

## **Errortrawling and Fringe Decision Competence: Ethical Hazards in Monitoring and Addressing Patient Decision Capacity in Clinical Practice**

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### **ABSTRACT**

This article addresses how health professionals should monitor and safeguard their patients' ability to participate in making clinical decisions and making subsequent decisions regarding the implementation of their treatment plan. Patient participation in clinical decision-making is essential, e.g., in self-care, where patients are responsible for most ongoing care. We argue that one common, fact-oriented patient education strategy may in practice easily tend to take the form of what we call *error trawling*. Illustrating with empirical findings from a video study of consultations between clinicians and adolescent patients with diabetes, we argue on independent grounds that this strategy not only risks to overlook significant weaknesses in patient decision competence, but also to undermine patient capacity for decision-making and implementing care. In effect, this strategy for clinically monitoring and addressing the problem of fragile decision-making capacity brings hazards in need of address. We close by suggesting complementary and alternative strategies, and comment on how these may call for broadened competency among clinical health professionals.

## 1. INTRODUCTION

In this article we discuss how health professionals should monitor, safeguard and promote the ability of their patients to participate in making clinical decisions and making decisions concerning their implementation, e.g., in self-care. Accepting this task as important and desirable, and relying on a standard understanding of which decision-making capacities are crucial in this respect, we scrutinise the use of one common, fact-oriented patient education strategy in the familiar case of patients with fragile decision capacity<sup>1</sup> and weak adherence to agreed treatment plans. We demonstrate how, due to a number of factors, this fact-oriented approach may, in practice, easily take a destructive form that we call *error trawling*. Using empirical findings from a video study of clinician-patient consultations in adolescent diabetes care to illustrate this phenomenon, we argue that error trawling has two risks: the risk of missing significant weaknesses in decision capacity that require attention, and the risk of actually undermining, rather than enhancing, patient capacities to adhere to agreed treatment plans. We close by suggesting complementary and alternative strategies, and comment on how these may call for a broadening of competency among clinical health professionals. Albeit we use adolescent patients to illustrate the phenomenon of error-trawling in this paper, these are just one group suffering from fragile decision capacity and weak adherence. Our general, ethical, argument applies also to other groups with similar characteristics, such as patients with milder mental disorders or cognitive impairments, and progressive dementia. In the final section we discuss how the exploratory research here presented can be expanded with regard to these other groups as well.

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<sup>1</sup> We use the concept of decision competence when talking about the conjunction, or the whole, of a patient's decisional capacities. Sometimes we use the phrasing decisional capacities when we want to emphasise that there are different capacities underlying competence.

In section 2, we present the ethical case for applying consistent clinical strategies to monitor and address decision-making capacity for patients with fragile such capacities, and who fail to adhere to care. We use a standard model to identify different kinds of patient decision capacities, why they are important and how they might motivate a variety of strategies. In section 3, we focus on patient educational strategies that aim to detect lack of capacity due to factual misconceptions or knowledge gaps, and to enhance this particular capacity by providing correct information. We describe how such strategies, applied to the patient group in question, given the expected focus of health professionals as well as contextual factors such as time constraints, can be expected to easily turn into a professional rehearsing of patient failures: both failure to comprehend medical facts and how these connect to the patient's care, and lack of adherence to agreed-upon plans and goals for care. We call this phenomenon *error trawling*, and describe how it is of concern in light of the ethical reasons presented earlier. In section 4, we concretely illustrate the phenomenon of error trawling in more detail with examples from a video study of adolescent diabetes care. These examples also illustrate in greater detail our arguments for how it may be expected and why this is of ethical importance. In the final section, we note that our findings regarding error trawling do not eliminate the need to detect and address factual misconceptions when these exist. We therefore conclude by discussing how the clinical monitoring and addressing of decision capacity in this general patient group may be improved.

## **2. THE CASE FOR CLINICAL MONITORING AND ADDRESSING PATIENT DECISION CAPACITY**

Patient decision-making capacity is important for a number of reasons. In Western health care, the most obvious example of its importance is due to the value attached to respecting

patient autonomy<sup>2</sup>, and the use of informed consent to that end. Respect for patient autonomy apply to patients who are *decision competent*, and have uncontested exceptions, such as unconscious or gravely cognitively incapacitated people, young children, and some severely mentally ill patients. In contrast, adults suffering no incapacitating condition are assumed to be paradigmatically competent, although the argument can be made that illness and disease always affect competence to some extent.<sup>3</sup> Between these (allegedly) clear-cut points on the spectrum is a rather wide range in which decision competence is less certain: patients whose capacities may be partially or gradually impaired, underdeveloped or fragile. Well-known and frequently occurring examples of this include temporary moderate confusion or fatigue, milder mental disorders or cognitive impairments, moderate intoxication and progressive dementia. In addition, just as young children are by default assumed to lack decision competence, and adults to possess it, older children and adolescents are in a phase of development toward adulthood, creating a similar uncertainty with regard to their decision competence. All these groups possess what we will henceforth refer to as *fringe decision competence*. They occupy a borderland between the obviously competent and the clearly incompetent, with fragile capacities that are easily undermined, often somewhat in flux during a care situation, and may vary considerably depending upon the exact issue being addressed. It makes sense for clinicians to observe some caution in their encounters with such patients, given the assumed importance of respecting patient autonomy. [2, 4-6] In section 3, we describe how this reason has had a particular impact in the area of research ethics.

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<sup>2</sup> Albeit not entirely uncontested [see 1], it is safe to say that this ideal nowadays enjoys strong and broad support throughout medicine, as well as healthcare ethics.

<sup>3</sup> Patients not considered competent need a surrogate decision-maker of some sort. Who might be suitable for the task is a matter of some debate, as are what requirements apply to decisions made by such a person. [2,3]

Another, related, reason for the ethical importance of monitoring patients' decision competence is the recent shift towards person- or patient-centred care (PCC), shared decision-making (SDM) and similar trends in health care organisation and policy, [7-13] especially when their use is advocated in areas involving fringe-decision-competent patients, such as dementia care. [11] Here, the ambition is not only to facilitate and respect but also to *promote* patient influence over health-care decisions<sup>4</sup>. This adds further nuance to the need to monitor the capacities of fringe-decision-competent patients and to address noted weaknesses, as this process may also include dialogic discussion, joint deliberation or negotiations about options and goals, based on patients' overall life situations and their resultant preferences. This shift towards stronger patient influence, moreover, often includes areas in which patients are directly responsible for administering their own care, typically in a domestic setting. This makes it even more crucial to pay attention to the capacities of patients with fringe decision competence, since they will lack professional assistance if they make incorrect or irrational judgements, decisions or actions. [14,15]

A further reason has to do with treatment efficacy and health. For adequate diagnosis and treatment decisions, health professionals usually depend on their patients to convey relevant information about themselves and their experiences and to understand and carry out instructions. The move towards the PCC- and SDM-type models mentioned above also makes this consideration weigh more heavily, as these models are often frequently intended to incorporate patients' own view of their situation, to adapt care to better suit individual needs and circumstances and to involve patients as clinical decision-makers in home or self-care settings. Thus, for fringe-decision-competent patients, the risks of diagnostic error and sub-optimal treatment and administering of treatment increase. The importance of managing and

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<sup>4</sup> Enabling the patient to better participate in medical decision-making by improving the patient's decision capacities is one means to this end often held out in the literature. [10,11]

minimising these risks thus provides a straightforward motivation for monitoring and seeking to improve patient decision-making capacity.

From an ethical standpoint, all of these reasons are also subordinate to one further reason that has to do with justice and equality: If special attention to fringe-decision-competent patients is not given, this patient group is less likely to receive adequate, quality-assured and ethically appropriate care than either clearly decision-competent or clearly incompetent groups.

### **3. FROM ASSESSMENT TOOLS TO INFORMAL PATIENT EDUCATION TO ERRORTRAWLING**

The need to monitor and address fringe decision competence has primarily been highlighted in clinical research, and several formal 'tools' have been developed to this effect. [16,17] Of these, the MacArthur Competence Assessment Tool for Treatment (MacCAT-T) stands out for addressing the clinical rather than the research context, [18] and has been suggested as a way to determine the actual capacities of patients with fringe decision competence due to dementia. [19] However, while such formalistic approaches might be motivated in exceptional cases with particularly critical stakes, which require a one-off decision on the binary question of whether the patient is competent or not (as in a clinical research situation), they seem highly impractical for *continuous routine* monitoring. Besides requiring quite a bit of time,<sup>5</sup> the resulting continuous, formal questioning of the patient's decision capacities risks undermining the development of a trusting, dialogic and respectful relationship between professional and patient. There are also indications that professionals both tend to overlook

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5. Appelbaum states that applying the MacCAT-T instrument will probably take about 20 minutes – more or less the standard length of a clinical consultation in ordinary care. [19]

the competence aspect and exaggerate the capacities of patients with weak competence. [20, 21]

The goal for the continues monitoring of decision capacity in fringe competent patients has a different goal than than in a research ethics context. In the latter case, the aim is to determine whether or not patients are at all fit to give informed consent. In the clinical setting, the need arises in the context of an extended challenge to continuously track the varying strengths and weaknesses of patients in order to adapt dialogue and care design accordingly. The continuous monitoring should therefore as a rule be approached informally, taking forms that may be seamlessly integrated into a well-functioning patient-professional relationship. Still, even though the formal tools should not be used in this context, they do provide guidance by setting out or assuming factors that professionals need to focus on, both when implementing such monitoring and when addressing identified problems. One such factor is what Grisso and Appelbaum call *understanding*, and in the remainder of this article, this is the factor we will focus on. [18] As will be further described in section 4, understanding was the decision-making ability most frequently monitored and addressed by the health care professionals in our illustrating empirical material, and the one that tended to developed into error trawling. In the remain of this section, we will describe both why understanding is important to monitor, why it can be expected to be frequently used by professionals, and why the resulting clinical monitoring of the patient group in focus in this paper may then easily slide into error trawling.

Understanding as an aspect of decision competence is about a patient's ability to intellectually comprehend general facts. These may include facts related to the nature of the disease or health problem, the relevant workings of the body, the way that treatment interacts with these factors to produce benefits and risks, and the actions the patient must take for the treatment to

work optimally. If a patient lacks understanding in any of these areas, the risk increases that they will misunderstand, misinterpret or overlook crucial aspects of what they are or are not agreeing to, and what they are supposed to do and why. Lack of understanding may thus cause an otherwise rational, stable and empowered patient to make poor decisions, from the standpoint of autonomy as well as health. If, in contrast, the patient does possess understanding, other factors may still undermine autonomy and adherence. These may include weak executive capacities, misaligned psychological reactions (confusion, panic, lack of self-esteem, etc.), lack of reasoning skills, or lack of so-called appreciation, i.e. the ability to map generally understood information onto one's own life situation. [4, 15, 18]

For a health professional, focusing on understanding is a very natural starting point, as it translates easily into the task of conveying and translating specialist knowledge to which the professional has privileged access. This puts the professional in the role of a teacher. Consequently, for many decades the notion of *patient education* has been increasingly put forward as an important response to concerns about patient autonomy and adherence, and it continues to be a main theme in the aforementioned PCC and SDM trends. [8, 11, 22] The focus on understanding is also strong in research-oriented discourse, where the informational aspect of informed consent is usually framed as requiring educational intervention in order to make sure that potential research subjects have an adequate understanding of the projects they are considering entering. [5] Mimicking traditional forms of teaching, such interventions typically involve textbook materials to read, instructive visualisations such as pictures or graphs, oral lectures and Q&A sessions in which a professional can detect and straighten out any misconceptions.



However, there is good reason to believe that applying this patient education strategy to *continuous monitoring* (rather than one-off checks) of decision competence creates particular hazards for the very group for whom it might appear most necessary: namely, patients with fringe decision competence and weak treatment adherence who suffer from chronic or long-term conditions. The problem connects to phenomena now being highlighted in discussions of how the extended conversational interaction of PCC and SDM may affect adherence and capacity to enact agreed-upon self-care, especially in the kinds of patients in focus here. [7, 14, 15, 22-27] These hazards all connect to the obvious risk that well-meaning educational interventions of the type just described may, in this specific context, turn into a destructive trawling for errors and misjudgements, especially damaging for those patients already suffering from a sense of failure and low self-esteem created by a history of weak adherence, accompanied by messages of denunciation for either stupidity or breach of trust vis-à-vis the health professional.<sup>6</sup> As exemplified in the next section, such deterioration in patient education predictably ensues when a professional sees biomedical test results that indicate inappropriate patient care. Just as the fisherman trawls the ocean for fish, the professional responds by engaging in a systematic search for the source of the problem in the patient's beliefs and behaviours. We will close this section by outlining why this slide from patient education into error trawling is both predictable and how hazardous for patients. These hazards are, of course, not a result of malice. Rather, they resemble the unintentional harm trawling fishermen do to the seabed and the bycatch when using all their knowledge and skill to fish as well as they can. In the next section, we will use outtakes from a study of adolescent diabetes care to illustrate some of the concrete forms these hazards may take.

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6. The pattern seems very similar to recent observations of how school grades tend to undermine rather than enhance the future performance of low- to average-performing students. [28,29] It is likely that similar psychological mechanisms explain both phenomena; some are laid out by Herlitz and colleagues. [15]

Herlitz and colleagues<sup>7</sup> recently argued that literature and conjecture about promoting patient autonomy and adherence, not least in the advanced forms PCC and SDM, rest on unrealistic assumptions about the nature of health care and the situation of most patients. [15] Much more care than normally assumed is carried out by patients outside of a health care context, where patient consultations and educational interventions allow professionals to exercise at least partial control. In addition, we have already pointed out how a much larger proportion of these patients than is generally assumed belong to the fringe-decision-competent population. Furthermore, there is the well-known fact that a large part of these patients exhibit weak adherence – a problem long acknowledged as a major challenge for health care delivery and organisation. [22]

These three factors combine to produce the risk that educational interventions focused on patient understanding will slide into error trawling.<sup>8</sup> Consultations take the form of repeated lectures and interrogations, usually combined with irrefutable evidence of the patient's failure to adhere to the care plan, since professionals believe that progress can be made by finding and drawing attention to factual mistakes and rehearsing the reasons for and description of the ideal treatment regimen. This behaviour makes sense to the professional, who (perhaps unwittingly) assumes that lack of adherence is probably caused by lack of understanding, and it also offers a means by which the professional's special qualifications can be applied to improve the situation. However, owing to well-known psychological factors, the expected result for the group of patients discussed here is actually the opposite. From the patient's point

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7. This analysis uses empirical material from the same study used in this article.

<sup>8</sup> We cannot on the basis of either this theoretical argument, or the empirical material used for illustration in section 4, say anything about the *actual extensor comparative prevalance* of error trawling, neither in the general patient group we focus on, nor in healthcare in general. The arguments developed in this section does however provide us with a reason to suspect that it is to be especially expected in consultation with fringe decision competent patients. This theoretical reason, together with the illustrative cases from our empirical material, is sufficient to create a strong reason to instigate empirical studies to probe the issue further. We expand on this prospect in the final discussion..

of view, such exercises can be expected to turn into endless trawlings for errors, in which professionals are likely to react negatively to even minor aberrations from the biomedical ideal (since they attribute such aberrations to the lack of understanding that they also believe underlies adherence problems). Meanwhile, the message received by patients is mainly about their own repeated incompetence and failure, which is bound to undermine their already frail capacities for adhering to care outside of the meetings. A number of general psychological theories predict that patients will generally react by failing to improve or even worsening their adherence; this may be described e.g. as disempowerment or a lack of access to basic capabilities. [14, 15] A person who perceives herself as failing repeatedly, and who has this perception regularly confirmed by negative feedback from supposed authorities, is likely to respond with confusion, fear and lessened trust in her own abilities. The patient starts to find the idea of making attempts to improve the situation becomes both more difficult to conceive of and pointless to act upon, in light of the expectation of continued failure. If the patient in question also has fringe decision competence, their pre-existing frailties make such a development even more likely to occur. The pattern that arises may also discourage patients from actively participating in future consultations, since error trawling tends to continually reaffirm the professional as an authority who may not be questioned. The very prospect of monitoring and addressing decision-making capacity over the long term may thus also be undermined. [30]

#### **4. A CASE IN POINT: ERROR TRAWLING IN ADOLESCENT DIABETES CARE**

As part of an exploratory qualitative study of person-centred professional-patient interaction in adolescent diabetes care, we made video recordings of 12 meetings between diabetes care professionals (pediatric diabetologists and nurses) and adolescents with type 1 diabetes, at a

specialist pediatric diabetes clinic strongly committed to patient education, PCC and SDM. Participants were recruited through standardized protocols at the clinic, after approval by an Ethical Review Board.<sup>9</sup> The same project also included in-depth interviews with some of the patients [23] and staff, [31] and the video data has been used in a critical analysis of standard approaches to PCC. [15] Adolescents are a good example of a fringe-decision-competent population, where particular frailties are well known to affect decision-making, not least with regard to health, risk perception, emotional stability and impulse control. [32,33] Type 1 diabetes is a demanding disease, requiring the patient to manage a wide battery of self-care measures lest very serious short and long-term consequences ensue, and adherence is a well-known challenge, not least for adolescent patients. [32 34] Global standards for pediatric diabetes care are heavily invested in patient education, which, as we have already observed, can tend towards monologic lectures and an emphasis on understanding above other sources of decision competence. [35, 36]

The research question for the present analysis – ‘How do health care professionals informally assess decision-making competence in consultations with patients?’ – emerged as a secondary outcome of the other analyses mentioned above. To probe this issue further, we used a method inspired by grounded theory, where two general taxonomical matrices were used to initiate analysis, for the purpose of finding more specific theoretical tools to make sense of this particular aspect. The matrices were 1) a model for understanding the ethical aspects of person-centred professional-patient interaction and shared decision-making, [10-11] and 2) the model of decision competence developed by Grisso and Appelbaum described above. [18] We also incorporated into our analysis the earlier results from the project that had inspired this particular research question.

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9. Regional ethics review board of xxxx, registration number xxx-xx.

We viewed and read transcripts of the video recordings, noting every instance when professionals informally assessed or attempted to address patient decision-making capacities. We then categorized each instance of assessment according to the aspect of competence in the Grisso and Appelbaum model that it addressed, and coded each instance. We found that fact-focused patient education was the most common form of informal assessment. It was when looking more closely at these instances that we observed the phenomenon of error trawling in meetings with non-adherent patients and immediately noted the associated hazards. These hazards (outlined above) were both directly emergent in the material and deduced from the theory matrices applied and earlier analyses and results in the same project. More specifically, we identified four generic hazard types associated with the error trawling phenomenon. They are illustrated below in concrete excerpts from our data. These excerpts also showcase different contextual facets of the error trawling phenomenon that we will describe.

The excerpts serve an illustrative purpose only. They cannot prove that error trawling, with its associated hazards, is a common phenomenon in the area of care of fringe decision capacity patients. They do, however, support the existence of error trawling, and we have argued on independent grounds that this phenomenon may be expected to appear when fact-focused patient education is applied to fringe-decision-competent patients with weak treatment adherence. The error trawling phenomenon and associated hazards are also consistent with documented types of patient experience and an understanding of the moral psychology of the meeting interactions springing from other analyses of the same project: for instance, a consistent finding that patients are passive, express low self-esteem and report fear and shame at the expected reactions of their carers. [15, 23]

It should also be borne in mind that this study focuses on only one patient group and only one aspect of decision-making competence. Larger studies could offer more complex analyses for all four kinds of capacities available for informal assessments, following the Grisso and Appelbaum matrix, based on a more variable sample of fringe-decision-competent patients with chronic or long-term illness.

Noting these limitations, we still judge the concerns related to error trawling that are outlined above (and concretized below) to be serious in their own right, the more so because, as we have argued, we can expect error trawling to be a recurrent outcome of fact-focused patient education that targets fringe-decision-competent patients with weak adherence. Further research would be needed to examine whether these concerns are substantiated. We will return to how further research may throw more light on these concerns, and what may be done to better safeguard against patient education for these patients sliding into error trawling.

The recorded meetings followed a recurring pattern in the standard treatment program for adolescent patients with type 1 diabetes. They all opened with the professional briefly questioning the patient about life in general and how the treatment had gone since the last meeting. The professional then invited the patient to review downloaded blood glucose values. The professional identified and addressed problems based on this review. As other studies have also done, [35] we found that the professionals tended to dominate the conversation, and that problems and solutions tended to be formulated within a predefined biomedical agenda that notably emphasized patient understanding and focused on related details about the frequency of blood sugar measurements, eating patterns and insulin injections. [15] This agenda usually became an entry point into error trawling, as it naturally prompted professionals to question and rehearse matters of fact which they considered

relevant to identified deviations from a biomedical treatment ideal, apparently assuming that the solution to the problem would lie in correcting a factual misconception on the part of the patient.<sup>10</sup> At the same time, since these patients had a pattern of non-adherence, this attempt at patient education turned into a serial declaration of patient failure and incompetence, which apparently missed addressing underlying problems and was often accompanied by disempowering feedback. [15] The interview study of the same population revealed that patients who were not performing well, while displaying quite good understanding, had strong feelings of fear and shame about the meetings, and often perceived themselves as incapable of doing well. [23]

We now present four sets of examples from our material to illustrate how a patient education approach may turn into destructive or counterproductive error trawling. We want to underscore that the point is not to demonstrate poor quality of care in the unit studied, or in adolescent diabetes care in general. Our material also contains several examples of professionals avoiding becoming locked into a narrow, understanding-focused approach, and monitoring and addressing patient decision capacity in an open-minded way. For this analysis, however, we have selected instances when this did not occur in order to illustrate our general point.

#### *Example 1: Missing the point*

The patient (P) has an automated insulin pump attached to his/her belly that provides continuous insulin flow, but the needle attaching the pump can slide out and if this goes undetected there may be acute danger unless complementary manual doses are administered,

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10. Again, this is an expected and understandable development, given the professional's typical training and focus on known biomedical risk factors.

or the problem is spotted in time. Thus, P needs to adhere to a control measurement regimen, but has not been doing so. The health professional (HP) begins to address this by noting that the downloaded glucose values show P to "be a bit high" in the mornings.

HP: Maybe you should have better control.

P: Yes.

HP: How many readings do you think you need for it to be safe to have a pump?

P: Four, I guess. And I think it's after two hours, right?

HP: What do you think I would say was the minimum?

P: Four or five, right?

HP: I think so, at least four or five.

P: Hm.

HP: Then, if you need to make adjustments, you might need to check after three hours and so on, but to know what's going on ... Do you know why I think you should take least four or five readings?

P: Because it's at breakfast, lunch, dinner and in the evening.

HP: Yes, and above all because it's for measuring the insulin dosage, but if something goes wrong with the pump ...

P: Hm.

HP: For instance, if it has fallen out ...

P: Yes.

HP: ... and you won't know, the only way of knowing is if you get a high reading.

P: Yes.

HP: Say you go to bed at night and don't take a reading, but the pump has fallen out and you haven't been getting any insulin.



P: Then I wouldn't know about it.

/.../

HP: So if you think something is wrong with the pump or there is something in the tube, how should you give yourself insulin?

P: I would use the pen.

After this, the conversation moves elsewhere, and it is obvious that by discovering P's incomplete understanding of the role of control measurements for the safety of the pump-based treatment, and making sure P knows that manual dosing is necessary if the readings are too high, HP, after leading off with the initial observation about the high 'morning readings', imagines the problem to have been resolved. However, nothing P says indicates that these high readings, or the imperfect pattern of control measurements that is revealed, is related to a lack of understanding. In fact, the issue of why P fails to adhere to the control measurement regimen (of which P displays a clear understanding) in the first place is not probed or addressed at all. We interpret this as a typical illustration of how a patient education agenda leads an HP from an initial observation of problematic biomedical values into an interrogation on facts whose relevance to the identified problem is quite unclear, whilst ignoring issues that would seem central from a treatment efficacy standpoint. This HP, meanwhile, appears to believe that he/she has attended to the problem by identifying an area of factual ignorance and teaching and rehearsing some relevant facts. The biomedical agenda supported by HP's spontaneous educational foray becomes both the implicit yardstick for assumptions about the nature of the problem, and the arbiter of when it has been successfully addressed. At the same time, the examination-style questioning that flows quite naturally from this stance makes P passive and deters him/her from offering any information about why he/she is not following the control measurement regimen or giving any explanation for the high 'morning readings'.

*Example 2: Systematic faulting*

Example 1 also showed how error trawling tends to fault the patient even when his/her response is close to the ideal of HP. Example 2 displays this feature of error trawling systematically, as HP addresses the situation of a patient whose blood sugar values are consistently very elevated:

HP: But if that happens during the day it's good to use an extra dose, you know. But when do you actually use extra doses then? What is, at how high a level should you give yourself a little more?

P: Around twenty.

HP: Twenty, right.

P: Twenty-five.

HP: Twenty-five? Okay. So what would you say is a good blood sugar? Where do you want to be?

P: Six, maybe.

HP: Hm. Five, six. And when do you think it's a bit too high?

P: Fourteen ...

HP: Fourteen ...

P: ... or thirteen.

HP: If I said the limit was ....

P: Or ten.

HP: ... eight ... eight, ten. How would you feel about that?

Here, HP's understanding-oriented approach reveals what he/she apparently sees as a gross factual error. This leads to a striking example of error trawling, where P is repeatedly faulted and finally, even after getting close to what HP wants, is still declared to be in error and then set straight in a way that openly deters P from challenging this 'final verdict'. This is an excellent illustration of one way in which error trawling is very likely to undermine decision competence: through attacking rather than promoting patient self-confidence and, in the long run, establishing fear of being proven wrong as a dominant ingredient in the relationship with the health care professional. Both these sorts of emotional feedback are prime examples of how strategies devised to boost patient autonomy may instead disempower patients. [15] We might also note that it is HP's immediate interpretation of P's responses as proof of factual misunderstanding that kicks off the error trawling, although in fact there is no support for this assumption in the dialogue. Even HP seems to (unconsciously) recognise that the issues could be framed not in terms of facts, but in terms of attitudes to risk. Unfortunately, if this is in fact what underlies P's responses (P accepts more health risks than HP), the serial faulting becomes even more hazardous, as it amounts to declaring P incompetent even to decide what is important in P's own life.

### *Example 3: Promoting fear*

We have already mentioned that patients who display poor adherence and are constantly reminded of this by their HPs can be expected to feel increasingly threatened and scared by the care relationship. But fear can also be conjured through the focus on biomedical facts itself. The following excerpt again involves a patient with very bad adherence (along with a parent, PP):

HP: ... and we have talked many times about possible complications or what is it that ...

Why... Or let me put it like this: why is it a good thing to maintain good control of your diabetes? To avoid ...?

P: There are a lot of things you have to try to prevent, definitely. I mean, it's about my health.

HP: Like what?

P: You prevent a lot of things if you control your diabetes.

HP: For example? I want to hear from you.

P: (mumbles)

HP: Sorry, I didn't hear you?

P: How long you live, maybe.

HP: Yes. What are the dangerous things about diabetes?

PP: Lots of things.

P: If you just ignore it you do a lot of damage.

HP: What do you damage?

P: Your body.

HP: What?

P: Everything, you do lots of damage.

HP: Is it dangerous?

P: Yes, you can die.

HP: Hm, not only die but also be disabled.

P: Yes, I know, I mean, you can be paralyzed

HP: Yes, at a young age.

P: Yes, I know

HP: Hm, and it's preventable.

P: I know.

P is severely mismanaging his/her treatment, prompting HP to rehearse basic health facts in order to motivate the treatment from a biomedical standpoint. In the ensuing error trawling, P is not faulted, but is clearly pressed to talk about unpleasant things, the effect being to repeatedly underscore exactly how P is hurting his/her body and future. It is obvious from the dialogue that P is very uncomfortable with this topic and wants to avoid it. The outcome we would expect is therefore that P becomes very scared of the consequences of his/her bad adherence, rather than positively engaged in his/her own future health. [15] Possibly, HP may have had some idea of eliciting a basic motivation in this way, following classic notions of incentivising.<sup>11</sup> Even if that were so, from the perspective of decision competence the expected outcome is rather destructive. People beset by high levels of fear are paradigmatic examples of sub-optimal decision-makers.

*Example 4: Blaming, shaming and humiliation*

Our final example, in two parts, presents two segments from the same meeting and picks up on a feature also present in Example 3, where the pressuring of P is tinged with humiliation. The patient in this example is also managing treatment quite badly. In the ensuing attempt by HP to educate P, not only does the conversation quickly turn into error trawling, but it is also openly linked to assigning blame to the patient for the problem identified by HP, and relieving HP of responsibility for the undesirable situation:

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11. However, we find it equally likely that HP (unintentionally) here mostly displays his/her own frustration over the fact that P is apparently unmotivated by factual information in the way that HP would consider ideal.

HP: That's why I keep saying that it's really important to take your insulin. Test your blood sugar and then calculate, how much insulin do I need right now?.

P: Hm

HP: It's really important, otherwise you lose the whole..., I mean, if you're at 15 and you're about to eat spaghetti and meatballs, how much insulin...?

P: 17 or 18, maybe...

HP: Was that just a gut feeling? Yes, but it's not good.

P: How should I ...?

HP: But I said this already. How much insulin, if you figure it out with the one hundred rule and the five hundred.<sup>12</sup>

P: Sure, sure.

HP: Do you remember, but you never, you never got the?

P: Papers? Yes, I did.

HP: But you never?

P: I never tested that.

In this segment, prompted by HP asking P when he/she takes control readings in relation to mealtimes, the open resentment towards P escalates, slightly aided by the parent (PP):

P: Usually after.

PP: After, that's the problem!

HP: I've told you repeatedly!

P: I know, I know...

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12. Refers to the so-called 500 and 100 rules for calculating insulin dosage based on food intake and blood glucose levels; standard components of diabetes patient education.

HP: What's ...

P: It's just turned into a habit, I've been doing it that way that my whole life.

P is openly humiliated here, as obvious joint shaming by HP and PP pressures P into trying to apologise in a way that functions simultaneously as a declaration of incompetence. In our reading, these two segments illustrate the most vicious way in which a narrow focus on understanding and education makes a systematically non-adherent patient into a psychological threat to the professional, predictably eliciting a defensive response from the latter, which in turn is very likely to undermine patient decision-making capacity. If the patient understands everything there is to understand and still mismanages their treatment, then, working under the assumption that the mismanagement ought to be solvable by addressing faulty understanding, the unhappy situation can no longer be the result of suboptimal care but must be laid at the patient's own feet, relieving the professional of responsibility.

## **5 FINAL DISCUSSION**

There are good reasons to clinically monitor and address the decision-making capacities of patients with fringe decision competence, especially in areas that require extensive self-care, and for patients who demonstrate weak adherence to agreed-upon treatment regimens. We have argued that such measures need to take an informal form, but that they may nevertheless be informed by existing technical tools developed for one-off assessments of decision competence. We have also suggested that the easiest aspect of such tools for health professionals to apply is that of understanding, which leads them to a strategy of fact-oriented patient education. However, focusing only on understanding poses severe hazards for the group of patients considered here – in respect of both their wellbeing and their decision-

making capacities – as the patient education may easily slide into the phenomenon we call error trawling. An educational approach to the clinical monitoring of decision competence may therefore be counterproductive and harmful. We have argued for this analytically, pointing to recent research on PCC and SDM and well-known psychological mechanisms, and illustrated our point with a number of concrete examples from adolescent diabetes care. A different kind of study would be needed in order to confirm that similar concerns apply across a wider range of fringe-decision-competent patients, or to assess variability with regard to how commonly patient education slides into error trawling. We have argued that the argument developed in this paper provides good reason to instigate such studies.

Such research could examine larger samples from a wider set of patients that share the general features of fringe decision competence, long-term illness and adherence challenges, but differ in other ways. Dementia or outpatient psychiatric care are areas of particular interest, as they host large numbers of patients. It might also include comparisons with patient groups in which the factors of decision competence frailty, length of illness and adherence pattern are varied to see whether the risk of patient education slipping into error trawling is mitigated, or if any error trawling pattern then appears less hazardous. For instance, it might be interesting to investigate the efficacy of patient education strategies for patients whose adherence is weak, but who are fully decision competent, such as adults with type 2 diabetes or hypotension. It would also be interesting to know if error trawling is connected to the perception of competence by the health professional in fringe-decision-competent patients, e.g. in adolescent or dementia care.

Both the general reason for clinically monitoring fringe decision competent patients' decision capacities, and the phenomenon of error-trawling, can be further explored from an ethical



standpoint through the notion of *epistemic justice*. This perspective has been applied to other areas of health care, such as care of patients with chronic fatigue syndrome. [37] Epistemic injustice occurs when parties are unfairly treated in terms of their access to and use of information and knowledge. Fricker [38] distinguishes between two types: testimonial and hermeneutical injustice. The first occurs when discredit the evidential value of each other's experiential testimonies. Hermeneutical injustice occurs when one part is unfairly disadvantaged by a shortcoming of shared understandings. Patient consultations are meetings where an epistemic power difference exists between the participants, and when the patient is fringe decision competent this difference is especially pronounced. Reasons of hermeneutical justice in particular seem to add reasons in favour of monitoring and addressing decision capacity in clinical encounters with this patient group. At the same time, the phenomenon of patient education sliding into error trawling illustrates how attempts to this effect may instead add to *injustice* by having the biomedical discourse silence and discount the patient's own testimony, as well as undermine actual decision capacities instead of enhancing them.

The argument that we have developed in this article for why error trawling is an expected result of patient education for fringe-decision-competent patients with long-term illness and weak adherence is connected to an understanding of how the identity of health professionals is bound up with a biomedical ideal and perspective on health and health care. Others who have studied the role of this type of ideal in patient-carer communications have suggested that it needs to be replaced or at least complemented by a broader conception of what health care is about, one that also includes the psychological, social and cultural dimensions of the patient's experience of illness. [39,40] Otherwise, a communicative gap between the patient and health care professionals threatens to undermine a mutual understanding of what is supposed to be the goal and value of the care, including the nature and point of treatment

components that must be enacted by patients. The present article highlights one specific and rather grim way in which this can occur, and additionally shows how the ambition to informally monitor and address the understanding of fringe decision competent patients, in itself praiseworthy, may result in outright harm.

We suggest, therefore, that it would be worth considering broader approaches to the much-needed informal assessment of the capacities of fringe decision competent patients, ones which focus more on motivational and emotional aspects of learning. However, since these factors may require that professionals downplay the need to ascertain factual understanding, they may be perceived to conflict with common readings of professional duties, especially among physicians. [15] They may also be less accessible to and less easily enacted by physicians and other health professionals whose competence is based foremost in knowledge of biomedical facts and related practical skills. Monitoring and addressing decision competence in patient groups mentioned here may therefore require substantial additional education and training for professionals, or expanded roles in clinical consultation for professional groups already possessing the required competence.

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