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New gateways to dialogue in general practice

Development of an illness diary to expand communication

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Objective – To present the development of a clinical communicative method based on illness diaries.
Design – Action research with qualitative evaluation of experiences leading to the clinical method.
Setting – The practice of one of the authors.
Patients – 16 patients with long-standing illness without clinical findings.
Main outcome measures – Description of the illness diary method grounded in patients' and doctor's experiences.
Results – The illness diary method includes the following approach: The patient presents his symptoms and the doctor may suggest the use of an illness diary. Together, they shape the format of the diary and identify items to be included. The patient uses the diary for home notes between consultations. The notes constitute the frame for a fresh dialogue about the complaints in the next consultation. The method has gradually been elaborated according to utilization experiences on an interactional level, leading to a more specific presentation of the method and how it can be used.
Conclusion – An illness diary and the subsequent doctor-patient interaction can be a feasible tool to expand the gateways to dialogue in general practice.

Key words: general practice, psychosomatic, clinical method, patient-centred method, qualitative evaluation, diary.

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Patients with long-standing illness without clinical findings challenge doctors because their complaints cannot be fully understood or categorized by medical concepts alone (1–3). These patients run the risk of being labelled "difficult". The ideas presented here originated from the unpleasant feeling one of the authors (PS) sometimes shared with patients, believing that the traditional frame of medical communication was hampering joint understanding. While the doctor felt he was a passive receiver of repetitive somatic complaints, the patient was striving to convey a message that he felt was not being properly heard. Some authors recommend the use of written material from the patient as a means to grasp the thoughts, feelings, and ideas following the symptoms (4). We have explored the use of illness diaries as a clinical method intended for this purpose in general practice. This was done in an action research approach where emphasis was put on both the development process and the resulting clinical communication method (5).

The objective of the article was to present the illness diary method as the endpoint of systematic elaboration, and to show how the implementation of the method has modified its characteristics. The description will emphasize matters related to method utilization. Outcomes and usefulness of the method will be presented separately.

METHOD AND MATERIAL

Development of the clinical communicative method is based on principles of qualitative evaluation (5), implying that preconceptions and perspectives of the researchers should be accounted for. We shall therefore briefly share some of the presuppositions of the study.

Context and theoretical frame of reference

The project was based on research in the practice of the main author, who had worked in a small village for 14 years. In this setting, the doctor has comprehensive information about the extended family even when the patient is new to him – often resulting in high contextual communication (6) leading to mutual trust as well as potential misunderstandings.

In the study of high contextual communication in general practice (6), an approach based on *systems theory* makes sense, because it stresses multifactorial explanations and the relevance of illness context (7). In our project the systemic perspective has been supplemented with perspectives from cognitive science about how ideas on subjective matters are formed and shared with others (8,9). Vygotsky (9) described how people create meaning from their experiences by exploring them through their own verbal language. Thought and language processes are seen as internal and external dia-

Table I. The steps of the illness diary method.

I. GENERAL FRAME OF FIRST SESSION
* Establish contact
* The patient is well known: Introduce a new communication tool
* The patient is new: Assessment of patient and complaint
  - Current complaint, illness narrative, result of previous examinations
  - Previous somatic and mental health
  - Patient's ideas and emotions related to present complaint
  - Patient's (and significant other's) management of the problem
  - Physical examination
* Introduction of illness diary
  - Shape format of notes which the patient finds useful
  - The dialogue identifies items to make notes on

II. PATIENT PREPARES NOTES AT HOME
Next session in 3–4 weeks

III. GENERAL FRAME OF LATER SESSIONS
* Establish contact
* Review of illness diary
  - Doctor reads patient notes with the patient present
  - Illness diary constitutes a verbal and contextual frame for dialogue about the complaints, elucidating ideas, emotions and impact on patient's life
  - The dialogue identifies new items to make notes on

IV. PATIENT PREPARES NOTES AT HOME

logues. Producing personal notes in writing may clarify internal dialogues.

The clinical method

First, we present the endpoint of the study – a brief description of the illness diary method. The intention of the method is to clarify the process of problem definition in the doctor-patient consultation in general practice, create a joint language, and recognize the clinical problem in its context. Here, we do not assess whether this intention has been accomplished, but take the intention as a frame of reference for development of the method.

The clinical method consists of the following steps (Table I): The patient presents his symptoms and the doctor may suggest the use of an illness diary. Doctor and patient shape the format of the diary and agree on how to make the notes – structured, or open on a blank sheet of paper. Patient and doctor identify items for note writing. The patient makes home notes between consultations and brings them for joint discussion at the next consultation. The doctor confirms the notes through reading them while the patient listens. The diary notes provide elements for fresh dialogue about the complaints. The procedure may be repeated, utilizing an illness diary in elaborated versions in succeeding consultations.

Table II. The patients – an overview.

Sex	Age	Complaint	Number of consultations with illness diary
F	47	Headache	3
M	40	Fatigue, chest pain, palpitations	8
M	55	Chest pain	1
M	12	Dyspnoea, asthma?	1
M	17	Headache	1
M	20	Dizzy, fatigue, loss of appetite	2
F	48	Headache	1
F	37	Tiredness, leg pain	2
M	36	Whiplash injury	3
F	46	Headache, neck and arm pain	1
F	24	Whiplash injury	2
F	27	Whiplash, loss of concentration	2
M	27	Headache, abdominal pain, tired	1
F	13	Abdominal pain	3
F	24	Headache	3
M	11	Urinary problem	2

The material

The clinical method was developed with 16 patients, aged 11 to 55 years (average 30), recruited from November 1993 to December 1994. They represented a purposeful sample (5) of eight males and eight females who had repeatedly presented their complaints to doctors, though clinical examination in general practice had been negative. Eleven of them had also been referred for repeated specialist investigations, and no relevant pathology had been found.

The symptoms had persisted for at least six months. The most frequent complaints were headache, dizziness, muscle aches and stomachache (Table II), but with no further definition in terms of diagnosis or illness groups. All of them had comprehensive medical records in the health centre. Five patients were previously known to the doctor, and in most other cases he knew the patients' families. The patients gave written consent to participate after receiving information about the project. Consultations with the illness diary took place within the usual average of 20 minutes per consultation.

The material consists of data from 36 consultations during which the method was applied. One patient had eight consecutive consultations with the illness diary, the median was two. Twenty-three consultations were audiotaped and transcribed (slightly modified verbatim) by the first author. The doctor's field notes from the other consultations, as well as all the patients' illness diaries, are included in the material.

Name: *NN*

Date	Headache strength	Duration	Nausea	Medication	Comments
15/7	Strong	1 1/2 day	No	1 suppository	Insecure. Irritable Negative thoughts
18/7	Ordinary	1/2 day	"	No	Angry. Managed without tablets
21/7	Strong	1 day	"	1 supp.	I'm giving up!
29/7	Strong left side	1/2 day	"	No	Too little sleep
9-10/8	Very Strong	3 days	One day	1 supp + 4 tabs	I'm depressed- John

Fig. 1. Illness diary from 47-year-old woman with headache, made for her second session.

EXPERIENCES AND RESULTS

From idea to method

The project started with a structured sheet meant to register symptom information along one axis and date/time along the other. The columns had no fixed headings, but were supposed to be labelled as the dialogue indicated items for further inquiry. The patient's own terms were used to describe such items and served as headings for the columns; initially, for example, the patient's expression for the symptom, its strength, localization, duration, accompanying complaints, and an open column for comments.

The patient returned after three to four weeks and the doctor read the notes, while the patient listened (Fig. 1). Notes varied a lot and might be elaborated or compressed, but because it was a personal contribution, the patient always seemed to put great emphasis on the doctor's response to reading them. The subsequent conversation often identified additional items for the diary (Table III). These might concern bodily changes or still unclarified somatic complaints. They also dealt with relational issues: who was present at the onset of symptoms, who was able to help, and what helped? Relational questions, which might have been provocative when presented alone, were more easily appreciated by the patients when integrated in a broader context.

The dialogues following from the diary notes demonstrated how perception of bodily symptoms may be accompanied by negative thoughts. Such accompanying ideas, expressed as repetitive, pessimistic "internal voices" could be elucidated through the illness diary. Patients were not used to thinking of days or periods when they were "normal" or not suffering. The illness diary was used to identify and characterize days when the symptoms were partly reduced.

In the course of the project, we found that the distinction between open (a blank sheet of paper) or structured format of the illness diary was important for some patients' participation. A flexible format, open for negotiation between doctor and patient, was necessary to make it suitable for the individual.

Table III. Frequent issues for illness diary.

* First session
The patient's words for the symptom, its strength, localization, duration, accompanying complaints, open column for comments

* Later sessions
The same as above, or supplemented by:
- From symptom to situation: Who was there, who could help, what helped?
- From symptom to accompanying internal dialogue: "Internal voices" attached to symptom perception
- From symptom to lack of symptom: Record periods when symptoms are less prominent

From technique to interactional frame

The initial project idea was to create a tool to clarify somatizing illness. This ambition changed during the project. From the original search for a device to help the doctor to know "what-to-do" in the consultation, more emphasis was put on the "how-to-do". This shift result-

ed from comments such as the following, made by a 47-year-old woman with headache:

P(atient): *Well, I was quite uncertain how to do this in the beginning. I had to ask, may I write like this, or like that,... are you going to understand? I hadn't done this before. After some time I found the best way for me to use an illness diary. And that was very important to me.*

D(octor): *It seems to be important to discuss the outline of the diary?*

P: *Yes, because when I had this sheet, it was supposed to be something that I should be able to use, not for me to complete for someone else... Feeling... this is my diary... if I had a form about me at that time, when I was so weary, I would have responded negatively.*

Inviting the patient to discuss *how* to talk about the problem was an extension of the ambition to let the patient's concepts and descriptions frame the medical dialogue. The mutual expectations of doctor and patients regarding somatic complaints commonly focus on examinations, laboratory results, and search for explanations. The move to a meta-dialogue on how to frame the dialogue in this project was encouraged by some of the (female) patients who had questions on how to expand the illness diary. A 37-year-old woman with weakness and pain in her legs said she literally needed more space to explain not only the symptoms, but how it felt to have them. Other patients have confirmed the need to discuss how to cooperate before they could enter such a patient-doctor cooperation.

Reported outcome

Most diary notes were scanty and compressed, but some female patients produced more elaborate reports. However, even brief notes enabled a new frame for conversation. This was the case for a woman of 27, who after shyly presenting her scanty notes, started to talk about the difficulties she had in describing her condition in various settings, which gave her the impression of never being really heard.

Adding an open opportunity for "comments" underscores the method's potential for patient reflection. This was stated by several patients, especially clearly by a 47-year-old woman:

The first time I was quite careful, I think, not to write too much. Then I concentrated on: hanging eyelid, headache, number of tablets, mostly such simple statements. But after a while I felt this column (points to "comments") as more important. Because then I could try to find an explanation by myself.

For the patient, writing an illness diary introduced a new anticipation of the next consultation. This was documented by comments on discussions with parents, spouses or children about the illness, as with the 17-year-old boy suffering from headache. By discussing the illness diary with his parents, he discovered his tendency (like his grandfather, according to his father) to tense himself whenever he was tired or exhausted.

The doctor also changed his attitude to the ensuing consultation. He positively anticipated being presented with material unknown to him, instead of going through another well-known session. Thus, the illness diary helped him to be more inquisitive, and reinforced a positive attitude to the conversation. This effect was most pronounced in the patients who made many repeat visits. A male patient of this type later expressed his improvement as a matter of being followed over time:

I think the most important thing was to know what the illness was. You know, you need time, time to believe that it is not such a threat. Time to experience relapses and improvement and to see that you can stand all of it.

For many patients the doctor seemed to learn about illness experience after taking part in a conversation based on the illness diary. A female patient regarded this as a crucial point; she stated that, by being listened to she was heard, given the opportunity to work with difficult subjects, and encouraged.

Limitations

One man and one woman felt that the method was not useful. In two middle-aged male patients, the doctor got the impression that they lacked the curiosity needed to search for more information, and the illness diary was not introduced. One woman was not included because the doctor felt he knew her so well that *he* lacked the curiosity for further collection of information.

DISCUSSION

Problem definition or treatment?

By giving the patients an opportunity to clarify their own beliefs, feelings and experiences, a method which might seem diagnostic may become a treatment (10). Most people seem to have supplementary narratives for their complaints (11,12). Through dialogue one may search for voices that offer alternatives and nuances. These voices, or embodied reflections, may thus be heard by means of the presented approach. Such doctor-patient relations call for patient empowerment in language and practice. The doctor may start an unproductive conversation if his premise for dialogue is a preset search for hidden meaning behind the symptom presentation.

Diaries in medicine

Most studies on diaries in medicine are prevalence studies of illness and disease, many of which focus on illness behaviour (13–15). Verbrugge (16) found that diaries differed from interviews in reducing memory errors, and in giving more comprehensive material on illness behaviour, unclear conditions, and chronic illness. Structured registrations have been recommended as part of cognitive approaches for functional somatic symptoms (4). Although there may be similarities between this and the present approach, the illness diary presented here does not require training in cognitive therapy. In systems-oriented psychiatric treatment, home notes are used to collect information, and as a means for intervention (17,18). This has been applied in paediatric practice for the management of unspecific abdominal pain in children (19).

Strengths and limitations of the study

The project design was action research in the GP's own practice. Sampling was done in order to include both patients with whom the method had beneficial and little observable effect, and atypical patients where the outcome was unexpected. Any effort by an engaged researcher to intervene may change the participants' behaviour (20). The present method has so far been tried by only one doctor (PS), and its potential for generalization needs to be explored.

For doctors who want to apply the method, it may be necessary to regard symptoms as part of everyday life and interaction with significant others. Some experience in reflecting upon one's relational distance to the patient may also be necessary. The method may induce a closer than professional relationship between doctor and patient, with the danger that some of them may feel "invaded" by the other. The doctor needs to know when to stop the diagnostic and specialist referrals, and to choose a different approach to the patient's problem.

Ethical aspects

Any communicative method may be regarded as manipulative by increasing the doctor's power. The history of systemic therapy underlines the need for cautious use of strategic communicative tools (18). The clinical method presented here is intended to empower patients to provide direction of the communication, which might counteract some of the manipulative potentials.

IMPLICATIONS FOR PRACTICE

The illness diary has an initial focus on symptoms. By putting symptoms in focus, the doctor may pay inadequate attention to the range of factors that affect not only the patient's symptom attention, but even the illness itself. Our experience is, however, that a written self-presentation has given patients a feeling of being heard, and has thus encouraged them to give their own perspectives on factors linking illness and life.

Our results emphasize the intention to use the illness diary as a facilitator of interaction, to be shaped and utilized together with the patients, rather than to be used on them. More than being a standardized "solution tool" in the consultation, this collaborative approach introduces additional communication channels, thus opening new gateways to dialogue in general practice.

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