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Strengthening Patient-Clinician Communication to Prevent Dismissal of Patients' Symptoms and Concerns

Engaging Patients to Advance Diagnostic Excellence: A Workshop
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The medical encounter is, fundamentally, the creation and exchange of stories between patient and doctor. …Having created a new edition of this patient's story, the physician must give that story back to her patient and to do it in a way that allows him to try it on and, if it seems to fit, to incorporate this new version of his story back into the bigger story of his life.

—Lisa Sanders, M.D.

(Jutel, 2019, p. xi)

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Validate Patients' Experiences

What is "Validation"?

Validation can be communicated explicitly through verbal comments (topographical validation) or implicitly by responding in a manner that implies one takes the other's experience as valid (functional validation)

In the context of diagnosis, functional validation would comprise clinicians' engagement in the information-gathering strategies as outlined by NAM (2015)

- Clinical history and interview
- Physical exam
- Diagnostic testing
- Referral and consultation

(Linehan, 1997; National Academy of Medicine, 2015)

Level 1: Listening and Observing

Validation at this level involves listening to and observing what the patient is saying, feeling, and doing as well as a corresponding active effort to understand what is being said and observed; demonstrating an *interest* in the patient.

Language that can be employed:

- "Tell me more"
- "I don't understand, please explain that"
- "What were you thinking at just that point?"

(Linehan, 1997)

Level 2: Accurate Reflection

Validation at this level involves the accurate reflection back to the patient of the patient's own feelings, thoughts, assumptions, and behaviors; requires that the physician actually understand the perspective of the patient; the essential goal is for the physician and patient to come to a shared understanding of the material at hand.

Language that can be employed:

- "So, you are feeling [insert patient description of symptom], is that right?"
- "So, you believe [insert belief about the symptom], is that right?"

(Linehan, 1997)

Level 3: Articulating the Unverbalized

Validation at this level involves communication to the patient the clinician's understanding of aspects of the patient's experience and response to events that have not been communicated directly by the patient.

Language that can be employed:

- "That sounds really [distressing/frustrating/etc.]."
- "That seems really [distressing/frustrating/etc.]."
- "I imagine that must be really [distressing/frustrating/etc.]."

(Bontempo & Saleem [unpublished manuscript]; Linehan, 1997)

Level 4: Validating in Terms of Sufficient Causes

Validation at this level involves validating behavior in terms of its causes. Validation here is based on the notion that all behavior is caused by events occurring in time and, thus, in principle, is understandable. Behavior is justified in showing that it is caused.

Language that can be employed:

- "It is reasonable to have made an appointment considering you are experiencing [symptom]."

(Linehan, 1997)

Level 5: Validating as Reasonable in the Moment

Validation at this level involves communicating that behavior is justifiable, reasonable, well-grounded, meaningful, or efficacious in terms of current events and the patient's healthcare goals.

Language that can be employed:

- "It is reasonable to have made an appointment considering you are experiencing [symptom(s)]."
- "It makes sense that you would come in today given your experience with [symptom(s)]."

(Linehan, 1997)

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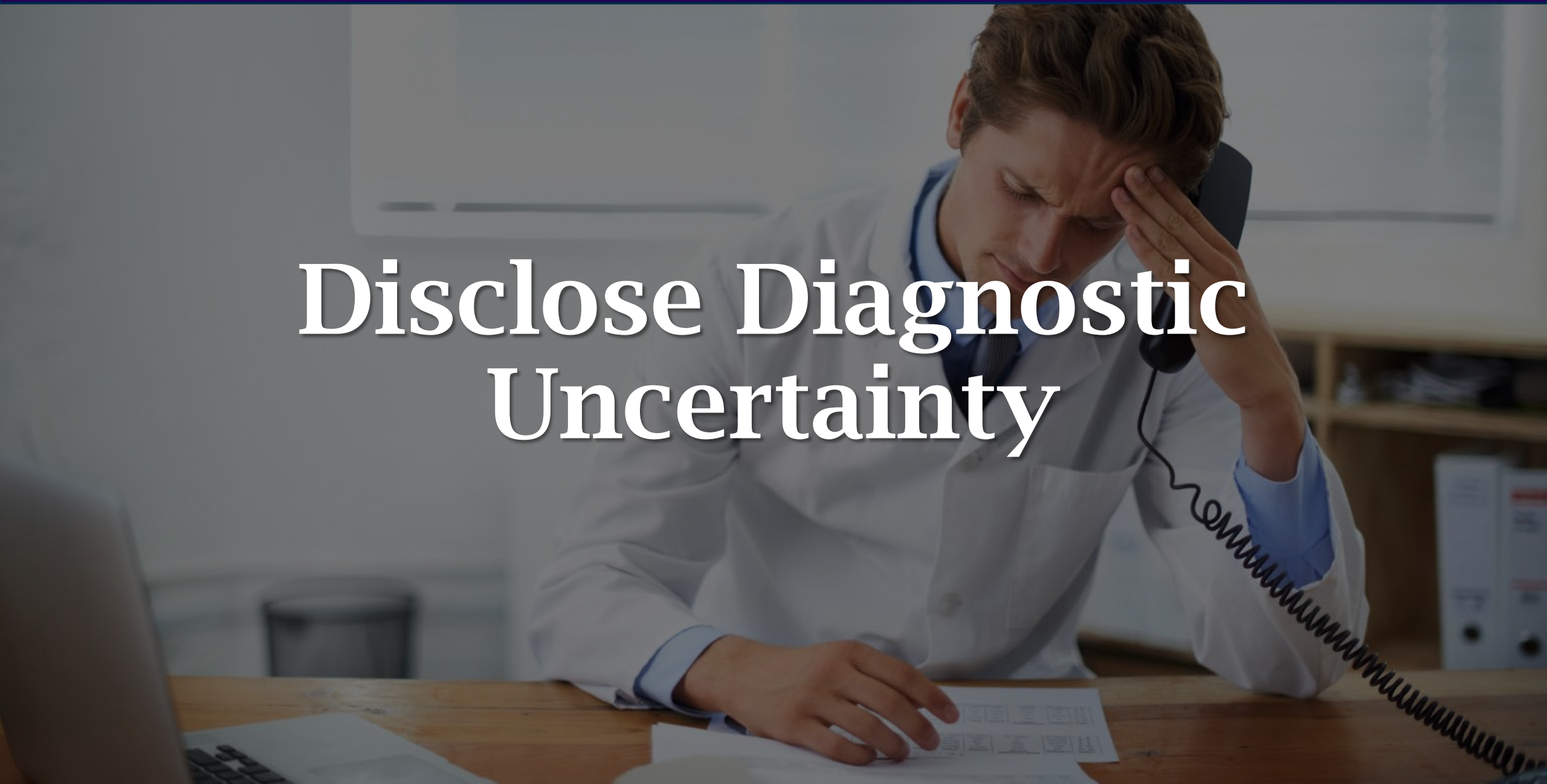

Disclose Diagnostic Uncertainty

Promoting the Disclosure of Diagnostic Uncertainty

- Increasingly advocated by patient safety scholars and patients alike is clinicians' disclosure of diagnostic uncertainty in the patient-clinician encounter

- One study showed that clinician disclosure of diagnostic uncertainty increases trust in clinicians and facilitates healthcare decision-making

> *"I'd rather have them be honest that they don't know rather than saying, "Oh yeah, it's this," and dismissing me or that thing. It would give me more faith in them. I mean, because they're doctors, they don't know everything. They know a lot, but they don't know everything."*
>
> (Bontempo, 2023, p. 4)

(Armstrong, 2018; Bontempo, 2023; Santhosh et al., 2018; Schiff et al., 2018)

These Findings are Generalizable

"As a patient I can say that having a doctor . . . not know something is okay."

(Kornelsen et al., 2016, p. 373)

"Patients would rather doctors were honest and if they 'don't know' then say that rather than humiliating, frustrating and angering patients by subtly suggesting we seek psychiatric help…just because diagnostic tests (which doctors rely on too much) don't show anything to assist with diagnosis."

(Picariello et al., 2015)

These Findings are Generalizable

"If a doctor actually said to me 'I don't know what's going on' I would be feeling, yes, yeah, that would thrill me."

(Kornelsen et al., 2016, p. 373)

". . . many of them [doctors] show disdain for patients when they themselves are uncertain and find themselves in unknown territory. Why can't doctors simply admit that they know little about this—instead of humiliating and mocking the patient when they are uncertain [. . .] that is the way far too many of us are received."

(Lian & Robson, 2017, p. 7)

These Findings are Generalizable

"Some [patients] explicitly stated that they 'don't expect doctors to know everything' (Sera) but that they should be 'honest' about what they do not know 'because it's not a weakness' (Maree)."

(Young et al., 2020)

One Caveat for Disclosing Diagnostic Uncertainty

- Disclosing diagnostic uncertainty alone is insufficient—it must be accompanied by a verbal commitment toward nevertheless helping patients and clinical action

> *"I don't think that that would hurt my trust for a doctor to be like, 'I don't know.' But I think that would hurt my trust if a doctor's like 'I don't know' and then did nothing about it."*
>
> (Bontempo, 2023, p. 5)

(Bontempo, 2023)

One Caveat for Disclosing Diagnostic Uncertainty

- Clinical actions taken by clinicians could include:
  - Consulting with colleagues
  - Conducting further research
  - Consulting with colleagues
  - Referring patients to a specialist
    - *Helping patients* find a specialist to whom to refer them
  - Scheduling follow-up appointments

(Bontempo, 2023)

Disclosing Diagnostic Uncertainty Can Be Validating

- Disclosing diagnostic uncertainty can be validating to patients
- **Disclosing diagnostic uncertainty allows for patients' symptoms to still exist despite the absence of a known diagnosis**

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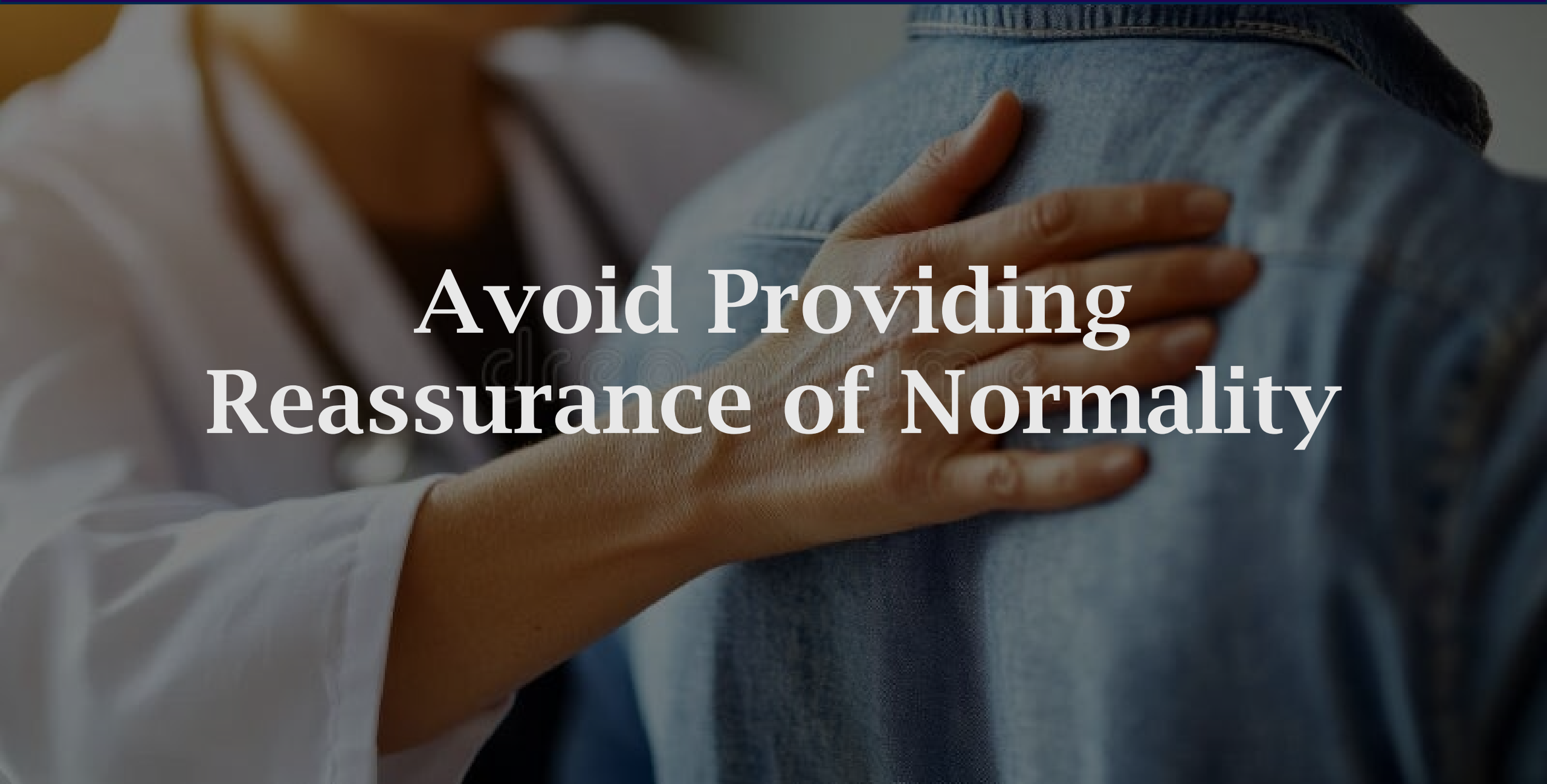

Avoid Providing Reassurance of Normality

Avoid Providing Reassurance of Normality

- Clinicians may be driven to quell patient concerns by providing reassurance that nothing is wrong, especially when a preliminary workup is unremarkable

- Yet, research demonstrates that:
  - Patients, especially those exhibiting increased anxiety, do not respond to reassurance and/or perceive it as invalidating
  - Reassurance, when it is a feature of clinical anxiety, perpetuates or even exacerbates anxiety in the long term
  - Reassurance invalidates patients' lived experiences by communicating these experiences are not relevant or meaningful
    - Can exacerbate patient self-doubt

(Rhidenour et al., in press; Stark et al., 2004)

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Avoid Using Mental Illness as a Scapegoat Diagnosis

Mental Illness as a Scapegoat Diagnosis

"In so far as a scientific statement speaks about reality, it must be falsifiable: and in so far as it is not falsifiable, it does not speak about reality."

— Karl R. Popper, Ph.D.

Mental illness is not falsifiable, making it the perfect scapegoat diagnosis.

DSM-5-TR Somatic Symptom and Related Disorders

"The previous criteria [of DSM-IV-TR] overemphasized the centrality of medically unexplained symptoms. Such symptoms are present to various degrees, particularly conversion disorder [FND], but somatic symptom disorders can also accompany diagnosed medical disorders. The reliability of determining that a somatic symptom is medically unexplained is limited, and grounding a diagnosis on the absence of an explanation is problematic and reinforces mind-body dualism. It is not appropriate to give an individual a mental disorder diagnosis solely because a medical cause cannot be demonstrated."

(American Psychiatric Association, 2022, p. 349)

Thank you!

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Patients Attitudes Toward Clinicians' Communication of Diagnostic Uncertainty and its Impact on Patient Trust

tinyurl.com/endo-uncertainty-study

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