

Patient Preferences as Guidance for Information Framing in a Medical Shared Decision-Making Approach: The Bridge Between Nudging and Patient Preferences

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Abstract: Guidelines and policies support the decision process to make sure that patients can benefit from the best treatment for their condition. The implementation of guidelines and policies is evolving, allowing decision makers to be able to choose between alternatives while considering the effect of biases and fallacies that may hinder their choice. Patient preferences play a precious role in those decisions in which is not possible to recognize an objective “best” alternative and it’s not possible to nudge them toward one alternative based on scientific evidence and clinical experience. Having patient input as part of the decision process itself would allow the recognition of the attributes related to what is relevant for patients, which can be considered as important as clinical data. The authors advocate that the integration of preference-sensitive attributes with decision policies could provide a benefit against fallacies in the decision process when there is not a “best” alternative, and a shared decision-making paradigm allows both patient and clinician to recognize and pursue the option that best fits the individual case.

Keywords: nudge, shared decision-making, health policies, patient preferences

Introduction

When facing choices in a medical decision-making context, clinicians’ contribution relies on their clinical experience and on results present in literature. The support from strong scientific evidence allows clinicians to identify a solution that has been proved to be effective in the majority of cases and to follow guidelines that aim to disseminate what can be recognized as “best practice”.^{1–3} These recommendations aim to assist both clinicians and patients in situations in which the outcome of an intervention may not be anticipated. Furthermore, evidence can be translated into implemented actions that direct the decisional process and, in some cases, provide an explicit indication that would prevent people from making a free choice to be sure that they go for the “preferred alternative”.² One of the downsides of clinical practice guidelines, however, is that they are considered by some physicians as a threat to their clinical judgement and their professional autonomy.³

The definition of what is “best” for a patient is not something that can always easily be defined. In some scenarios, each treatment alternative presents pros and cons that must be considered. In these cases, the preferable alternative can be recognized as the one that, on average, provides a positive benefit/risk trade-off on measurable clinical outcomes, such as survival period or symptoms reduction.

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This evaluation can be agreed upon only on a rational perspective in which quantifiable elements are considered and appraised in order to “measure” the alternative that provides the largest benefits. Human information processing, however, does not always have this objective. Humans’ bounded rationality⁴ binds them to limitations that alter their perception of information and steers their choices.

Nudging Guidelines and Policies

For this reason, the implementation of scientific evidence on decision-making is fundamental, especially in critical situations in which patients face life-altering choices. The role of the context is a key element in the decision-making process; it impacts patients, as well as physicians, making them vulnerable to systematic misrepresentations of information and biases, and leads to systematic errors, or fallacies, due to the application of ineffective heuristic strategies.^{5,6} In this context, biases can be considered as obstacles to an “effective” decision-making process and may lead to regret and low satisfaction for the choice made. For this reason, interventions aiming to reduce the impact of potentially harmful biases and fallacies are crucial to the patients’ care process.

Recently the focus on decision-making in cognitive psychology moved toward the libertarian paternalism approach.⁷ The two main elements that constitute the cornerstones of this approach are the paternalistic view, that aims to direct patients in the decisional process toward the best alternative, and the libertarian view, that has the objective to grant people the freedom of choice and to prevent coercive interventions that would eliminate specific alternatives from a patient’s range of choices.

This theoretical framework relies on the assumption that it is impossible not to have an influence on other people’s decisions when presenting alternatives; moreover, the format of the information conveyed when communicating influences the interpretation of the content of the communication itself.^{6,8} However, in order to guarantee that freedom of choice is preserved in nudge interventions, people should be able to choose between any alternative, undermining, if they want, the effect of any nudge intervention, without a significantly different effort between choices. A classic example of a nudge, which in this case focused on the placing of alternatives, may be linked to dietary changes: placing a healthier choice in front of someone in a buffet makes it easier for people to choose it compared to scenarios in which the placement is different. It is still possible not to choose this alternative and opt for another one if someone decides to do so for the same “price”. Another

crucial requirement for a nudge intervention is that the overall economy of the choices is not altered. In the diet scenario, this means that making unhealthy alternatives more expensive to direct people choices away from them may not be considered a nudge.^{7,9} The focus of this kind of intervention is not to change the preference of a person, but to target those choices that are implicitly influenced toward a “bad choice” and to not necessarily meet people’s values and desires.

In the medical decision-making context this may be translated into the implementation of guidelines for physicians and patients in a format that may favor a transparent comprehension of the communicated information; these guidelines, moreover, would allow decision-makers to be aware of how to appraise different pieces of information to avoid those misleading elements that may lead to regret after outcomes develop.

Choosing Without a “Best” Alternative

A pivotal limitation for the application of all paternalistic interventions, and their libertarian versions such as nudging, is that they require an a priori indication of what is the “best” choice in a given circumstance.⁹ Since the architecture of choices defined by nudge interventions applies to the context in which a decision is made from a top-down perspective - in which general knowledge about decision process phenomena is applied to a specific situation - the need for an a priori indication supported by evidence is a necessary requirement. In the dietary example presented above, it may be generally agreed that it would be “good” for people to eat healthy, so to recognize the “best” alternative to nudge it should be evaluated by how healthy it is.

Some scenarios though, feature elements that may hinder the applicability of these top-down strategies and that require contributions of all the individuals involved in the decision process (eg patients, clinicians, caregivers, nurses) to direct choices and evaluate which alternative is the “best” one for each specific situation. Examples of contexts in which guidelines and decision policies may not be effective are those in which decisions under high uncertainty, competing goals, and different outcome evaluations are present.

Uncertainty is a common element in medical decision-making.¹⁰ Treatment outcomes always entail a probabilistic component that requires clinicians and patients to decide according to probable events and uncertainties.¹¹ These scenarios make it difficult to apply policies that aim to prevent systematic errors because since nudging is “welfare-

promoting” and “beneficial” to the patient,¹² this can only be possible if we know with near certainty that the course of action we nudge is good for the patient. If clinicians are not able to rank alternatives and define a preferable one with their scientific knowledge, it is not ethically acceptable to steer a patient’s decision toward an alternative over another. Considering consequences of a medical choice on a continuum from more to less certain outcomes, it is possible to recognize in which contexts a shared decision-making approach is to be preferred to a more paternalistic one that directs patients’ choices.¹¹ An outcome that is almost certain allows the clinician to make quick and effective decisions without requiring the patient’s input after they agreed on the desired goal; a highly uncertain outcome on the other hand, implies that the physician cannot favor one option over the other. In this scenario patients are the only ones who can take the responsibility to make a choice and their values could work as a guideline in weighing the importance of each feature involved in the decision-making process. Uncertainty, hence, could be considered as a threshold factor that may discriminate those choices in which guidelines and decision policies may not be effective and patient involvement is more relevant.

Another element that limits the efficacy of top-down decision policies is that policies are conceived to be applied in a specific context, but they affect different types of individuals. Other than clinical components and behavioral habits that differentiate each patient, the applicability of a policy is influenced by the variability of goals across individuals.⁹ If there is a marked heterogeneity of goals among patients or if an individual has conflicting goals, the application of a priori general policy that gives more relevance to an outcome related to a given objective (ie, “to live as long as possible”) may not be effective for those patients who may have other priorities (ie, “I want to suffer as less as possible”). In order to apply a policy that favors the “best” option, a main goal must be clearly defined so that different alternatives may be analyzed and evaluated according to this objective. If the goal adopted when designing the policy is different and/or in conflict with one or more of patient goals at the time of the choice, its application may potentially be harmful to the patient and may produce a regret for the choice made under a decision policy when dealing with its consequences.

The effectiveness of an intervention becomes more complex to evaluate as the number of criteria to be considered increases. Since treatment outcomes cannot be evaluated by clinical indicators alone, but must take into consideration patients’ perceived well-being in general, the evaluation of

different alternatives must account for unpredictable life events, psychological processes, and social interactions that have an impact on patients’ perception of their medical condition. A different frequency and duration of treatment sessions, for example, require arrangements that involve patients as well as their caregivers and may be disruptive for their everyday life if not effectively implemented in their routines and may lead to poor compliance and adherence. For this reason, evidence-based interventions cannot be rigidly applied in all contexts and it is fundamental to integrate the best research evidence, clinical expertise and values of patient¹³ to evaluate the benefit-risk trade-off of all alternatives. In a broader interpretation, contributions to the decision should originate from all individuals involved in the care process (eg patients, clinicians, caregivers, nurses) since they are a crucial element that allows to evaluate which alternative is the “best” for each specific patient.¹⁴

The Patient Role

In situations like these, the role of the patient becomes crucial. In recent years, the shift toward a “patient-centered care approach” already led to a greater importance of patients’ contribution in the medical decision-making process. The increase of patient agency within their own care process originates from elements that can be considered as enablers of patient empowerment^{15,16} toward a shared decision-making approach that may be considered the best expression of the patient-centered approach in the clinical context.¹⁷ In the shared decision-making process, patient and physician, as well as health care providers, develop a partnership.^{18,19}

The shared decision-making paradigm can be considered as a model that stands in between the paternalistic model, whose efficacy is limited by the impossibility to clearly define a priori the course of action, and the informed model, in which the doctor provides information to the patient who is in charge of making decisions.^{18,20} Shared decision-making proved to be particularly valuable in situations in which different treatment options are available and none of them is clearly the “best”,^{11,17} since patients’ participation in the medical decision making process allows them to tilt the scale according to their specific needs, values and preferences.

In order to benefit from their contribution, the shared decision making-process needs patients to be aware of risks and benefits of each alternative, thanks to the support of the clinician’s expertise and communication skills, and to define their preferences, concerns, needs and values to identify the preferred option via a bidirectional communication process^{21,22} in which each member contributes by sharing

different elements in the interaction.²³ The expertise coming from patients and clinicians is specific so that each part cannot replace the other. In a shared decision-making approach, while the clinician has an expertise in diagnosis, prognosis, and treatment alternatives, patients are experts in their anamnesis, values, preferences, and goals.²⁴

The ability for patients to participate in the decision-making process allows to consider elements that may not be strictly related to the clinical perspective but may be highly relevant to the patient's quality of life. Patients' quality of life may steer decisions away from the "best" clinical option in favor of an alternative that may have a lighter impact on everyday quality of life at the price of a decreased survival rate or the increased emergence of some symptoms to reduce other effects that may not be perceived as relevant compared to the first ones. The optimal result of this process is an agreement on the care plan and shared responsibilities about the consequences of the decision made.¹¹

Patients' values, needs, preferences, and desires gain importance in steering choices considered "preference-sensitive": in these cases the clinician will provide more than one possible clinical intervention, allowing patients to make a choice.²⁵ This may occur when: 1) multiple treatment options exist and none of them is clearly superior for all patients, 2) the evidence supporting one option is considerably uncertain or variable, and/or 3) patients' views on the most important benefits and acceptable risks vary considerably within the patient population or differ from those of health care professionals.²⁶

Patient Preferences and Biases

A critical feature of patient preferences is that they are not stable in the medical decision-making process - from the diagnosis to the treatment phases - and that their heterogeneity makes it difficult to have a ranking of attributes across different patients.^{27,28} The formation of preferences is linked to the nature of the decision framing and may be influenced by elements that are not relevant to patients' values and beliefs, but rather ones that are dependent on the specific decision.²⁷ Some patients may also have a lack of preferences and would rather delegate any decision to the clinician.

Even if the instability of preferences is clear in the literature, it's not the same in the everyday clinical practice or in the patient's view: projection bias refers to patients' tendency to expect that their preferences will be consistent in the future even though they recognize that their preferences changed in the past.²⁹

Since preference formation is vulnerable to the framing of the information shared between patients and clinicians, biases due to the format of this information may have an impact and lead the patient-physician dyad to opt for an alternative that may lead to a future regret based on the misrepresentation of elements considered in the decision-making process.³⁰ The effect that biases and heuristic strategies have on the decision making gets to a further level of complexity when considering that in the shared decision-making context each agent that contributes to the choice may also impact the contribution of the other and vice versa.

One of the downsides of shared decision-making, in fact, is that while it may work in a theoretical frame, it is highly vulnerable to cognitive biases and rational decision making.⁶ Specifically, in fields in which shared decision making is crucial to define the treatment plan, such as the oncological care, the format in which information is presented - risky choice framing, attribute framing, absolute versus negative risk presentation, defaults, optimism bias - and timing of information - projection bias, present bias - may have an impact on treatment choices. This calls into question patients' ability to make informed treatment choices.⁶ This applies to physicians and family members as well. All these potential influences could affect the shared decision-making process, requiring strategies to avoid biases and systematic errors.

Even though nudge policies are recognized by patients and clinicians as precious instruments to help them deal with critical choices, in real life practice nudges can be a threat to shared decision-making and could lead to lower satisfaction. The balance between shared decision-making and paternalistic policies, then, needs to carefully address the freedom of choice of all parts involved, such as patients, clinicians, and caregivers before being implemented.³¹

On the continuum of possible uncertainty of outcomes, as the effectiveness and applicability of nudge policies fades, with high uncertain outcomes the importance of shared decision-making and patient preference increases. For this reason, it is hard to clearly define an area of overlap between choice architecture policies and interventions focused on the development of strategies and skills of the decision maker. It would also be possible to consider these two approaches as conflicting due to the different perspectives that originate these constructs:³¹ the libertarian paternalism approach and the shared decision making paradigm. While the first one relies on a top-down perspective, in which general knowledge is applied to an individual situation, the latter values a bottom-up focus on

the very specific needs and contributions of the single patient to define a general plan to direct the patient decision-making process.

Nudging Patient Preferences

While more and more perspectives and studies have appeared in the last few months regarding the application of nudge policies in the shared decision-making context, we could not find any input on the role of patient preferences in the application of nudge decision policies. The integration of these two constructs could provide a precious input to a shared decision-making context by directing communication according to patients' perceived relevance and ability to process information. This integration could help prevent regretful choices while securing that patients' contribution is free of bindings that they may not be aware of.

Since decision architecture policies cannot favor one alternative over the other when it is not possible to identify "objective" better alternative, it is hard to compare descriptive responses with normative ones in order to recognize "non-rational" choices and identify potential biases. Nonetheless, benefits of nudge policies, which aim to contrast information processing errors, and indications provided by patient preferences, which are precious for recognizing relevant information, are not in direct conflict.

Since nudge policies affect the environment in which the information is framed, but not the content itself, an integration of these two approaches would allow to rely on patients' preferences to recognize elements that are crucial to them and to provide tailored interventions on the choice architecture based on specific targets that are perceived as relevant in the care process. The comprehension of a message is not influenced solely by the content that is expressed literally, but also the frame in which the information is provided impacts as well the meaning of what is understood by the target of the communication.³² As defined by the relevance theory³³ the interpretation of what is said varies depending on the perceived intention of the speaker, hence, one fundamental element to be considered when evaluating the choice architecture of a shared medical decision is the relational context between physicians and patients. Shared decision-making is a communication process that relies on a social interaction between at least two people who contribute by providing different elements.²³ Even if healthcare professionals would try to refrain from influencing patient choices, they cannot avoid having an impact on patients.³¹ For this reason, it is fundamental to be aware that the

information given to patients are deeply influenced by the person who provides the communication, namely the clinician, and attention should be paid to its format so that it is as clear and transparent to the patient. Nudge can then be conceived as an example of an aware implicit orientation of people's behaviors due to the communication of the information itself.⁸

These approaches could be applied, at first, in scenarios in which the patient has to learn and elaborate a large amount of information in a short period of time. Investigating which attributes are more relevant to patients, when evaluating different therapeutic options, may inform physicians on what information is worthwhile to have a deeper understanding by the patient, such as toxicity effects in everyday life, and which information is not easily relatable to their condition. The diagnosis communication - or the planning of future treatment plan - could be a context in which time is crucial and is also present a large emotional component. Receiving a large amount of information in such a context is difficult. Patients may not be able to process all the information received and, hence, they may not be able to form and ask questions in the time window dedicated to them.

Clinicians often account for this difficulty and prompt patients to contact them after some time, hours or even days, to receive new information or find an answer to their doubts. Although, being able to allocate time and attention to those critical elements could help them have a clearer impression of those aspects that are important to patients *hic et nunc*, to make it easier to process the information in the most natural way possible. In this perspective, a nudge-oriented choice architecture could allocate space for different sets of information to be processed, according to the relevance given by patients' values, so that information considered more important by clinicians and patients as well may be evaluated as more salient.

Another example of a situation in which patients would benefit from a tailored communication of information is related to risks and uncertainty, since they are a key element in some circumstances of medical decision-making. Since uncertainty is a common element when evaluating possible treatment outcomes, it is fundamental to address patients' understanding of probabilities and risks so that they may not be misled with false hopes or inaccurate outcome expectations.

It is definitely helpful for a clinician to be trained to mitigate the effect of the potential misperception the patient may incur and to adapt the formulation in a format that is more accessible to each patient.⁶ On the other hand, nudging a choice so that enough relevance can

be given to a low probability outcome that can be erroneously perceived as remote and almost impossible can help patients adjust their expectations and reduce the impact of a regret if that improbable outcome actually becomes a reality.

An additional crucial element when evaluating a choice is the comparison between the anticipation that patients develop regarding a specific outcome of the treatment and the actual experience. One example of this misperception may be the anticipation of long-term effects of a treatment compared to the expectation linked to side effects. It is common for patients to overestimate the impact of the implications of a treatment considered critical due to their acute impact (eg ostomy appliances, amputations) while other effects are vastly underestimated because their impact is not as severe in the acute phase, but with a chronic effect on everyday life (eg migraine, tinnitus, chronic pain).²⁷ This might lead patients to prefer an alternative with a smaller improvement, selecting an intervention perceived as less invasive instead of a more effective one that entails a bigger change in their lifestyle. Since the evaluation of outcomes is not stable in time, this anticipation may be regretful for patients who have to deal with an outcome that they underestimated when the choice was made. Present bias⁶ may be an example of patients' expectations for future costs of a choice considering the present weight disproportionately when compared with future costs. An intervention that targets elements that are important for patient's everyday life in advance may help reduce the gap between expectations and reality by facilitating the representation of a more accurate future and may reduce regret due to an unexpected poor quality of life.

Finally, patients' wish for participation in the medical decision-making process is not something to be given for granted. Different patients may desire for different levels of involvement and for different degrees of cooperation with the clinician.¹⁵ Each condition leads to specific risks and the decision policy definition may have a different impact with specific situations. In this case the role of default policies seems crucial for those patients who do not wish to be involved and the choice resides mainly on the clinician.

Having an instrument to guide clinicians into a better understanding of patient preferences and values could help them offer a communication of the alternatives in which patients may feel more able to contribute and to take responsibility for an important choice that will critically influence their life.

Conclusions

Being aware of systematic misperceptions and situations in which the patient's choice may lead to regret allows policy makers to identify critical points that should be tackled in order to have an effective decision-making process. Clinicians provide clinical knowledge and expertise to the table and present information related to patients' conditions to guide their choice. On the other hand, patients are the only ones who can recognize elements that they deem relevant when making a life-altering choice. Since both clinicians and patients are vulnerable to biases and fallacies, decision policies could give a precious contribution to the shared decision-making paradigm by providing a structure that allows patients and clinicians to integrate their values and beliefs in order to recognize what is the "best" outcome for each specific scenario and, hence, favor the alternative that leads patients as close as possible to the goal they defined with the support of the clinician.

Even though both nudge and patient preferences are salient in current literature, we believe that a bridge between these two constructs could represent a novel perspective in the healthcare context and have a positive impact for both patients and physicians, in the shared decision-making process. Future research should focus on methods to implement decisional support in specific contexts in which challenges may impair decision quality, such as low literacy or situations in which agreement on an optimal choice is not easy to reach.

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