



Physician–patient shared decision making in the treatment of primary immunodeficiency: an interview-based survey of immunologists

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ABSTRACT

Background: Patient–physician shared decision making (SDM) can result in better care as well as reduced treatment costs. A better understanding of the factors predicting when physicians implement SDM during the treatment of primary immunodeficiency (PID) could provide insight for making recommendations to improve outcomes and reduce healthcare costs in PID and other long-term chronic conditions.

Method: This study made use of grounded theory and was based on the interview responses of 15 immunologists in the United States. It focused on their decision making in the diagnosis and treatment of PID, how they interact with patients, and the circumstances under which they encourage SDM with patients.

Results: All invited immunologists took part in the interviews and were included in the study. All but one had 10 or more years of experience in treating PID. The study found that SDM is bounded/limited by “nudging” bias, power balance considerations, and consideration of patient health literacy alignment. Immunologists also reported that they were mainly responsible for coordinating care and for allowing sufficient time for consultations.

Conclusion: SDM occurs between the physician and patient throughout the treatment of PID. The study also shows the ways physicians influence SDM by guiding patients through the process.

Statement of novelty: Little is known about the factors that influence SDM in the long-term management of chronic diseases. The present study investigated the extent to which immunologists experienced in the treatment of patients with PID include SDM in clinical practice. Findings such of these may be of use when formulating treatment guidelines and improving the effectiveness of long-term management of PID.

Introduction

Long-term immunoglobulin G (IgG) supplementation by the intravenous or subcutaneous route is indicated and recommended for the most common types of primary immunodeficiency (PID). Optimal dosing needs to be determined on an individual basis due to the high costs of IgG as well as to minimize the risk of adverse reactions (Bonilla et al. 2015; Betschel et al. 2017). As with any treatment for a lifelong chronic condition, the benefits of challenges or therapeutic options

should, whenever possible, be discussed with the patient on an ongoing basis. Such a process of shared decision making (SDM) (Friesen-Storms et al. 2015) has been defined as an “approach where clinicians and patients share the best available evidence when faced with the task of making decisions, and where patients are supported to consider options, to achieve informed preferences” (Elwyn et al. 2010). SDM has been promoted at policy level in many countries whether for enhancing patient involvement as a desirable goal in itself or for benefits incurred, such as greater treatment adherence

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and the preferences of some patients for more conservative and lower-cost treatment options (Elwyn et al. 2010; Barry and Edgman-Levitan 2012; Lee and Emanuel 2013). Moreover, the Institute of Medicine report on healthcare inefficiencies in the US made 2 recommendations aimed at improving healthcare delivery while reducing costs: (i) that greater consideration should be given to patient preferences and (ii) that the care of chronic diseases should be seen as the most effective means to reduce overall costs in the healthcare system (Barry and Edgman-Levitan 2012; Gerteis et al. 2014). However, despite the existence of developed and defined SDM models, the implementation of SDM in most forms of chronic care is limited and little is known about how it can serve as a useful and practical way for doctors and patients to interact (Légaré et al. 2014; Couët et al. 2015). Because PID is a lifelong chronic condition that must be managed over the long term, it is an excellent model to study SDM because of the complex and challenging dimensions of the disease and complex ongoing treatment decisions. As with most chronic diseases (Noonan et al. 2017), the use and effectiveness of SDM have not been adequately studied to date. The study described here specifically addressed the knowledge gap in SDM in the treatment of PID by means of a qualitative survey of 15 immunologists experienced in the treatment of PID focusing on their decision making, including the extent to which they included patients in decision making.

Methods

Qualitative approach and research paradigm

The study was conducted from a constructivist and interpretivist point of view, applying grounded theory. A qualitative method was chosen in this initial study as a way of obtaining rich detail and explanatory theories on the topic of treatment decisions in PID, a topic on which little is known. The study was based on interviews with immunologists currently treating patients with PID and thus making use of specialists' extensive experiences and acquired knowledge. Questions aimed to be open ended and focused on treatment decision making in the immunologists' clinical practice including the level of shared decision making with patients. Simultaneous data collection and analysis facilitated the identification and pursuit of themes that shaped

data collection and framed the emerging analysis (O'Reilly et al. 2012). Under grounded theory, data collection and analysis proceeds in stages, data collection, open-coding for preliminary analysis and labeling of data, axial coding for grouping of open coded labels and focused coding for constructing a formal framework within a variable (Corbin and Strauss 2008; Weick et al. 2008; Charmaz 2014).

Concepts used in developing the questionnaire

Dual Process

Under dual process theory, decisions may be reached in 1 of 2 ways (Tversky and Kahneman 1986; Scott 2000): heuristic decision making (System 1), the faster of the 2, relies on experience and recognition (Croskerry 2009; Kahneman 2011; Gigerenzer 2015); rational thinking (System 2), is a slower, more effortful process of problem solving by conscious analysis (Kahneman 2011; Gigerenzer 2015). Dual process theory is applicable to medical decision making processes (Djulbegovic et al. 2012).

Uncertainty

Physicians are usually confronted with 3 types of uncertainty when making clinical decisions: limitations of medical knowledge, the physician's perception of the gaps in his or her medical knowledge, and the tolerance of uncertainty (Jones 1992). Knowledge limitations often require the need to use clinical skills and judgement when there is incomplete empirical support of a decision (Flynn 2003). Any conflicts between research evidence and the physicians own experience can add to uncertainty (Timmermans and Berg 2010). A greater tolerance to uncertainty may increase a physician's willingness to deviate from standard protocols to accommodate the patient's lifestyle and preferences (Flynn 2003). Chronic care requiring complex management, decision making and coordination, as well as management of comorbidities can be a source of uncertainty (Whitson and Boyd 2016). However, dual process theory implies that greater uncertainty requires System 2 thinking.

Bias (and nudging)

Bias consists of flawed evaluations of initial information. For example, a physician may treat a new patient with the same methods and drugs as previous patients on the basis of similar symptoms and insurance

coverage (anchoring, availability, money-priming, and status quo bias). Training as a resident may drastically affect how physicians think and potentially reinforce bias: initial exposure to real patients is often the link between knowledge and experience (Patel et al. 2002, 2009). Perhaps the most important bias related to SDM is how word framing can alter decision making. For example, in deciding whether to have a hypothetical drug administered, the advice “This treatment has a 95% survival rate” is met with more favorably by patients than “This drug has a 5% death rate.” Words have power and verbal primes impact decision making (Topol 2015).

Both biological and behavioral theories support the hypothesis that how doctors frame a treatment has profound effects on how patient receives, interprets and experiences that treatment. One method to combat bias is for the physician to practice meta-cognitive “slow” thinking, or to study how they reach conclusions (Klein 2005). A bias may be considered either a negative attribute or a “nudge” aimed to encourage advantageous decisions (Sunstein and Thaler 2008).

Power imbalance

Power dynamics are a fundamental aspect of human relationships and the physician–patient dyad is no exception (Fiske et al. 2016; Mirowsky 2017). Physicians are likely to categorize themselves and colleagues as highly educated when compared to patients. Asymmetries of information may explain why physicians are slow to adopt SDM (Tapscott 2010). Their interactions with patients, who are regarded as being in different category, affect the physician decision process depending on the particular patient. These categories, or identities, lead to a power imbalance in the physician–patient relationship and likely a reduction in SDM.

Traits (physician and patient)

Trait theory predicts that decision making is influenced by both physicians’ and patients’ background and sociodemographic characteristics (Kaplan et al. 1996). The following traits are thought to most influence physician decision making: age, gender, race, experience, trust, culture, and family (Hawley and Morris 2017). Participants in the medical dialogue bring with them all of their personal characteristics which affect patient–provider communication (Cooper-Patrick et al. 1999; Cooper and Roter 2003; Cooper et al. 2012).

Experience

Experience refers to the cumulative knowledge and frequency a physician has treated patients for the particular disease state. Experienced physicians, who tend to make greater use of intuition to make decisions based on patterns, could decrease the potential for SDM with patients (Marinova et al. 2016).

Trust

It has been hypothesized that trust between physicians and patients is necessary for SDM to occur. It is well-documented that trust improves patient compliance, satisfaction, and outcomes (Cook et al. 2004; Schoenthaler et al. 2014) and, conversely, lack of trust is associated with non-adherence to medication (Bauer et al. 2014). Research has shown that the use of decision aids may facilitate the SDM process by increasing the level of trust (Nannenga et al. 2009).

Organizational

Physicians and patients interact within a larger health-care system. Rules determine how much time a physician can spend with a patient. Feedback is an organizational process that influences future behavior. Patient care frequently needs to be coordinated between providers. Other decisions are required on how care is paid for and who must approve treatment costs (DeMeester et al. 2016).

Policy

The selection of 1 treatment approach over another can be based on various factors such as efficacy, safety, and cost (Liras and García-Trenchard 2013; Peyvandi et al. 2014). The physician’s practice or institution functions in a larger macro system, which includes regulatory agencies, patient advocacy groups, and accepted standards of care. Policies are thought to reduce decision making between a patient and physician and limit SDM options (McMurray et al. 2011).

Rules and time

Time constraints can limit decision making in care of chronic diseases (Légaré et al. 2012; Légaré et al. 2013; Légaré and Witteman 2013).

Coordination

Poor coordination of care is thought to be a barrier to SDM due to sub-optimal information flow between physicians. Conversely, good coordination of care supports SDM (Joseph-Williams et al. 2014).

Feedback

Effective feedback methods can help improve how the physician and healthcare organization meet the patient’s

needs (NORC 2014). One study has shown that physicians and patients agree that patients can evaluate healthcare providers based on infrastructure, staff, organization, and interpersonal skills but are not able to effectively evaluate technical skills (Rothenfluh and Schulz 2017). In the instance of Medicare accountable care organizations, measures, feedback and auditing methods incentivize physicians to use SDM (CMS 2016).

Colleagues

The extent of colleague influences on the physician decisions process has not been extensively described in the literature. A colleague's advice can sometimes be sought for a decision that is out of their expertise, for confirmation, or on ethical matters (Hickner et al. 2014; Godager et al. 2016; Rothman 2017).

Reimbursement

Reimbursement of healthcare costs can limit the physician's decision process. Insurance companies in many instances apply their own cost effectiveness analyses to determine what is covered. Reimbursement policies are widely perceived as limiting the physician's decision process (Casto and Layman 2006) and have been shown to limit choices in SDM (Scalone et al. 2009; Wilson et al. 2014).

Reflexivity

Reflexivity was maintained by the research team through the analysis and writing by recording, discussing, and challenging established assumptions. The author conducted all interviews and discussion groups. The author was familiar with PID through a long association with the development and commercialization of IgG products. Only one of the 15 study participants was acquainted with the author prior to undertaking the study.

Participants and interview

A purposeful homogeneous sampling method was used to identify potential participants with diverse perspectives. In this type of sampling, participants are selected or sought after based on pre-selected criteria based on the research question. For example, the study may be attempting to collect data from a particular region of the US. The sample size may be predetermined or based on theoretical saturation, which is the point at which the newly collected data no longer provide additional insights.

Board certified immunologist physicians who treat PID were primarily identified through the Immune

Deficiency Foundation (IDF), a US based nonprofit patient advocacy organization, or through the author's network. Data were collected using individual, in-depth, semi structured interviews, which were conducted by both the author in person, mainly at an IDF conference in May 2017, or at the immunologists' offices. Two interviews were conducted by phone. The interviews were conducted by May and July of 2018, with each lasting between 30 to 90 minutes depending on scheduling and the flow of conversation. Questions related to the physicians' approach to diagnosis and treatment of PID, with emphasis on the ways in which patients were involved in decision making. Questions were designed to be open ended and time was included for follow up questions if needed. The full questionnaire guide is shown in Appendix A.

Reliability and validity were addressed based on Silverman's guidance (Silverman 2015). The initial interview protocol was revised based on feedback from pilot interviews. All interviews were recorded and transcribed to ensure fidelity of the data.

Each interview was transcribed by a third-party transcription service (Rev.com, San Francisco, CA, USA). Responses were coded both by the author and his assistant, Ryan Dagenais, using a multi-stage open coding procedure. Codes were derived from participants' words and were added or modified as necessary when new meanings or categories emerged. All interviews were recorded and transcribed to ensure fidelity of the data. Exact quotes from participants were used to state findings. To enhance reliability, the interview protocol was first pilot tested with 3 healthcare professionals who treat PID (non-specialists), and assessed for clarity, appropriateness, and relevance of the interview questions. The interview protocol was revised based on this feedback. Data were extracted using NVivo, a software and data analysis tool specifically designed for qualitative research.

Ethics

This study received approval from the Institutional Review Board committee of Case Western Reserve University before participants were contacted. All participants provided written informed consent in order to participate in this study. Persons' names and any other potentially identifying information such as employers or academic institutions were redacted from interview transcripts.

Table 1: Study participants.

Category	Number	%
Total	15	100.0%
Male	12	80.0%
Female	3	20.0%
White	11	73.3%
Non-white	4	26.7%
Age: 40s	1	6.6%
Age: 50s	9	60.0%
Age: 60s	5	33.3%
PhD	5	33.3%
North East	4	26.7%
South East	1	6.7%
Midwest	8	53.3%
West Coast	2	13.3%

Results

Participants

Participants' characteristics are shown in Table 1. Twelve were men and 3 were women. The participants all treated patients with PID, and their patient numbers ranged from approximately 100 to 4000. All participants were highly educated; all with an MD, and 5 also having a PhD. The average number of years practicing was approximately 15 years with a standard deviation of 7 years. Planned recruitment had been for up to 20 participants based on previously published recommendations (Morse 1994; Creswell 2013). Enrolment was stopped at 15 participants when it was evident that data saturation had been reached and no further themes were emerging.

Interview development

After pilot testing with 3 non-specialist healthcare professionals, the questionnaire was revised based on

the themes that emerged. No subsequent revisions were made during the study. All invited immunologist participants successfully completed the interview.

Interview findings

Table 2 summarizes the findings from the interviews with study participants for the 12 key categories identified.

Long diagnosis period

PID is notorious for long diagnosis time frames averaging about 5 to 7 years. All physicians who I asked about diagnosis timelines (7 of 7) confirmed this and described the problem in context. The physicians attributed diagnostic delays to imperfect data, insufficient screening for PID by primary care providers, and lack of awareness of PID. One participant discussed the context of the 7-year diagnosis average across regions and an imperfect research method:

It varies from one region to another. In rural areas, yes. In major cities like NY, Toronto, LA, no. The moment you start lumping up different regions, you are not going to solve well what is behind it. I would say that if there is a delay of treatment I don't see very much of this in our place. We need to study it more carefully. Nothing is simple. If you say a delay of diagnosis in [IA], I say no. if you say overall PID, possibly yes; not because only knowledge, but progress of the field. We identified [IA] that had infections for a long time that never had PID, but even if we did, I doubt we would have managed to label that way because our diagnostic tools are much better today. Also do you include autoimmunity in that category? Or cancer? The delay in diagnosis for PID is hard for me to accept 7 years. It was a survey, not a study. Part of pushing the enzyme issue. We all support it, but it is not studied. (P07)

Another participant felt that the disease is overlooked in the primary care setting:

Table 2: Summary of findings.

#	Key category	Summary of interview findings
1	Rational decision making	Pattern recognition > Evidence-based medicine
2	Bias/nudging	Physicians provide options they approve of first.
3	Power balance	Patients go to the physician with high expectations because they were unsatisfied with previous care.
4	Health literacy	Patient health literacy must align with the physician.
5	Trust	Trust is assumed.
6	Culture	Culture can change the entire interaction with the patient.
7	Coordination of care	Most act as a coordinator of care
8	Rules (Time)	—
9	Reimbursement	Insurance does not affect decisions or participation.
10	Performance reviews	No reliable performance feedback.
11	Cost	No reliable/consistent cost information.
12	Electronic medical records	Helpful, yet inconvenient.

Often times that's because people don't get in to see a specialist in primary immunodeficiency. I think that many patients who talk about these diagnostic delays will talk about, "Oh, it was this breath of fresh air when I got to see Dr. X." Well Dr. X was just somebody who's trained in this process of true pattern recognition, and has the 90 minutes to go through and do it, as opposed to community-based allergist that's trying to fit this into an otherwise 20-patient workday. I also think that ... That's one reason for diagnostic delay, getting to the true specialist. The other is that some of these diagnoses do evolve over time, so that when you see someone at point A, the laboratory tests may not necessarily have caught up to what their history is, and some of that evolution does happen over time as well. So those two reasons. (P12)

Lastly, one participant (P11) believed that the lack of awareness of PID contributes to the delay:

I think, again, another kudos to the advocacy networks like Jeffrey Modell Foundation, Immune Deficiency Foundation. I mean, they get the word out to inform people and put placards up in airports, community areas that have a lot of traffic, to tell people about these conditions. As physicians, we don't do a good job of that. So people are becoming more aware. But I think there's still an awareness gap. I do think patients are coming, and I've seen it frequently. I mean, I just saw a patient who's 67 years' old who actually makes absolutely no antibody whatsoever; none whatsoever; makes no antibody-producing cells; was actually diagnosed 35 years ago and put on IgG replacement therapy, but then stopped due to faulty information, and has been on antibiotics time, and time, and time again, essentially, continually for 35 years. *[How did they get to you?]* She ended up seeing a very good colleague in the community who was like, "Whoa, you've got a big problem. You need to go to the center where they're used to taking care of this." So they came over. Gave her her first infusion of IgG, and bridged her with some antibiotics because she was sick, and then hopefully she's going to do well. (P11)

Rational/slow thinking

Participants were more in favor of pattern recognition and experience than evidence-based thinking. Although they expressed the importance of following the literature for quality control purposes, they pointed out the inherent flaws in approaching patients with a data-driven mindset; many study results are adequate for the population, but not the individual.

I think that evidence-based medicine is, it's there to provide some type of quality control and some type of guidance towards where we want to move. But we always have to understand where evidence-based medicine comes from. (P08)

I have a general idea of how much gamma globulin I want to give somebody based on data but I can tell you that individual patients don't respond the way the median response in a paper, so I can tell you that lots of people will do fine with a gamma globulin replacement of about let's say 500 milligrams per kilogram per month and there are other patients

with exactly the same kind of characteristics that may do fine with 400 and others who may need 1000. (P01)

Bias and nudging

Nudges are the subtle suggestions in the decision process; methods or strategies to compel limited responses. [Kahneman \(2017\)](#) has described nudges as "explicitly paternalistic" because they set the "choice architecture" by setting predetermined options. The physicians were aware of their potential bias but knew there are some situations where nudging the patient towards a certain treatment pathway is necessary. For instance, one physician discussed the importance of using encouragement to help patients choose treatments, rather than forcing options:

I guess it's listening to the patient and offering things in a fair and objective way. I think those are the most important factors. So if I can understand someone and lay things out fairly and help guide them, 'cause I'm sure that I'm biased with what I think is right, but I don't want to ever force someone to do something, because I think it'll backfire. I'd rather encourage them and tell them why I think they should do something and have them agree and buy in, otherwise you don't get the compliance and outcome you want. (P03)

Another physician described a subtler approach to nudging patient decisions:

As a pediatrician, dealing with the issues, that what you did not want to have is a scenario set up where anyone would perceive blame. So you don't want the physician to be blamed for whatever is done, you don't want a parent, either parent, to be blamed or feel blame. And so, what's done is a collective decision making. Now there's sometimes when the cost of your medical knowledge, you believe the decision should be in a certain direction. And if the parent wants, or the patient wants, are counter to that, you try to use, for want of better words, savvy psychology to help them understand why that may be a preferred route to what they're thinking. Many people have mixed perceptions of things or read testimonies that are incorrect because someone has a grudge on one or the other. And so what you do is you lay out the perspectives. If they're equally good, you don't add any bias to it. (P02)

One participant acknowledged bias as inevitable. However, they believe that experience helps mitigate the issue of bias:

I'm very sensitive to this issue. I would say if I'm unbiased, no way. Everyone has their own ideas and experiences. Everyone is biased one way or another. We try to present in an unbiased way. It is just human nature. You just try and find the best way. I found that you get better over time in dealing with being challenged by patients and ideas and being open to new ideas. Experience gives you flexibility. I think it also has to do with egos as well. I am definitely better than 25 years ago. (P07)

Findings related to SIT and agency theory

Power balance

When asked about how their authority affects the patient, many participants (7/15) stated that their authority is helpful and makes the interaction more comfortable for the patient. They described the patients coming to them for advice, to validate their experiences with a specialized and professional opinion.

I think when they come here to us, already they have the highest expectations because either they can come here because they didn't get the satisfactory treatment or approach elsewhere or they came here for unique things we do for newborn screening, or they're just referred to us because the other part didn't know what to do. (P15)

The physicians were open to SDM for treatment decisions, but not for the diagnosis. In particular, the choice of treatment administration routes is a shared decision to best fit the patient's lifestyle.

I would, usually, emphasise to the patient that in order to progress along this path of diagnosis to treatment, we need to do x, y, z. In order to understand the problem more clearly. There isn't usually very much of a discussion about the pro's and con's, and risk, benefit, cost, et cetera. Most of the time, during that process. There are circumstances where, specifically, cost will become an issue. (P04)

I mean sometimes somebody would say, "I want to try facilitated subcutaneous, because I heard about it." That's fine. That's great. If their insurance will let them have it, we'll get that for them. If somebody's on IV and wants to go to subcu, that's great too. (P12)

Physicians are aware of the power balance. Some physicians try to mitigate any intimidation by reading body language or maintaining a humble persona. However, they try to keep a professional distance to maintain some power in the relationship for the more difficult decisions.

That's an area that I've thought a lot about and kind of very conscious about, so I never address an adult patient of mine by their first name, no matter, I've known people for 30 years, I've gone to their kids' weddings or whatever, I never ever ever address an adult patient of mine except as Mr. or Mrs. or Ms. and I do it because I think I need to maintain a certain degree of professional distance, maybe part of that is to protect myself but part of that is there are certain times in a doctor–patient relationship when you have to say to somebody, you have to give somebody bad news or you have to say to them "I know this is what you want to do but I think this is really wrong". (P01)

Health literacy

The physicians mentioned how modern access to medical information is a double-edged sword, meaning it can be beneficial or detrimental to SDM. To mitigate

this risk, many participants had taken steps to have literature, links, decision aids, and other health information on-hand that they personally approve. One participant described going as far as to correct and manage Wikipedia pages to ensure their patients are exposed to the most relevant information.

So, there are people who have read x, y, and z on the 'net and they may consider themselves to be health literate but they're getting a lot of misinformation which can really cause problems. Because now you've gotta sort of undo what they've read and redirect them to what the actual reality is of the treatment. (P05) I think it's helpful; in general, I do. I think the internet is a great resource for people. Problem is when they go to chat rooms and hear weird things from different people, it means nothing. You have to use reputable sites, so we actually give out our list of reputable sites for information on immune deficiency for patients, so they can read at their leisure and look things up. (P03)

The physicians often (7/15) mentioned that there are no guarantees of patient adherence, whatever their education and health literacy levels. Some participants described examples of educated patients having poor outcomes due to non-adherence, while uneducated adherent patients had better outcomes. Participant P06 stated, "In fact, sometimes people who are very highly educated go out there and make up their own mind what they want to do, and it was a pretty dumb decision."

Patient networks are the personal and professional connections and programs that assist in providing access to the information and care to the patient population. Networks catering to the needs of particular groups such as teens may be particularly effective ([Shama and Reid 2018](#)). All participants of this study praised the patient and family support that patient networks, especially those through IDF and JMF, can provide. Some participants refer their patients to such networks as a resource for the more personal needs; physicians may not always appreciate some of the details of daily life with PID.

I feel like those patients feel like they have a plan. That they can go and find people . . . I think humans, by nature, are herd animals. When they find like-minded people that are going through the same thing, and they don't feel so isolated, then you don't have the anxiety, depression, and all of the other issues related to treating a child with a chronic disease or having a child with a chronic disease. They can find like-minded people that have been through the same things and can help them with the day-to-day things that I don't necessarily have advice for because I don't live with it every day. (P13)

Findings related to traits

Patient and physician traits inherently influence decision making. For instance, physicians may approach

patients as either individuals or examples of the disease (e.g., a patient with PID or a PID patient, respectively). Participant P02 made this distinction:

I think it's really good, but I always keep telling them, take everything with a grain of salt, because each patient is really their own individual disease process. We look at each patient as their own individual experiment. And so what's solely true for this other patient, and because you think the symptoms are the same, there only telling you a fraction of the process. And while that fraction may seem to match up, may not be the direction towards getting the right answer type of thing. So it's very helpful, but it also helps the patients to get guided to the right physicians to help with the thing. (P02)

Trust

Trust in the patient–physician relationship is built quickly or present from the beginning for immunologists, and is not built over multiple visits. Some participants credited their professional distance to the patient; usually by their formal or informal persona:

I think for my personality, and again, coming as a pediatrician, my patients call me by my first name, and because their parents call me by my first name, and so some of the kids will start calling me by my first name. And I've never been pretentious about that issue, and never tried to correct people on that. And so I think I come across, for myself, less intimidating, and so there's a trust that builds up because I'm not trying to snow them, I'm not trying to pull the wool over their eyes, I'm not trying to intimidate them, and so I think happens is because they realize I'm well educated, many actually want me to help more in the decision, not realizing that I'm psychologically trying to help them in the process. They're actually wanting more of my input. Even physicians I've dealt with. (P02)

Other physicians recognize that some patients will try to take advantage of trust or need to earn it depending on their intentions:

I use their noncompliance, or the dishonesty as evidence in a very professional and transparent way, as to why I feel the way I feel, and then I'm very clear that I'm going to document that this is my recommendation, and they don't take it, that they're going against medical advice. That it's their choice to go against medical advice, and if their child gets sick, there are consequences for that. I'm very clear about that and because when you set that expectation, in a patient that has good intentions, they will work with you. They will understand that they have been at fault, but if their intentions are good, and there's no secondary gain, then 9 times out of 10, they will actually comply with you. When there is secondary gain, then I have protected myself, and told them what the consequences would be and set expectations. When they fail to meet my trust again, then I can take recourse to protect the child. *[What would be the secondary gain?]* "My child is my proxy-ish" kind of thing. I don't know. Parents like the attention. That's what we consider secondary gain. For everybody, I don't know what that would be. (P13)

Culture/family

Cultural differences between the patient and physician influence the decision-making process to take an alternative approach to care. One physician pointed out encountering this differences with cultures such as Middle Eastern, African American, and Hmong patients:

And so, for example, I've dealt with individuals from the Middle East, and so one of the things we learn as being a pediatrician, obviously, is to make contact with the individual. And so shake their hand, depending on the severity of the process and things that are going on. Perhaps hold their hand a while. Usually a mother, or a female, or the child type of thing for that. Especially a child. Have them sit in your lap, you know younger children, sit in your lap while you're doing all this and hold them, so that you reach out. Some of the Middle Eastern cultures, you know, it's very offensive for a male to touch a female, for example. And so you have to learn to know that you can't use the same context for connecting. *[Is that something you just learned over time?]* Part of that was learning, but part of it was also when having interpreters and others that would help explain the cultural differences on there. In the U.S., African American tends to be more concerned about . . . So the African American, there is more distrust of the healthcare system. With good reason for a variety of the things that have occurred. And so you have to develop that trust from the very beginning, and honesty from the very beginning on there. And establish the fact that you recognize they're African American. You point out there's specific items and issues that are more unique towards African Americans than to Caucasians. And you, again, you create these, not boundaries, but openness to that where you can generate that trust, you know?! That "I'm not gonna be perpetrating on you things that are against your will, or that otherwise would be harmful. That color of your skin is not a barrier to being able to achieve the healthcare that you need." Hispanics, different cultural things. (P12)

This participant continued into an example of the decision-making process incorporating entire families:

Hmong believe in a lot of tribalism. From Southeast Asia. Gypsies. Gypsies are very interesting . . . they're always very distrustful of anyone because they think everyone's always out to get them. And usually, with the gypsies, you are in a room of ten people, because they bring in the elders and everybody to all that. (P12)

Findings related to organizational context

Coordination of care

Some participants adopted the role of coordinator of the patient's care because the patient–physician relationships are often long-term when treating PID. These immunologists, with a highly specialized knowledge-base, would assist in health-related appointments that could have implications for the management of PID.

... I'm a pediatrician so there I'm much more of a coordinator, but the continuity doesn't change, I think that's one of the really big things that we offer in our clinic is from the time that I started and I was the junior person with two people in the clinic, we decided the way we were going to operate is that each of us was just going to take new patients, we would split them up or whatever way it worked but once you had seen the patient that patient was just going to be your patient and whenever they came into the clinic for a follow-up, if it was my patient I would see that patient, if they were admitted to the hospital, I would go to see them in the hospital. (P01)

Other physicians prefer not to be considered the coordinator, but rather a temporary coordinator at most. Participant P06 was adamant about treatment roles between specialists:

... when it comes down to the therapy that I'm proposing; for example, immunoglobulin, or gamma interferon, or Rituxan, or antibio, or anything else, naturally, I'm going to coordinate and make that happen. I'm going to make sure it happens. If it's a person who has a gastrointestinal condition, it's not me. I'm not a gastrointestinal doctor. So I'm going to help them see that other doctor. So I'm going to coordinate on one hand, and do continuity on the other. Mine's continuity; the things that I have suggested. If I have to send them to a rheumatologist, or to a pulmonary doctor, their pulmonary hypertension, or their hematology, I have to send that person over to the other quadrant for all of that. (P06)

Rules related to time

Most of the participants specified that they treat patients over a long period of time (10/15) ranging from 10 years to a lifetime (5/15). Before receiving adequate chronic care, which can take approximately 5 years, the participants compared their meeting time with patients to the short appointments of primary care physicians. Participant P02 stated, "When I schedule patients, initial visit's an hour, an hour and a half when I was doing outpatient, and the follow-ups were 45 minutes to an hour depending on the needs of things". They emphasized the need for prolonged meetings to explore the patient's illness and lifestyle. The same participant drew concern to the state of medicine today:

... in the ideal world, as I think you're eluding to, what we'd have are primary care physicians that would be set up in a scenario where they would not be having to see 50 patients a day, but be able to see 25 patients a day. (P02)

Reimbursement

A common limitation of SDM is the reimbursement method; patients can only afford a limited selection of treatment options. Physicians are constantly battling with insurance companies regarding the treatment of patients with chronic diseases. Many have incorporated

strategies to "never lose" arguments with insurance, whereas others prefer to pick their battles.

Yeah, I don't win all the time. The big issue is that the insurance companies out there are not aware of what the evidence shows in the literature. Most of the time what they do is they rely on "physician review" and these physicians have absolutely no understanding of any particular field. ... Most of those cases get approved after a lot of fighting. Even then sometimes insurance companies are like no we're not doing this. (P14)

Findings related to feedback

Performance reviews

The physicians described the presence of feedback systems, but few found them useful. One physician stated the benefits of extended conversations with the patient, which allow for direct feedback. This direct feedback increased patient confidence in the physician:

I don't think I'm an intimidating presence. That's not my style at all. I mean, I will tell somebody if I think they're making a bad decision, certainly. But, I think because I really do try to make this a discussion, you know, a lot of feedback from the patient. I think most of the time they tell me they feel much more comfortable with the diagnosis, much more comfortable with the treatment plan, because we've had this conversation. And I do get a lot of referrals from people who come in and see me specifically. So, I think they feel like they've talked to somebody who's got a lot of experience, a lot of expertise. (P05)

However, most of the feedback is not useful or ignored. In most cases, the feedback comes from the patients in the form of surveys, wherein patients motivated enough to participate are often displeased with the physician; the conflict may be related to their illness or irrelevant topics. One physician describes the system of feedback and why they rarely view it anymore:

[Is there any systematic feedback?] There's not any systematic feedback. Usually ... I've been fortunate enough that no one has lodged a complaint against me where administration and patient advocacy have had to get involved. I have gotten feedback when patients have said nice things to me, nice things about me. I don't get consistent feedback and I think the only consistent mechanism, by way that the hospital has the patients rate us is through the Press Ganey surveys. After that incident where I had that horrible review online, I have stopped googling myself. I'm a caretaker, I'm a feeler. I take those things really personally because I don't want other people, and other patients, who I take care of to read something like that and then lose their trust in me because of something they read on the internet. These last two years is a perfect example of seeing things on the internet that aren't really true or not the full side of the story. They rely on that too much ... (P13)

Cost

One aspect of feedback that physicians are lacking is cost. Most physicians do not have direct feedback

regarding cost outcomes to treatment. One physician mentioned that the insurance companies will occasionally inform them of costs.

[In the 300 patients that you have, is there any way that someone looks at the cost of treating them over the course of the year and the outcomes? Is there any way that someone says, "Wow, here's the 300th." And why not?] You know, what I'll say is that there's no systematic way that is intentionally done for my individual patients that gives me feedback. I do hear from payers, from time to time, to say, "This patient on X asthma therapy," again, not talking about immunodeficiency, but kind of an easier disorder to talk about because there are just much more metrics in place to track quality and so forth, "you might consider stepping them down from drug X to drug Y." And I think that's based on guidelines. It's also based on cost. For sure. There's no doubt. I mean, let's face it. We all get that. So there are some of those things. There's also, even within our own system, like, our health plan covers women and children who are of lower income. It's a medical assistance, Medicaid-based payer. So we will get feedback on use of expensive medications and lower-cost alternatives. There are some of those things out there, but there is nothing that tracks, "Yeah, here's your 300 patients. 250 of them are optimally treated based on these outcome measures. You're providing as cost-effective care as you can based on the complexity level of the patient, available resources, et cetera" (P11)

Electronic medical records

The physicians' opinions were split regarding electronic medical records (EMRs). Some were enthusiastic because they could lead to better care coordination between physicians, whereas the others mentioned flaws such as accidentally nullifying clinical trial participants. Every participant that discussed EMRs described benefits and issues:

[Are electronic data records a good thing?] Oh yeah. I think so because I can read everybody's notes. *[Any downside to electronic records?]* Sometimes, you need to be careful what you really need to write. For example, some of the patients, but we do sometimes research testing, of course after getting consent, it's not ... But some other sub specialist that's taking care of the same patient for another thing, they ... If parents tell that to that doctor and they put it down, that's a problem because research data cannot be in the medical records for clinical care. They happen to me a couple of times which is difficult because then you have to addend. But, it's not good to disappear completely. If the medical records wants to go back and look at it, they can see it. It's going to go to the record that the other provider will see, but it will be in the records see, there is no way you can correct it or get rid of it. *[In general terms of caring for the patient]* It makes it very easy. (P15)

Discussion

Although SDM is widely advocated for being a patient-centric approach to care that is best used for the care of chronic conditions, the study findings

suggest that SDM in the management of PID is also influenced by "nudging" in toward the physician's choice of treatment. It was also evident that individual physicians have their personal thresholds for adopting SDM. For some of these thresholds, the physicians try to encourage particular choices while guiding the patient in SDM, such as having decision aids available for patient learning. Therefore, contrary to the literature, the paternalistic approach is not entirely obsolete but has adapted to the patient-centric movement of the last 30 years. Participants specifically mentioned use of SDM for the choice between subcutaneous and intravenous routes. In this context, the current Canadian guidelines for IgG replacement endorse patient choice when deciding on the route of administration (Betschel et al. 2017).

Other limitations of this study involve the sample, which was not demographically diverse and was recruited based on participant availability rather than being a truly random sample, thereby exposing the study to potential bias, although there is no evidence that the sample participants did not accurately represent the population of immunologists in the US. Future research might purposefully recruit a larger sample across the widest demographic range, in order to obtain insights about treatment decisions by female and minority physicians. Furthermore, all but one of the participants had more than 10 years' experience in the immunology specialty. It may well be that immunologists with less than 10 years' experience make treatment decisions differently. The study did not consider physicians outside the immunology specialty who treat patients with PID.

In conclusion, this study offers an analysis of physician decision-making for the treatment of PID. It may also be useful as an example of how treatment decisions are made in the management of a lifelong chronic disease that incurs high treatment costs. It also expands on the literature by characterizing the boundaries in which SDM exists. Immunologists are open to incorporating SDM as long as the patient is aligned with the suggested treatments; the physicians likely nudge the patient to that alignment if necessary. Understanding physician perspectives of SDM and how they guide it in clinical practice has practical implications for the care of patients with chronic illnesses. Forming an environment which favors SDM can lead to better treatment outcomes and reduce overall costs and, for this reason,

policy makers and departments responsible for setting treatment policies—such as hospital standards or insurance reimbursement—may also benefit from a greater understanding of how SDM works in real life settings.

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Appendix A

Interview guide

Introduction and Explanation—read to the interviewee before proceeding

- a. Greeting → “Hello [*name of participant*]. Thank you for taking the time to meet with me today. Your participation is greatly appreciated. Before getting started, there are a couple things I would like to cover.”
- b. Purpose and Format of Interview → “As a current student in the Case Western Reserve University Doctor of Management (DM) program, I am interested in developing a greater understanding of the factors that influence physician decision making for the treatment and management of PID. I will ask you a series of open-ended questions on this topic, and I will ask one or more follow-up questions as you respond. The interview will last approximately 60 to 90 minutes.”
- c. Confidentiality → “Everything you share in this interview will be kept in strictest confidence, and your comments will be transcribed anonymously—

omitting your name, anyone else you refer to in this interview, as well as the name of your current organization and/or past organizations. Your interview responses will be included with all the other interviews I conduct.”

- d. Recording → “To help me capture your responses accurately and without being overly distracting by taking notes, I would like to record our conversation with your permission. Again, your responses will be kept confidential. If at any time, you are uncomfortable with this interview, please let me know and I will turn the recorder off.”
 - a. “Do you have any questions before we begin?”

Introduction

1. Name
2. Education
3. Current job title and responsibilities
4. Years of experience (total + specialty as an immunologist)
5. Involved with research (clinical or otherwise)
6. Practice setting/site of care (multiple?)
7. How many PID patients have you treated in your career/how many now?
8. What is the average length of time with the patient?
9. Most have co-morbidities?
10. Are all receiving IG: IV or SC?

Focus in on factors that determine how you make decisions

1. Describe a typical patient
 - a. How do they get to you?
 - b. Diagnosis to treatment to maintenance
2. Describe the types of decisions you make?
 - a. SC vs IV
3. Do you use decision aids (describe/evidence-based?)
4. Do you find that your patients are educated or well educated on self-management?
 - a. High levels of self-efficacy (I am confident I can manage my situation)
 - b. High levels of self-activation
 - c. Do you think more informed patients result in fewer health resources and better outcomes?
 - d. Are you patients actively involved in patient networks (IDF, JMF, internet networks such as patients-like-me)?

- e. Do you have a patient portal where patients can review their health history?
5. What seeing a patient: look for patterns that match past experience?
 - a. Tend to quickly assess symptoms and diagnosis or it's a slow painstaking process that has lots of complexities (particularly with comorbidities)
 - b. Tend to spend more time on protocol or treatment
 - c. Would you describe yourself as patient-centric or evidence centric (Evidence-based medicine)?
6. If you were to guess: do you as the physician make the final treatment decision or leave it up to the patient
 - a. Protocols
 - b. Drugs
7. Does your DM style vary based on the patients' level of understanding and interest?
 - a. Does it vary based on complexity or uncertainty?
8. Do you think your status as a physician or authority figure influences how patients respond to you in a clinical setting?
 - a. Is Intimidated or encouraged to share information or
 - b. More likely to tell you their treatment preferences or express an option on treatment options?
9. Do you routinely ask about patient preferences: lifestyle and how treatment will affect patient goals and values?
10. When discussing pros and cons of a potential treatment (protocol or drugs) do you tend to lead with the pros or cons
11. How much and in what way do cost or reimbursement influence your decision making
 - a. Protocol
 - b. Drug
12. Do patients want to play an active role in their decisions
 - a. Function of health literacy
 - b. Function of health numeracy
13. Do you see yourself a continuation of care or coordinator of care?
 - a. Is coordination of care an issue for your PID patients
 - b. Are patients actively looking for you to coordinate their care?
 - c. Do your PID patients have problems accessing healthcare services or getting adequate treatment?
14. Have you ever made a mistake/misdiagnosis?
 - a. Proper follow-up
 - b. Diagnostic test
 - c. Adequate history
15. Prefer face-to-face or is phone or internet possible and how often
16. Trust → impact on patient participation
17. Does DM change over time as uncertainty changes
 - a. Less shared decision making
18. Provider number
19. Are you rated? Do you recall your score?
20. How would you assess or describe the quality of your communication style?
 - a. Outgoing
 - b. seeking
21. Do patients tend to speak up or does it depend of the context and your relationship
22. Impact of the organization on your decision making
 - a. IOM: patient-centered care: patient perspectives are now being factored into Medicare value-based payments to hospitals