - of both the practitioner and patient's explanatory models in the consultation is crucial to the mutual insight and ultimate outcome of the interaction. McWhinney[5], in his discussion of Kleinman's work notes: "It is difficult for physicians to accept that their construction of clinical reality, based on pathology, is only one of many possible constructions. If the patient's construction is different, and no attempt is made to reconcile the difference, the probable outcome will often be a breakdown of communication and a failure of treatment". Yes, Jenny, Margaret and the other women "got better" - the medication rendered them apsychotic within a relatively short time and they could continue with their lives. But they left the hospital with a handful of "sleeping pills" and very little else! Their perceptions, fears, and explanations had fallen on deaf ears. After all, what wisdom can be gleaned from psychotics!!

But if patient's explanatory models are even allowed to surface in the consultation, let alone be discussed, how can this be done? Kleinman[4] has suggested questions which correspond to the five main issues referred to in explanatory models and which could be used (in whole or part and appropriate to the patient) to facilitate discussion:

(a) What do you call your problem/ what name does it have?

(b) What do you think has caused your problem?

(c) Why do you think it started when it did?

(d) What does your sickness do to you? How does it work?

(e) How severe is it? Will it have a short or long course?

(f) What do you fear most about your sickness?

(g) What are the chief problems your sickness has caused for you?

(h) What kind of treatment do you think you should receive? What are the most important results you hope to receive from the treatment?

But direct questions such as those above are often very daunting to the patient and unanswerable for someone who has never thought of his illness experience in such an ordered, rational way. As McWhinney suggests it might be better to keep the questions to oneself and instead use the skill of the trained family practitioner: "much of the information we seek will only come by attentive listening and responsiveness to the subtle cues by which patients convey their meaning".

To be effective, and responsive practitioners we should:

- be alert to, and aware of explanatory models in all consultations and interactions with our patients and their families;
- have a commitment to elicit them when appropriate;
- be cautious about simply dismissing "strange" ideas as simply "cultural nonsense" or ignorance requiring us to "educate our patients";
- be sensitive (and responsive) to cues alluding to explanatory references;
- be prepared to share our own model in a less than a "top down let-me-educate-you way";
- attempt to understand the context of our patients, knowing their "language", metaphors, customs and beliefs, and realise the immense power that their explanations can play in the pathogenesis and natural history of their problems.

The Library ...

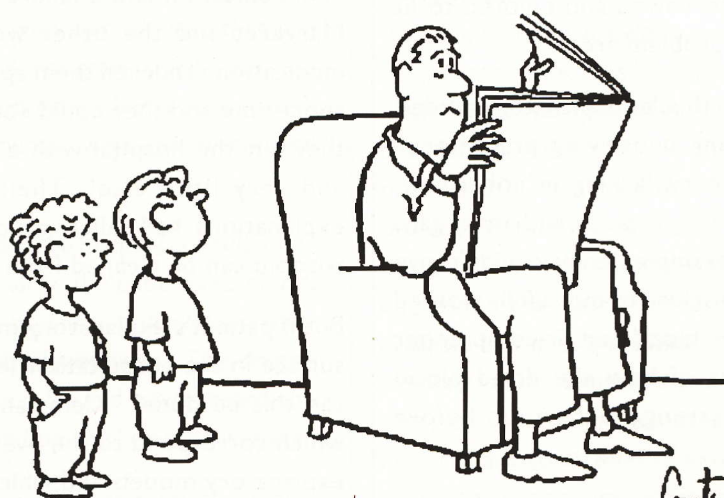
1 These beliefs are well documented in the literature cf. Snow LF, Johnson SM and Mayhew HE. The behavioural implications of some Old Wives Tales. Obstet Gynecol. 1978; 51: 727 - 32; Ngubane H. Body and mind in Zulu medicine. London: Academic Press; 1977 and Helman CG. Culture, health and illness. Oxford, Butterworth-Heineman; 1990: 32 - 36.

2 Sparks B and Wright A. TIAs for Family Doctors. No 1. Exploring the Patient's Narrative. SA Family Practice October 1999.

3 Kleinman A. Patients and healers in the context of culture. California, University of California Press; 1980: 104 - 110

4 Kleinman A (ibid): page 106

5 McWhinney IR. A textbook of Family Medicine. Oxford, Oxford University Press; 1997: 111 - 113



"Don't get too close to my dad.... his cholestrol is 280"