Tell me what’s wrong with me: a discourse analysis approach to the concept of patient autonomy

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Abstract
Background—Patient autonomy has gradually replaced physician paternalism as an ethical ideal. However, in a medical context, the principle of individual autonomy has different meanings. More knowledge is needed about what is and should be an appropriate understanding of the concept of patient autonomy in clinical practice.

Aim—To challenge the traditional concept of patient autonomy by applying a discourse analysis to the issue.

Method—A qualitative case study approach with material from one consultation. The discourse is interpreted according to pragmatic and text-linguistic principles and provides the basis of a theoretical discussion of different concepts of patient autonomy.

Results—The consultation transcript illustrates how the patient’s wishes can be respected in real life. The patient, her husband and the doctor are all involved in the discourse dynamics, governed by the subject matter, namely her mental illness.

Conclusion—We suggest a dynamic and dialogue-based conception of autonomy as adequate for clinical purposes. These perspectives, based on mutual understanding, take communication between patient and doctor as their starting point. According to this approach, autonomy requires a genuine dialogue, an interpersonal mode of being which we choose to call “authentic interaction”.

Material and method
Our material is drawn from a larger research project about linguistic and paralinguistic interaction in general practice. The conversation from one visit was audiotaped, transcribed as a concentrated dialogue between doctor, patient and patient’s spouse, and translated from Norwegian to English. Theoretical and methodological assumptions and transcribing rules are presented elsewhere.

First, we present a transcript intended to emphasise the interactive elements of the patient-spouse-doctor discourse. Next, we interpret the patient-spouse-doctor interaction, highlighting what happens in the consultation. Then, we apply different versions of the concept of patient autonomy to the consultation. We conclude by defending a dialogue-based autonomy model, also called authentic interaction.

The consultation
The transcript represents one single encounter between a female patient complaining of mental problems, her husband and their family physician.
Tell me what’s wrong with me

(P=patient; H=husband; D=doctor; ... = significant pause/ hesitation; _italics_ = intonational stress)

D asks how the patient feels today.
P answers: “I feel much better. I have recovered considerably.” She says that she still feels depressed every morning “until half past twelve”, but she feels “much better” afterwards.
P asks her husband if she shares her opinion about this.
D says: “Yes, maybe we should listen to your husband.”
H confirms that “it’s a bit up and down.”
D asks if she has a tendency to stay in bed all day long.
P/H both state that she does.
H says: “You were miserable on Sunday”.
D asks what was wrong on Sunday.
P says that she felt everything was against her: “Felt that I couldn’t handle it any longer.”
D asks if she was restless on Sunday: “Please try to remember.”
H adds to the doctor’s question: “How did it start?”
P demands (irritated) of her husband: “Why don’t you tell it yourself if...”
H answers: “Thought maybe you could remember a little yourself.”
P comments: “When I feel depressed I am really depressed...”
D repeats her question: “Only depressed, or both depressed and restless?”
P answers: “Restless and depressed, weeping and... feel like giving up altogether.”
D asks if she knows why she wanted to give up.
P answers: “No.”
D asks: “Do you sleep well?”
H says that she, on his advice has taken one sleeping pill in the middle of the day.
P discusses with her husband if this happened on Sunday or Monday.
H says the sleeping pill didn’t make her fall asleep, “but it did help enormously, anyhow”.
H says his wife has no sleeping problems.
P asks how she feels about “the people who you are a bit... a little afraid of and feel uncomfortable with, have you had such thoughts recently?”
P states that this is just what she is thinking about when she gets her problems.
D asks if she knows why she gets these thoughts.
P (a little uneasy) asks to be allowed not to speak about that “at all, because I try to forget about it”.
D changes her agenda: “I have been considering whether you should increase your dosage from two to three tablets a day, to see if that will work better.”
D states that: “You are much better, but you aren’t back to normal.”
P says she has taken between two and five benzodiazepine tablets every day.
H states that his wife is better when she is with her doctor than she is otherwise.
P expresses irritation with her husband, who tries to undermine what she is saying herself.
D repeats about how to use her medicines.
P asks if she has to come back next week.
D confirms that: “In my opinion, you have to come until we know you don’t have too many dark days.”
D argues: “Maybe we have to examine your head, to be sure.”
P refuses this.
H argues with the doctor: “It has nothing to do with psychiatry.”
D tries to calm the situation down, explaining that she is thinking about an electroencephalography test (EEG).
H tries again to motivate her for this examination.
P again refuses an EEG examination.
H accepts her refusal: “If you promise not to stand there with the breadknife tomorrow.”
D says: “If we don’t succeed in making you well, I would advise you to accept this examination.”
P tries to escape her dilemma: “When I’m nervous... Maybe everyone with nerves has such problems. But after a while things get better.”
(D (encouraging) says: “We shall not bother you if you recover completely.”
H returns to the quarrel about whether she was bad on Sunday or on Monday.
H says: “You don’t have to boast you were fine ‘cause you were miserable.”
H invites a discussion with the doctor as to whether benzodiazepines are something that might help his wife.
P invites her doctor to let her use sedatives instead of neuroleptics.
D doesn’t agree to this.
H says: “It’s a very persistent condition.”
D says to the patient: “You are much better, just like day replacing night.”
H (ironically, addressing the doctor) says: “You should come and stay with us for a week.”

D accepts doctor’s fee.

D says: “Let us try this, and then you come back in a week.”

P says: “But I cannot help it if I’m not better by next time.”

D says: “No, no, you have to tell me just how you feel.”

H (simultaneously) says: “No, no, that’s just why I wanted to come with you. You have boasted many times about how well you feel now, but it’s not true.”

D says that she knows how to ask: “To get you to speak frankly.”

H says: “You don’t have to lie to ... ‘cause nobody goes to a doctor to say nothing.”

D agrees with patient’s husband.

P (a little humorous) says: “Find out what’s wrong with me.”

D (laughing) says: “It’s a matter of cooperation, you know.”

P and D laugh together.

An overall interpretation of the discourse

The consultation starts in a conventional manner, with the doctor asking how the patient feels today. She tries to involve the patient in reflections about why she feels depressed, by exploring possible reasons for her feelings: “the person who you are a bit ... a little afraid of and feel uncomfortable with, have you had such thoughts recently?”

The patient admits that this is a problem, but refuses to talk more about it.

Next the doctor talks about medication. She also states that the patient is much better, but not back to normal, and subsequently suggests an EEG examination. Her husband agrees, and confirms that an EEG exam has nothing to do with psychiatry. However, the patient again refuses. The doctor increases the patient’s neuroleptic medication from two to three tablets a day, and makes an appointment for next week.

All three participants are implicitly referring to a mental disease, which the patient is supposed to have. Her husband especially, appears to be a conventional medical thinker. Apparently acting as a medical co-worker - a social role quite different from being a husband - his question complements the doctor’s question: how did it start?

Further, he puts focus upon clinical effects of medicines, and states that his wife has no sleeping problems. He is very eager to get his wife to accept an EEG examination, but finally has to resign from acting as his wife’s therapist. Falling back to an ordinary quarrel of daily life about when she was feeling bad, he has to admit that it’s a very persistent condition.

The patient seems to be afraid of getting a fixed diagnosis, refusing both to speak about it and to undertake further examinations. Her apparent fear and her rejecting attitude against further investigations or any changes whatsoever are hidden in her last statement, which can be read as an ironically coloured challenge to both her doctor and her husband: find out what’s wrong with me.

After the doctor’s initial remark, the first communicative act is the patient inviting her husband to give his own opinion about his wife, with the doctor apparently, however ambiguously accepting it as appropriate: yes, maybe we should listen to your husband.

The patient’s husband goes into the question of everyday life, which is first accepted by the patient. But when her husband takes a therapeutic position: how did it start, his wife promptly puts him back to a patient position, why don’t you tell it to yourself if you...

The doctor gains control by establishing a dialogue with the patient, but the patient takes control by refusing to talk about her interpersonal difficulties. The doctor then changes the agenda: The patient seems comfortable when the doctor talks about medicines. Her husband, however, disrupts the harmony by stating that his wife is better when she is with the doctor than when she is at home. The doctor seems not to be influenced by that. The patient, however, expresses irritation with her husband. The doctor challenges, perhaps even orders, the patient to accept further examinations. The patient rejects both her doctor’s and her husband’s advice. In response, both of them try to make the patient responsible for the consequences of her decision.

Towards the end, all three participants express a sort of uneasiness and discomfort about the situation. The patient states that she cannot promise to become well. Her husband accuses her of misleading the doctor, and her doctor expresses a somewhat ambiguous attitude. On the one hand, the doctor underlines that she has interactional power to get you to speak frankly. On the other hand, this power is not unproblematic: it’s a matter of cooperation, you know.

Discussion

AUTONOMY AS A PATIENT RIGHT OR AUTONOMY AS MENTAL COMPETENCE?

What does it mean to regard a patient as an autonomous moral agent? We will answer this question by reading the consultation through the lenses of different autonomy concepts. First, we will emphasise the conceptual difference between
autonomy as a patient's right and autonomy as mental competence. Next, we will contrast two main traditions which offer quite different moral attitudes towards autonomy as mental competence: the authenticity tradition and the vital lie tradition. In doing this, we will draw upon the moral philosophical work of Martin about self-deception and morality.7

THE PATIENT'S RIGHT TO INFORMED CONSENT

Figure 1 outlines a provisional scheme of the concept of autonomy. Within the biomedical tradition, patient autonomy implies a right to set limits for medical intervention. Patients are supposed to know their own good as autonomous moral agents, and medical intervention presupposes formal or informal consent from the patient. The notion of informed consent is a modern invention, resulting from the interaction of medical scientists and lawyers. It embodies a new vision of morality which is not derived from medical ethics, but, on the contrary, forms its foundation.8 9

Figure 1

1. Patient autonomy as a medico-ethical right
   - to set limits to medical intervention
   - a consumer's right to health care

2. Patient autonomy as a mental competence
   - the authenticity tradition
   - the vital lie tradition

When the patient, as in our example, refuses to follow the doctor's advice to undergo an EEG examination, it is the doctor's duty to accept the patient's decision. However, the patient, by her refusal, violates a duty traditionally associated with the sick patient role - the patient's duty to seek competent help and follow the doctor's advice.10 Furthermore, she may be suspected of violating another patient duty, namely the obligation to get well. As a response to the doctor's reply: ...if we don't succeed in making you well, I would advise you to accept this examination... the patient expresses her reservations: ...I cannot help it if I'm not better next time...

According to Parsons, the obligation to get well ensures that those who enter the sick role pledge themselves to leave it speedily, not at their own discretion, but at that of their significant non-sick environment.11 However, both of this patient's duties as a member of society - to seek competent help and to get well - are now reversed. According to a free market and individualistic ideology, the patient's duties have been transformed into "dutiless rights" to health care.12

AUTONOMY AS MENTAL COMPETENCE

Within moral philosophy and applied ethics, however, the concept of autonomy is not the same as a patient's rights. Traditionally, the notion of autonomy describes a free and independent individual; autonomy is a sort of mental competence that determines both our inner states and our outward behaviour. According to Kant, to live autonomously means to live by one's own laws, doing what is in accordance with being rational.13 Thus it follows that autonomy has a close relationship to mental health. Following Edwards: "mental health" is understood as an appropriate capacity to deal in an autonomous way with ourselves and our social and physical environment. Being autonomous has, within a mainly androcentric tradition of ethics, been defined as having and freely actualising a capacity for making one's own choices, managing one's own practical affairs and assuming responsibility for one's own life, its station and duties.14

The inner relationship between autonomy as a patient right and autonomy as a mental competence is that autonomy as right presupposes a mental competence to act autonomously. At the same time, people might seek help, and indeed often do, just because they act against their own interests, often perceived as lacking competence to act autonomously. Examples are people with mental health problems as well as life-style-related matters such as smoking, alcohol abuse or eating disorders. Hence, we may say that clinical experience has a paradoxical character. As doctors we are taught to see our patients as autonomous moral agents. At the same time, the concept of therapy, as well as prevention of illness, presupposes a manipulative relationship with the patient, legitimised by the goal of pursuing the health of the patient. Seeking to protect the autonomy that we have learned to prize as doctors, we still aspire to refrain from inappropriate manipulation of the patient. However, in our attempts to put our medical knowledge about, for example, smoking, into practice, we actually sometimes try to manipulate the patient to change behaviour through subtle coercions. As the doctor in our case puts it: we shall not bother you if you recover completely.

In clinical medicine, especially on preventive health matters, it is an everyday dilemma to decide whether to respect the patient's apparently autonomous resistance to well-intended clinical intervention, or to try to change his or her decision. Even though none of us are fully
autonomous and being ill usually implies some fundamental loss of autonomy, patients’ proposed decisions have ultimately to be approved by doctors. O’Neill emphasises that the whole point of concern for autonomy and hence for genuine consent is that it is not the task of the initiator of action to choose what to impose: it is up to those affected whether to accept or to reject proposals that are made. To respect others’ autonomy requires that we make consent possible for them, taking account of what ever partial autonomy they may have, without sending subtle signals to do with subsequent punishment. The practitioner’s fundamental duty is to make it possible for the patients, with their different limitations, to obtain an adequate understanding of the basics of their diagnosis and their proposed treatment, and make them feel sufficiently secure to refuse the doctor’s suggestions. Hence we may conclude that all autonomy implies adequate autonomy in human interaction, namely to be respected by others. Patients may be adequately autonomous, however not “fully” autonomous, as patients’ autonomy has to balance the autonomy of the doctor to act according to professional standards and moral obligations.

AUTONOMY AS AUTHENTICITY

The confirmation from the doctor that she will not bother her patient is a concluding statement. The doctor has, together with the patient’s spouse, argued for some further investigations, which the patient has resisted. We may read this preliminary intervention from the doctor as an attempt to explore reasons for the patient’s malfunctioning. In the first episode, she had tried another approach, to get the patient to talk about interpersonal matters and related thoughts; the patient refused.

Surely the doctor has her reasons for wanting the patient to talk about interpersonal matters. Trying to forget about problems can be perceived as mental repression or self-denial, as the patient adopting a strategy of putting problems and uneasiness back to unconscious forces, which is considered unhealthy for the patient. We will extend this idea with a look at the authenticity moral tradition.

Authenticity is valued by psychotherapists who are concerned with self-realisation, self-fulfilment or self-actualisation. An authentic person has typically been understood as pursuing the higher self within the range of possible selves. This higher self is supposed to be healthy, mature, unified and self-aware. Inauthentic persons, by contrast, are described as fragmented, self-ignorant, frustrated and self-alienated. Authenticity is associated with the idea of genuineness; it is bona fide, real, official and authoritative. The psychoanalyst Karen Horney located the authentic or real self in the active core of the personality, containing the person’s special talents and creative possibilities. Within this tradition, authentic persons are integrated in that they consciously interrelate their various dimensions of their lives. Neurotics, by contrast, are alienated from their real selves, which they betray through obsession with an idealised, unrealistic self-image.

When the doctor is eager to get her patient to speak about troublesome interpersonal relationships, we suggest the doctor is thinking in Freudian terms. Following Martin, we are conscious of something in a Freudian sense when we attend to it, whether our attention is explicit and focused or more diffuse and peripheral. Accordingly, ideas, motives, beliefs, purposes and emotions are said to be conscious to the degree they are attended to. Unconscious mental contents cannot be attended to except under special circumstances, such as psychotherapy, hypnosis, or extreme stress. To speak about something in a therapeutic relationship may imply turning unconscious conflicts into conscious thinking and hence to devoting oneself to a more authentic and autonomous performance. In this case, we suspect that the doctor more or less consciously and explicitly holds an authentic and autonomous self as a standard for mental health and wellbeing. She invites the patient “to talk about it” to unravel unconscious conflicts and thereby regain mental health. This is a highly valued approach both in psychiatry and general practice.

THE VITAL LIE TRADITION

The patient refuses to talk about her problem. On the contrary, she asks to be allowed not to speak about it: ... at all, because I try to forget about it... Apparently, her own approach to her mental problems is, at least partly, quite opposite to her doctor’s. Trying to forget what one should not forget, can thus be regarded as self-deception.

However, according to Martin, the vital lie tradition presents us with the possible benefit of self-deception and the possible harm in seeking to eliminate it from ourselves or others. According to this tradition, self-deception is perceived as benign, and frequently beneficial and healthy. Furthermore, it emphasises the role of self-deception as a valuable coping technique, promoting vital human needs such as self-respect, self-improvement, hope, friendship, love, and a viable community. Martin defends a vital lie position illustrated by the Norwegian playwright Henrik Ibsen’s drama The Wild Duck. In this...
drama Hjalmar Ekdal is a ludicrous self-deceiver who blinds himself both to his failures and to his complete dependence on others. His greatest joy is the veritable worship he receives from his teenage daughter Hedvig. Hjalmar lives on many illusions about his nascent creativity, which his physician, Dr Relling suggested and helped cultivate. Relling is a benevolent cynic who prescribes remedies for both the physical and psychological ailments of his patients. He encourages life-lies designed to bring peace and happiness. As Relling proclaims “take away the life-lie from the average person, and you take his happiness along with it”.

Relling’s antagonist is Gregers Werle who speaks on behalf of the “claim of the ideal”, insisting on the unqualified pursuit of virtue and devotion to truth. Gregers finds his mission in informing Hjalmar that Hedvig is not his daughter, but in fact the offspring of Gregers’s own father. He then believes that Hjalmar will create the perfect marriage for himself and his wife based on complete candour, forgiveness and trust. Instead, all goes wrong. Hjalmar grows completely indifferent to Hedvig, leaving her despondent. In an attempt at personal sacrifice to regain Hjalmar’s love, she goes to the attic and shoots herself.

AUTHENTICITY OR SELF-DECEPTION?
Returning to our patient-doctor dialogue, both “trying to speak about it” and “trying to forget about it” may be regarded as potentially valuable coping mechanisms, depending on the context and the overall situation. In some cases, it may be right to challenge, and even urge the patient to speak frankly. However, Dr Relling’s attitude, to help people to forget failures and weaknesses, bad experiences and shortcomings, may also be appropriate, and in many cases the only appropriate attitude. This is the case when the alternative outcome is worse. If a psychotherapeutic intervention changes a patient from being heavily neurotic to becoming chronically psychotic, then we may have a damaging Gregers Werle effect, destroying more than curing. Perhaps the patient is right in trying to avoid speaking about a problem, and the doctor is right in accepting the patient’s endeavour. If we respect her judgment, her autonomy may in this case best be preserved by leaving difficult problems untouched.

Ideally and analytically speaking, the authenticity and the vital lie approaches to life are rivals. To support a vital lie for oneself can be regarded as inauthentic and self-alienated. Yet in real life it is neither possible nor required to be completely authentic under any circumstance. Furthermore, when the autonomy of patients is of basic rather than of derivative moral concern, it is morally highly questionable to try to impose this notion of pure authenticity on others. Some people may have both the cognitive and volitional conditions to make highly authentic choices. Others may equally autonomously choose the path of denial. It is the function of the medical dialogue to reflect and elaborate the patient’s choice, inviting the patient’s positions to be clarified. The goals of medical action cannot be determined independently of patient’s goals, and assessment of patient’s autonomy must be contextual.

AUTONOMY AND DIALOGUE
Feminist philosophers insist that autonomy, implying that people are in charge of decisions concerning their own life, judged from the subjective rationality of the actual person, always inhabits a field where relationships to other people imply responsibility and interaction. Recognising and accounting for the interdependency between patient and spouse and between doctor and patient, may help us understand more of who is actually making the decisions during the clinical consultation.

Supporting the feminist autonomy tradition, we suggest a dynamic concept of autonomy which explicitly takes dialogue as its starting point. Instead of a purely individualistic model of autonomy, it is based on mutual understanding and respect. According to Buber, a person can never be seen in isolation, but always appears in relation to another person. Whenever there is an “I” there is also another, “you”. Buber states that man and language are interwoven. Rather than saying that language is in man, he prefers to say that man is in language. A dialogue-based model of autonomy reflects the linguistic nature of man which makes him radically dependent on interpersonal relationships and understanding.

A patient-professional encounter is a discourse; a dialogue is an interpersonal mode of being which at its best may be called authentic interaction. The “magic” of authentic interaction is that we do not control it completely as individuals, but are caught up in it and give in to its own movement. The dangers of patient-professional dialogues are related to the imbalance of power, which is frequently very subtly present. A dialogue-based openness is a necessary condition for authentic interaction between patients and professionals where the inequality of power is accounted for. Elements of the dialogue in the text above make us believe that the doctor intends to advance authenticity and genuine dialogue, by inviting the patient to reflect upon her inner thoughts and relationships to others.
The tension between the respect related to autonomy and the concern for welfare is at the heart of the patient-professional dialogue. To act autonomously is to exercise one’s own authority of reflection rather than passively submitting to others’ views or to social convention. To avoid self-deception is to acknowledge significant truths, including truths about oneself as a person and truths about the appropriate goals in exercising autonomy. These potential contradictions of clinical practice are just what our consultation is dealing with.

Conclusions
The notion of patient autonomy represents a two-sided concept, both a medico-ethical right and a therapeutic ideal for good patient care. Pure rights without duties are nonsense, but must be balanced within the inequalities of power within the medical encounter. Patients and doctors should have as their common goal the realisation and maintenance of the patients’ capacity to be free and autonomous persons. This can be achieved through patient-doctor dialogues which provide empathic and caregiving relationships, in which the patient is invited to represent herself in her context and flag her personal choices. We choose to call this authentic interaction, as a prerequisite for patient autonomy through dialogue.

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References
5. See reference 3:403.
15. See reference 9:175.