

## WHO DECIDES FOR THE PATIENT? A REVIEW OF LITERATURE ON MEDICAL DECISION-MAKING IN PAKISTAN

Farid Bin Masood<sup>1</sup>

### ABSTRACT

*Over the past two decades, a growing body of literature has examined medical decision-making in Pakistan across diverse clinical contexts, but the evidence remains fragmented because many studies are small in scale, disease-specific, or focused on a single stakeholder group. This review synthesizes published literature to identify prevailing attitudes, preferences, and practices concerning the roles of patients, families, and physicians in medical decision-making. A focused literature review with thematic synthesis was conducted using Google Scholar, supplemented by reference-list screening, organized through a stakeholder-centered framework comprising three interconnected lenses: patient/public perspectives, healthcare provider perspectives, and conceptual/ethical frameworks. The findings suggest that medical decision-making in Pakistan is shaped by the socio-cultural and structural context in which care occurs. Rather than fitting neat binaries of individual autonomy versus collectivism, or a simple account of paternalism, decision-making appears to operate through a relational structure in which patients often want substantial information and recognition, families remain central to care and deliberation without necessarily being desired to lead, and physicians are trusted to provide both expertise and direction. The central task, therefore, is to make this relational process more ethically robust by further exploring patient and public perceptions and aligning decision-making practices with the cultural and socioeconomic realities of the Pakistani context.*

**Keywords:** Medical Decision Making, Autonomy, Paternalism, Family, Collectivism

### 1. INTRODUCTION

Medical decision-making rarely involves only technical judgment; instead, they emerge from interactions among patients, families, healthcare professionals, and the information, beliefs, and preferences each stakeholder brings to the clinical encounter (Laidsaar-Powell et al., 2013). Although the aim

<sup>1</sup>Senior Lecturer, Centre of Biomedical Ethics & Culture (CBEC), SIUT, Karachi.  
Email: faridbinmasood8@gmail.com

of medical decision-making is to arrive at choices aligned with the patient's best interests, the process through which those choices are made is neither universally uniform nor value-neutral (Alden et al., 2018).

A substantial literature demonstrates that decision-making patterns vary across societies, particularly along the spectrum of individualism and collectivism (Alden et al., 2012; Alden et al., 2015; Alden et al., 2018; Charles et al., 2006; Samanta & Samanta, 2013). The decision-making process is further influenced by religion, social hierarchy, health literacy, gender norms, power dynamics in the patient–doctor relationship, and structural features of the healthcare system such as cost. These contextual differences are not merely theoretical. They shape who receives medical information, how risks and options are communicated, who is expected to deliberate, and ultimately who decides. A nuanced understanding of medical decision-making therefore requires attention both to the socio-cultural environment in which decisions occur and to the heterogeneity of preferences among the stakeholders.

Pakistani society is characterized by predominantly collectivistic values and strong family centrality (Zaman, 2014). Familial interdependence and obligation commonly shape major life choices, which also includes health-related decisions. These social features intersect with a healthcare system that is fragmented across public and private sectors, heavily reliant on out-of-pocket payments, and marked by constraints in resources and access (Moazam, 2000). Together, these factors shape both the ideals and the realities of medical decision-making.

Over the past two decades, a modest but growing body of literature has explored medical decision-making in Pakistan across diverse clinical contexts, including oncology (Hussain et al., 2014; Jawaid et al., 2010, Kumar et al., 2010), nephrology (Malik et al., 2022), diabetes (Baig et al., 2020), antenatal care (Ahmed et al., 2018; Ahmed et al., 2019), orthopedics (Rahman et al., 2019), end of life care (Saeed et al., 2020) and pediatrics (Khowaja-Punjwani, 2018). However, most of these studies are small in scale, disease-specific, or focused on a single stakeholder group. Consequently, the literature remains fragmented, and a comprehensive synthesis of existing evidence is lacking.

The objective of this review is to identify and synthesize the published literature on medical decision-making in Pakistan. The review aims to map prevailing attitudes, preferences, and observed practices relating to the roles of patients, families, and physicians, drawing on both normative statements about how decisions should be made and descriptive accounts of how they are made in clinical practice. By identifying recurrent themes, patterns, and contradictions, this review seeks to provide a structured and evidence-based

overview of medical decision-making in the Pakistani context and to highlight areas where further research is needed.

## **2. METHODOLOGY**

This review used a focused literature review with thematic synthesis to examine how medical decision-making has been described and analyzed in Pakistan. Given the conceptual and methodological heterogeneity of the literature, the review was designed to retain differences in perspective rather than collapse them into a single undifferentiated set of themes. To do so, the analysis combined a stakeholder-centered analytical framework with a structured thematic coding process.

### **2.1 Literature Search and Study Selection**

Studies were identified primarily through Google Scholar using the search terms “medical decision making” and “Pakistan.” The rationale for prioritizing Google Scholar was that locally produced literature in Pakistan is often published in unindexed or regionally focused journals that do not appear in PubMed or other international databases (McDonald et al., 2024). This exclusion occurs for multiple reasons, including high publication charges, low impact factors, and the limited willingness of journals in high-income countries to publish data from low- and middle-income countries (LMICs) (Sun & Litavec, 2025). As a result, Google Scholar provided the most comprehensive access to both empirical and conceptual work relevant to the Pakistani context.

The search was designed to capture both empirical and conceptual literature relevant to healthcare decision-making in the Pakistani context. In addition to database searching, the reference lists of identified studies were examined to locate further relevant sources that may not have been retrieved in the initial search. All records identified through these processes were reviewed, and duplicate records were removed before screening.

A total of 32 records were identified through database searching and reference list checks. After removal of duplicates, 28 records remained for screening. Of these, 8 records were excluded for not substantially addressing medical decision-making, being too focused on procedural consent or disclosure only. The full texts of 20 articles were assessed for eligibility, all of which met the inclusion criteria and were retained in the final sample. The inclusion criteria required that articles address medical decision-making and be either conducted in Pakistan or consist of commentary, editorial, or opinion-based work written by Pakistani authors for the Pakistani context. Studies were excluded if they did not substantially concern healthcare

decision-making or were not situated in Pakistan. The search and selection process included all eligible studies published up to the end of 2025.

## **2.2 Analytical Framework**

To synthesize this diverse body of literature, the review adopted a stakeholder-centered analytical framework organized around three complementary lenses: patient/public perspectives, healthcare provider perspectives, and conceptual/ethical frameworks.

The patient/public lens focused on the experiences, preferences, expectations, and reported involvement of those receiving care. This perspective enabled a bottom-up understanding of how decision-making processes are experienced by patients and families and how these processes are evaluated by those most directly affected.

The healthcare provider lens examined clinicians as central actors in the decision-making process. This lens was used to identify how professional norms, institutional routines, and practice-related constraints shape communication, authority, and participation in clinical decisions.

The conceptual/ethical lens captured theoretical discussions, editorials, and normative analyses that sought to interpret, critique, or model decision-making in the Pakistani healthcare context. This lens provided the interpretive scaffolding needed to situate the empirical findings within broader debates on autonomy, relationality, responsibility, and ethics.

## **2.3 Thematic Framework**

The synthesis was guided by six a priori themes selected for their relevance to decision-making in healthcare. These themes were used as an organising framework for reviewing and comparing findings across studies:

1. Information disclosure and communication: patients' desire for information, communication practices, and reported patterns of disclosure.
2. Patient involvement: patients' preferred and actual participation in decision-making, including barriers to involvement.
3. Role expectations and relational dynamics: expected and observed roles of patients, family members, and physicians in decision-making.
4. Contextual determinants and constraints: variations in decision-making associated with gender, education, socioeconomic position, disease type, and care setting.
5. Procedural and experiential dimensions: practical aspects of decision-making processes, including informed consent, perceived exclusion or neglect, satisfaction, and clinicians' moral distress.

6. Conceptualizations of decision-making: how decision-making, autonomy, and related concepts are defined, interpreted, and operationalized in the Pakistani context.

## **2.4 Data Extraction and Synthesis**

Findings relevant to each of the six pre-defined themes were extracted from each included study into a structured coding matrix. In the initial round of coding, 45 first-order codes were generated inductively across the three analytical lenses (patient/public, healthcare provider, and conceptual/ethical). These codes captured recurring patterns and illustrative examples. A second round of coding was then conducted to refine and consolidate overlapping codes, resulting in 22 second-order codes organized under the six thematic categories.

This process ensured that both convergence and divergence across studies were retained rather than collapsed prematurely. For example, within the theme of patient involvement, codes ranged from “expressed desire for disclosure” to “experienced exclusion in dialysis,” highlighting the preference–practice gap. Similarly, under family involvement, codes captured both supportive caregiving roles and ethically ambivalent substitution of patient authority.

The final synthesis was produced by integrating these refined codes within and across the three stakeholder-centered lenses. This process generated descriptive analytical statements for each theme, allowing the review to capture both the substantive content of the literature and the different standpoints from which medical decision-making in Pakistan has been understood.

## **3. FINDINGS**

A total of 20 studies were included in this analysis, spanning publications from 2000 to 2024 (See Table 1 for overview). The majority (n = 15) were published between 2010 and 2024, reflecting a growing body of literature on medical decision-making in Pakistani healthcare contexts. The studies varied considerably in methodological approach: quantitative surveys were the most common design (n = 9), followed by qualitative studies using individual or focus group interviews (n = 7), with the remaining articles were opinion articles (n = 2), a comparative case analysis (n = 1), an ethnographic study with participant observation (n = 1), and a Q-sort methodology (n = 1). The populations studied were diverse, encompassing patients, caregivers, and healthcare providers across a range of clinical conditions and settings. Patient populations included cancer patients (Studies 3, 4, 11, 12), dialysis patients

(Studies 8, 13), chronically ill patients (Studies 10, 18), antenatal screening participants (Studies 16, 17), orthopedic patients (Study 14), and parents of pediatric patients (Study 9). Healthcare provider perspectives were represented across several studies, including physicians (Study 2), endocrinologists (Study 6), and clinicians managing self-harm presentations (Studies 15, 20). Geographically, the studies were concentrated in major urban centers, particularly Karachi (Studies 2, 4, 7, 9, 14) and Lahore (Studies 6, 16), with others drawing from multiple sites across Pakistan (Studies 12, 13) or from settings such as Quetta (Study 10) and Multan (Study 11).

### **3.1 Patient/Public Perspectives**

#### **3.1.1 Information desire is generally high, but communication is inconsistently delivered.**

Across cancer-focused studies, most patients report wanting comprehensive diagnostic and treatment-related information, including prognosis and treatment alternatives (Hussain et al., 2014; Jawaid et al., 2010; Zafar et al., 2016). This finding challenges persistent assumptions that patients in Pakistan generally prefer non-disclosure. Instead, the evidence consistently indicates that many patients seek clinically relevant detail and often prefer that such information be communicated directly by physicians (Hussain et al., 2014; Jawaid et al., 2010). In contrast, studies of real-world practice document notable gaps between preferences and delivery, with information frequently filtered, delayed, or redirected to family decision-makers, particularly in contexts of severe or advanced illness (Jafarey & Farooqui, 2005; Moazam, 2000; Memon et al., 2024a).

In one oncology sample, 76.2% of patients wanted disclosure of their diagnosis, 83.7% preferred receiving that information directly from physicians, and 69.4% expressed a desire to be actively involved in treatment decision-making. Notably, 55.8% explicitly disagreed with families being informed without prior patient knowledge (Jawaid et al., 2010). A second oncology cohort yielded comparable findings: 71.9% wanted full disclosure regardless of favorability, 94.3% wanted prognostic and cure-related information, and 68.0% specifically requested information about treatment side effects (Hussain et al., 2014). Even in advanced cancer, three out of five patients reported wanting detailed prognostic and life-expectancy information (Zafar et al., 2016). Taken together, these figures reinforce the argument that non-disclosure cannot be treated as a culturally universal or default patient preference.

### **3.1.2 Stated preferences for involvement do not reliably translate into experienced involvement.**

Studies document substantial participation deficits, including extremely limited direct patient involvement in some public-sector settings and pronounced inequities by gender and educational attainment (Waheed et al., 2020). Across oncology settings, many patients report an interest in participating in treatment decisions, yet decision-making pathways remain predominantly physician-led or mediated through family members in practice (Hussain et al., 2014; Jawaid et al., 2010; Kumar et al., 2010). In another study, 4.1% of respondents reported being asked their treatment preference, and just 5.6% described having a mutually agreed treatment plan; large majorities (approximately 79.6%–84.3%) disagreed that treatment advantages and disadvantages had been adequately explained, and alternatives were reportedly discussed in only about 5% of cases (Waheed et al., 2020).

Evidence from dialysis care is particularly salient, as high levels of decisional dissatisfaction and regret are reported alongside limited prognostic disclosure and minimal communication with the patient (Malik et al., 2022; Saeed et al., 2020). While 54% of patients reported they wanted prognostic information, 80% stated that no prognostic discussion had occurred. Similarly, 63% considered end-of-life planning important, yet only 5% recalled such a discussion with a physician in the previous year; and nearly 62% reported regret about initiating dialysis on doctor's advice (Saeed et al., 2020).

Qualitative studies add texture to these figures, describing patients who "felt poorly informed and resented their decision to initiate dialysis" (Malik et al., 2022). A patient described informational gap regarding dialysis "They do cleaning with this machine. I do not know what things [they] remove from the inside [the body] with this machine." She linked consent regret to unrealistic counseling: "The doctor said your kidneys would recover after two or three dialysis sessions. Now it is the second year of dialysis" (Malik et al., 2022). Another patient talking about communication gap noted that "the patient should be considered a human being," and that patients are often not even asked how they are feeling (Malik et al., 2022).

Taken together, these findings point to a recurring preference–practice gap across clinical domains.

### **3.1.3 Family involvement is structurally central, functionally beneficial, and ethically ambivalent.**

Across literature, family participation emerges not as peripheral but as foundational to decision-making ecologies in Pakistan (Aslam et al., 2005; Jafarey & Farooqui, 2005; Moazam, 2000). Families routinely provide financial

support, caregiving labor, transportation, and continuity of care, and these roles become salient in chronic and resource-intensive conditions such as dialysis and cancer (Malik et al., 2022; Saeed et al., 2020). In cancer contexts, patients themselves often express a desire for family members to be informed and involved (Hussain et al., 2014; Jawaid et al., 2010).

At the same time, family centrality can shift into substitution. Multiple studies describe situations in which relatives request non-disclosure to the patient or assume decisional authority for themselves, particularly when prognosis is poor or treatment options are limited (Jafarey & Farooqui, 2005; Moazam, 2000; Memon et al., 2024a). This produces tension: the same relational structures that offer social protection and practical care can also constrain patient involvement.

Moazam's clinical vignette captures this family-mediated logic with particular clarity. After learning of a metastatic cancer diagnosis, relatives asked the physician, "We do not want him to know that he has cancer," followed by, "Doctor Sahib, tell us what we should do next" (Moazam, 2000). The same account notes that families and clinicians may justify non-disclosure or partial disclosure as a way of "protecting the patient," often by communicating in deliberately "ambiguous terms" (Moazam, 2000). These formulations are significant because they reveal that concealment is framed as care rather than control.

This dynamic is corroborated in other oncology studies, where family attendants resisted patient disclosure at high rates (Jawaid et al., 2010; Zafar et al., 2016). This thus cannot be evaluated in simple autonomy-versus-family dichotomy. Hence, family involvement operates simultaneously as a source of support and as a site of ethical tension.

#### **3.1.4 Patients' expectations of doctors combine trust, deference, and desire for guidance.**

Multiple studies indicate that patients often expect physicians to lead the decision-making process and, in some settings majority, prefer that physician makes the decision (Baig et al., 2020; Kumar et al., 2010; Qidwai, 2003). Yet this should not be misread as a desire for informational exclusion. Most patients appear to prefer a kind of informed guidance. They want doctors to explain options and risks, but also value clear recommendations in moments of uncertainty and distress (Hussain et al., 2014; Jawaid et al., 2010; Zafar et al., 2016). This pattern is better interpreted as guided participation than as simple passivity.

Provider narratives also illuminate why this trust can drift into deference. In a study in diabetes context, physicians described patients as

hesitant to question doctors and, in some cases, viewing the doctor as a paternal “messiah” (Baig et al., 2020). This is important because it signals a moral authority, not only technical authority. This authority may stabilize adherence to treatment regimen, but it may also suppress question-asking and preference expression in decision-making process.

### **3.1.5 Determinants of participation and preference are patterned, not random.**

Education emerges repeatedly as a predictor of higher involvement and better shared decision-making (SDM) engagement, functioning to facilitate participation preferences (Waheed et al., 2020). In cancer studies, literacy was significantly associated with earlier disease suspicion ( $p = .03$ ) and awareness ( $p = .05$ ) (Kumar et al., 2010). Patients' health literacy also shapes the entire trajectory of care and often enabling patients to actively question physicians' decisions (Rahman et al., 2019). However, from the provider perspective, the impact of formal education is sometimes contested. Gender differences are also significant, reflecting general societal patterns. Male patients consistently report higher involvement in decision-making process (Waheed et al., 2020), while women usually encounter gendered constraints, sometimes apparently willingly or expectedly “assuming a back seat in the decision making process” (Jafarey & Farooqui, 2005). In a study in antenatal screening context, women strongly reject autonomous decision-making in favor of shared decisions led by their husbands (Ahmed et al., 2018). Providers also note that in strong family setups, the eldest or dominant male member typically acts as the primary decision-maker for all others (Baig et al., 2020). Socioeconomic position is also an important determinant as financial strain significantly influences decision-making (Rahman et al., 2019). Waheed et al. (2020) reported significant associations between monthly income and patient's involvement in decision-making, consistent with evidence from another study where respondents with household incomes below PKR 25,000 were significantly more likely to prefer that information be withheld from patients (Zafar et al., 2016). Finally, contextual clinical factors like age and disease severity also shape preferences. Those aged 60+ with advanced cancer were about half as likely to request detailed prognosis as compared to patients with breast cancer. Respondents with lung and gastrointestinal cancers were approximately 21 and 6 times more likely, respectively to prefer information routed to family rather than directly to themselves (Zafar et al., 2016).

### **3.1.6 Decision-making outcomes show why communication matters.**

Studies in context of cancer report heterogeneous anxiety responses, and dialysis literature documents high decisional dissatisfaction and regret when communication and preparation are weak (Jawaid et al., 2010; Malik et al., 2022; Saeed et al., 2020). Pediatric consent literature adds another layer: parental endorsement of consent does not necessarily imply support for child assent, highlighting a gap between procedural compliance and participatory ethics in younger populations (Khowaja-Punjwani, 2018). Overall, emotional outcomes reinforce that decision quality cannot be inferred from consent form completion alone.

Decision-making outcomes show why communication matters, particularly given the stark gap between patients' desire for comprehensive information and their actual receipt. Cancer disclosure studies report heterogeneous anxiety responses when information is poorly managed, as illustrated by Kumar et al. (2010), where 72.2% of patients believed they were adequately informed about side effects, yet only 39.6% possessed accurate knowledge about their disease course. The dialysis literature also documents the high decisional dissatisfaction and regret that emerge when communication is weak. Patients report feeling unacknowledged (Malik et al., 2022). Furthermore, instances of providers giving "false hopes" generate resentment and undermine the very foundation of decision-making, prompting regretful reflections from patients stating they "would not have opted for it" had they been given accurate information (Malik et al., 2022). Providers themselves acknowledge structural culpability in these outcomes. Severe time constraints and heavy workloads also lead to shortened interactions (Baig et al., 2020). Overall, these outcomes reinforce that decision-making is more than a technical procedure.

## **3.2 Healthcare Provider Perspectives**

### **3.2.1 Clinicians acknowledge ideals but report constraints.**

Clinicians do acknowledge the ideals of involvement of individual patients in decision-making but in studies like that of Jafarey and Farooqui (2005), they report a concern "whether [they] as physicians were imposing 'foreign' values on the patients by thrusting upon them unwanted and unsolicited autonomy." They also describe substantial contextual constraints on achieving the ideals in practice that impede these standards in real clinical environments. Physicians frequently cite family dominance, literacy variation, stigma, and resource limitations as major obstacles, particularly in settings with compressed consultation times and limited communication support (Baig et al., 2020; Memon et al., 2024a, 2024b). Because of these variable factors,

decision-making dynamics manifest variably. Jafarey and Farooqui (2005) observed a “wide divergence of view,” ranging from near-complete disclosure to “outright deception.” They also described the interpreter bottleneck: “I take ten minutes to tell the interpreter what is wrong ... and he takes inside of a minute to talk to the patient and obtain the thumb imprint.” Similar pressures appear in diabetes clinics, where consultants reported workload compression and even intimidation-by-delay tactics: “after a wait for three hours, they don’t want to talk a lot” (Baig et al., 2020). Consent-focused studies echo these themes. “Family deciding for patients,” “Gender disparity in consent process,” and clinician-reported implementation challenges appear as central patterns in analyses of everyday consent practice (Memon et al., 2024a, 2024b).

### **3.2.2 Shared decision-making barriers are both structural and relational.**

Diabetes-focused qualitative work identifies time pressure, insufficient communication training, and patient hesitancy to question doctors as major barriers to involvement of patients in decision-making process (Baig et al., 2020). Similar themes emerge in broader patient-centered care studies, where both providers and patients emphasize the importance of empathy and counseling but point to lack in continuity of care and weak team-based coordination as persistent shortcomings (Rahman et al., 2019). Together, these findings show that low patient involvement is not simply a reflection of clinician preference, it is produced through interacting system-level and sociocultural constraints.

At the same time, provider narratives indicate that perspectives are shifting, though variably. In Baig et al. (2020), one physician noted, “Shared decision making is a relatively new concept for me...but now my perspective has changed, and now I try to involve the patients in decision making,” while another stressed that “Shared decision making is only possible if the doctor acknowledges his role as a facilitator and not as the sole decision-maker.” Most consultants in that study simultaneously maintained that majority of the patients are also interested. “If you talk to them, they participate in the treatment program” (Baig et al., 2020).

Provider satisfaction with involvement processes was similarly heterogeneous. Jafarey and Farooqui (2005) reported higher satisfaction among clinicians with less time pressure, and lower satisfaction among those dependent on interpreters. Surgeons were often the least satisfied with information-delivery processes. Such findings help explain why some clinicians explicitly acknowledged participation failures. As one physician reflected, “A small percentage of patients do perhaps come up and say, ‘well, you tell us,’...I

think that's a failure on my part because I haven't been able to involve them properly" (Baig et al., 2020).

Experiences in orthopedic settings further illustrate this complexity. Rahman et al. (2019) noted a clear preference among participants for "a collaborative decision-making process," yet found that even well-educated patients who had searched online often asked clinicians to decide on their behalf. This placed providers in a difficult facilitative role, navigating between their ideal of supporting patient involvement and responding to requests for an authoritative role.

### **3.2.3 Physicians balance their duty to comfort patients vs truthfulness.**

Studies in nephrology and oncology settings show that many patients desire comprehensive prognostic information and meaningful communication. For instance, 94.3% of cancer patients desire detailed information (Hussain et al., 2014), and 60% of those with advanced cancer seek explicit information about life expectancy (Zafar et al., 2016). Similarly, 67.6% of dialysis patients view detailed medical information as highly important (Saeed et al., 2020). Yet, documented physician-patient discussions on prognosis and end-of-life planning remain infrequent in key settings. Clinicians frequently bypass direct patient disclosure, often confronting family members first to hurriedly arrive at a joint strategy, or utilizing euphemisms like "growth" rather than "cancer" to avoid patient distress (Jafarey & Farooqui, 2005; Jawaaid et al., 2010).

This mismatch places clinicians in ethically complex positions where they must balance non-maleficence concerns, entrenched family expectations, patient rights, and resource realities. The tension between truthfulness and protecting patients from distress is articulated by providers who operate under the protective paradigm that "the job of a doctor is to reassure and comfort the sick, not to frighten them" (Jafarey & Farooqui, 2005). Consequently, clinicians may intentionally exclude distressing facts or present an overly optimistic picture, a practice sometimes tacitly supported by patients themselves, half of whom in one study agreed providers were right to withhold information if they feared a loss of patient hope (Zafar et al., 2016). Furthermore, these ethical dilemmas are compounded by systemic resource realities, such as severe time constraints (Baig et al., 2020), and economic pressures, including the candidly expressed fear by physicians of losing patients to competitors by providing too honest a prognosis (Jafarey & Farooqui, 2005).

### **3.2.4 Provider authority persists but is increasingly questioned from within the system.**

Earlier discourse on paternalism characterized the patient as a passive recipient within traditional practice models (Qidwai, 2003). More recent provider-focused research reflects growing awareness that such models are inadequate for contemporary chronic disease management and for ethically robust consent practice (Baig et al., 2020; Memon et al., 2024a). Literature thus depicts not a static culture but an evolving one. Clinicians increasingly recognize the need for patient involvement yet continue to work within contexts that do not support it. Jafarey and Farooqui (2005) also reported that clinicians often link the nature of interaction to perceived patient "level of intelligence." One survey reported substantial support for physician-dominant planning and a "guardian" model while simultaneously documenting endorsement of patient autonomy among many respondents, illustrating a transitional status rather than consensus (Baig et al., 2020).

## **3.3 Conceptual and Ethical Frameworks**

### **3.3.1 The core conception is a relational autonomy.**

Conceptual bioethics analyses argue that cross-cultural medical practice requires broader interpretations of respect and autonomy than narrow individualistic formulations (Padela et al., 2015). Nuance is especially important in relational-autonomy debates. For example, in an antenatal screening study majority viewpoint held by participants was that autonomous decision-making involved spouses in making decisions rather than individual choice, and a follow-up analysis revealed that women preferred decision-making "with health professionals and/or their partner" (Ahmed et al., 2018, 2019). Participants reported trusting professional intent noting that many "believed that doctors acted in patients' best interest." In another study doctors report that patients "don't want a doctor who is just explaining it to them" (Baig et al., 2020). In a study 62.9% of dialysis patients view active family involvement in medical decision-making as essential (Saeed et al., 2020). These formulations specify the social conditions in which autonomy manifests.

From the professional side, the authors describe a relatively explicit model preference: HCPs "endorsed parents' autonomy for screening decisions, including non-directiveness" and viewed it as "the couple's responsibility to make decisions ... based on their own circumstances and values." But physicians in another study voiced a pragmatic reality where they are concerned whether they are imposing "foreign" values by "thrusting upon them unwanted and unsolicited autonomy" and describe that in practice, there is "no difference between the patient as an individual and his family. Both are

one and the same" (Jafarey & Farooqui, 2005). This is because they interact with patients who experience illness as a shared experience within a familial network rather than confined to the individual alone.

### **3.3.2 Paternalism in Pakistan is layered rather than singular.**

The literature describes physician-led paternalism, family-mediated paternalism, and negotiated forms where patients request directive guidance (Aslam et al., 2005; Kumar et al., 2010; Qidwai, 2003). This layered pattern matters because ethical evaluation depends on distinguishing coercive substitution from requested support. A framework that treats all physician guidance or all family involvement as ethically equivalent misses this complexity.

Empirically, this layered paternalism can be seen in three forms. First is classic physician-led paternalism, described in older language where the "patient is just a passive recipient" (Qidwai, 2003). Second is family-mediated paternalism, where relatives become gatekeepers of what the patient is told and when (Jafarey & Farooqui, 2005; Moazam, 2000). Third is requested decisional delegation, where patients explicitly ask the doctor or family to decide, often under severe uncertainty or financial strain (Aslam et al., 2005; Kumar et al., 2010). Distinguishing these forms is crucial because they differ in ethical implications. Qidwai (2003) captures the social legitimacy of authority language directly: 61.4% reported that the doctor is next to "God." Doctors are also placed alongside the "father, priest, or molvi" as authoritative figures not to be questioned (Baig et al., 2020). This helps explain why many Pakistani patients can simultaneously seek full information and still prefer directive recommendation.

### **3.3.3 Ethical decision-making requires moving from process to integrity.**

Studies on informed consent repeatedly show that signatures and filled forms are insufficient procedural checklists if understanding is weak, options are not clearly communicated, or patient preferences about role and disclosure are not elicited explicitly (Jafarey & Farooqui, 2005; Memon et al., 2024a, 2024b). Clinicians' own accounts also show how family-centered practice is institutionally routinized. Jafarey and Farooqui (2005) reported that all physicians "accepted the key position enjoyed by the family" and that most treated patient and family as "one unit." In suspected cancer, physicians were described as often confronting family first and then "hurriedly" developing a joint disclosure strategy before approaching the patient (Jafarey & Farooqui, 2005). Even in pediatric literature, this extends to the recognition that parental

consent does not necessarily extend to child's involvement (Khowaja-Punjwani, 2018). A procedural-ethics lens is therefore not appropriate.

### **3.4 The Operative Model**

The literature reviewed here suggests that the operative model of medical decision-making in Pakistani society is best understood not as simple paternalism, nor as straightforward individual autonomy, or a family led decision-making. It could be described as family-inclusive, physician-guided, informed participation often with delegated decisional trust to physicians. In this model, patients want meaningful and often detailed medical information about diagnosis, prognosis, treatment options, and side effects. Patients desire to know what is happening to them and to receive that information directly from physicians. They also often want some degree of involvement in treatment decisions. However, involvement usually does not take the form of isolated, self-sufficient individual choice. Rather, patients tend to participate within a relational setting shaped by family interdependence, economic constraints, and trust in medical authority to the level of a guiding figure.

The family occupies a structurally central place in this model. Relatives provide financing, transport, emotional support, and continuity of care, especially in chronic and high-burden conditions such as cancer and dialysis. Therefore, family inclusion is not merely a cultural preference but often a practical necessity. Yet the same family structures that support patients can also substitute for them. Relatives may request non-disclosure, filter information, or assume decisional authority, particularly when prognosis is poor. Thus, the operative model is not accurately described as purely family-centered in a traditional sense. It is more precisely a negotiated field in which patient voice and family involvement coexist, but not always on equal terms. Physicians are generally expected to do more than neutrally present options. Patients often trust doctors for guidance and may actively prefer recommendations, especially under uncertainty and distress. This indicates delegated decisional trust rather than passive exclusion. Patients do not desire passivity, instead, they want informed guidance from someone they regard not just technically authoritative, but also morally. At the same time, the reality at ground is that most clinicians work under severe time pressure, resource shortages, and family-dominated consultation structures.

The operative model is therefore best described as a relational and asymmetrical participation model. Decision-making is thus commonly shared in social form, but uneven in power. Patients desire informational participation

while allowing family support and physician delegation without wanting substitution and exclusion.

#### **4. EVIDENCE GAPS AND FUTURE DIRECTIONS**

Literature provides a valuable foundation, but important evidence gaps remain. First, much of the available research is concentrated in oncology, dialysis, and a limited number of tertiary-care or urban settings. This makes it difficult to infer how decision-making operates across primary care, rural facilities, emergency care, surgery, maternal health, and other specialties. Future research should therefore broaden the clinical and geographic base of evidence, especially across public– private sectors and provincial contexts. Second, literature relies heavily on one-dimensional surveys and small qualitative studies. These designs identify preferences or reported experiences, but they are less able to capture different aspects of decision-making, how decisions unfold over time, how preferences change with worsening illness, or how family and physician roles shift across the treatment trajectory. Longitudinal and mixed-methods research would help clarify these dynamics. Third, several studies document a preference–practice gap, but there is still limited observational evidence on what actually happens during consultations. More direct study of communication encounters is needed, including who speaks, who receives information first, how disagreement is handled, and how decisions are ultimately recorded and justified.

Finally, there is very little intervention research. We still know too little about which communication models, consent practices, clinician-training approaches, or decision-making tools are effective in enhancing decision-making processes that results in satisfied patients in Pakistan.

#### **5. CONCLUSION**

In conclusion, this review shows that medical decision-making in Pakistan is shaped not only by clinical judgment, but also by the wider socio-cultural and structural context in which care occurs. Consistent with the article's starting premise, decisions emerge through interactions among patients, families, and physicians, within a setting marked by collectivistic values, family centrality, unequal power relations, and material constraints within the healthcare system. The literature indicates that medical decision-making in Pakistan is neither well captured by the neat binaries of individual-autonomy vs collectivism nor by a simple account of paternalism. Rather, it operates through a relational structure in which patients often want substantial information and recognition, families though remaining central to care and deliberation, are not desired to lead, and physicians are trusted to provide both

expertise and direction. The central task, therefore, is to make this relational process more ethically robust by exploring more aspects of patient and public perceptions and aligning it with cultural and socioeconomic realities of the context.

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## Appendix

**Table 1**

| S No. | Title and Authors                                                                                                                                              | Year Published | Methodology                                  | Population                                                                                                                                                      | Key Findings                                                                                                                                                         |
|-------|----------------------------------------------------------------------------------------------------------------------------------------------------------------|----------------|----------------------------------------------|-----------------------------------------------------------------------------------------------------------------------------------------------------------------|----------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| 1     | Moazam F. Families, Patients, and Physicians in Medical Decision-making: A Pakistani Perspective.                                                              | 2000           | Opinion article based on personal experience | Pakistani families involved in pediatric surgery                                                                                                                | Emphasizes the interconnectedness of family as organic whole in decision-making; doctors often seen as senior family members entrusted with decision-making.         |
| 2     | Jafarey AM, Farooqui A. Informed consent in the Pakistani milieu: the physician's perspective.                                                                 | 2005           | Qualitative Study with interviews            | Doctors in a private teaching hospital, Karachi                                                                                                                 | Doctors felt responsibility to include individual patients in decision-making but valued family involvement; preferred to maintain physician-patient-family balance. |
| 3     | Kumar S, Jamal Shaikh AK, Khalid S, Masood N. Influence of patient's perceptions, beliefs and knowledge about cancer on treatment decision making in Pakistan. | 2010           | Quantitative Survey                          | 230 cancer patients receiving chemotherapy at Aga Khan University Hospital (private), Karachi, Pakistan.                                                        | 32.2% preferred physician to make final decisions; 23% preferred collaborative decision-making; only 9% emphasized family role, 1% prefer autonomy.                  |
| 4     | Jawaid M, Qamar B, Masood Z, Jawaaid S. Disclosure of cancer diagnosis: Pakistani patients' perspective.                                                       | 2010           | Quantitative Survey                          | 147 cancer patients from 3 public hospitals: Jinnah Postgraduate Medical Centre, Civil Hospital Karachi, and Pakistan Institute of Medical Sciences, Islamabad. | 57% wanted to know all treatment options; 70% preferred active involvement in disease management.                                                                    |

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| 5 | Padela AI, Malik AY, Curlin F, De Vries R. [R e]considering Respect for Persons in a Globalizing World                                                                                                 | 2015 | Comparative Analysis of Cases     | Two Cases involving Pakistani and Arab patients and families                                | Family involvement facilitates informational exchange, family perceives decision-making physician's responsibility, physicians grapple with how much to share, second-order autonomy is complicated by socio-cultural norms and gender socialization.                                                                      |
| 6 | Baig AM, Humayaun A, Mehmood S, Akram MW, Raza SA, Shakoori T. Qualitative exploration of factors associated with shared decision-making in diabetes management: a health care provider's perspective. | 2020 | Qualitative Study with interviews | 11 endocrinologists residing in Lahore, Pakistan; interviews conducted at their workplaces. | Patients receptive to shared decision-making; strong family influence; doctors viewed as authority figures. Doctors cite time constraints and communication skills training as barriers to SDM. Patients' hesitation, paternalistic perceptions of doctors, and limited education also hinder SDM in doctor's perceptions. |
| 7 | Qidwai W. Paternalistic model of medical practice.                                                                                                                                                     | 2003 | Quantitative Survey               | 420 adult patients at a teaching hospital, Karachi                                          | 61% viewed doctors as next to God; mixed views on disclosing cancer diagnoses; majority wanted detailed treatment explanations.                                                                                                                                                                                            |
| 8 | Malik S, Allen RJ, Vachharajani TJ, et al. Dialysis Decision Making,                                                                                                                                   | 2022 | Qualitative Study with interviews | 20 individuals receiving in-center maintenance hemodialysis at 2                            | Patients dissatisfied with communication; desired more involvement and                                                                                                                                                                                                                                                     |

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|    | Dialysis Experiences, and Illness Perceptions: A Qualitative Study of Pakistani Patients Receiving Maintenance Hemodialysis                                                                                 |      |                     | urban outpatient dialysis units in Pakistan.                                                                    | information; family support varied, often against patient choice but helpful post-decision.                          |
| 9  | Khowaja-Punjwani S. Pakistani Parents Understand Informed Consent but not Assent: A Pilot Study                                                                                                             | 2018 | Quantitative Survey | 128 parents of pediatric patients admitted in a pediatric intensive care unit in Karachi for at least 24 hours. | Fathers mostly provided consent; majority disagreed with involving children in decisions.                            |
| 10 | Waheed H, Haider S, Iqbal Q, Khalid A, Hassali MA, Bashaar M, Saleem F. A Cross-Sectional Assessment of Shared-Decision Making Among Patients Visiting Public Healthcare Institute of Quetta City, Pakistan | 2020 | Quantitative Survey | 465 chronically ill patients visiting a public healthcare institute in Quetta City, Pakistan.                   | 86.9% indicated no involvement in treatment decisions; positive correlation between SDM and education/income levels. |
| 11 | Hussain M, Shair NA, Sulehri FU, Zubair M, Jadoon NA. Information needs and preferences: perspective of Pakistani cancer patients                                                                           | 2014 | Quantitative Survey | 464 Cancer patients in Multan                                                                                   | Majority wanted full information about their condition and prognosis; preferred family to be informed.               |

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| 12 | Zafar W, Hafeez H, Jamshed A, Shah MA, Quader A, Yusuf MA. Preferences regarding disclosure of prognosis and end-of-life care: a survey of cancer patients with advanced disease in a lower-middle-income country. | 2016 | Quantitative Survey                           | 520 Cancer patients in Pakistan                                                        | Majority aware of diagnosis; preference for detailed prognosis information; varied views on withholding information to maintain hope.                                                                                                                                                                                                                                                                                                                                              |
| 13 | Saeed F, Sardar M, Rasheed K, Naseer R, Epstein RM, Davison SN, et al. Dialysis Decision making and Preferences for End-of-Life care: Perspectives of Pakistani patients receiving maintenance dialysis            | 2020 | Quantitative Survey                           | 522 patients receiving maintenance dialysis in 7 different dialysis units in Pakistan. | Low informed consent about medical condition; majority regretted starting dialysis due to physician influence, but still high reliance on physicians' wishes; preference for family in decision-making, limited knowledge of hospice/palliative care Over half (54%) wanted to know their prognosis, but 80% had no related discussion. While 63% felt EoL planning was important, only 5% recalled discussing it with a doctor in the last year. 62% regretted starting dialysis. |
| 14 | Rahman R, Matthews E, Ahmad A, Rizvi SM, Salama U, Samad L, et al.                                                                                                                                                 | 2019 | Qualitative Study with Focus Group Interviews | 18 healthcare professionals and 18 patients in the orthopaedic                         | Educated patients took active initiative to search information but preferred                                                                                                                                                                                                                                                                                                                                                                                                       |

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|    | Perceptions of patient-centred care among providers and patients in the orthopaedic department of a tertiary care hospital in Karachi, Pakistan.                                                         |      |                                   | department of a tertiary care hospital in Karachi, Pakistan.                   | doctors made decisions for them; lower literacy patients also defer to doctors; patients and doctors make efforts to involve family especially more educated ones. |
| 15 | Memon R, Asif M, Shah BM, Kiran T, Khoso AB, Tofique S, et al. Ethics of Informed Consent in Medical settings: A qualitative study of clinicians managing patients presenting with self-harm in Pakistan | 2024 | Qualitative Study with interviews | Clinicians managing patients presenting with self-harm in Pakistan.            | Collective decision-making involving families; consent from both patient and family; gender dynamics and literacy levels influence decision making.                |
| 16 | Ahmed S, Jafri H, Rashid Y, et al. Autonomous decision-making for antenatal screening in Pakistan: views held by women, men and health professionals in a low-middle income country.                     | 2019 | Quantitative Q-sort Methodology   | Women, men, and healthcare professionals in Lahore, Pakistan.                  | Couples often see screening as standard practice, and defer decisions to husbands or doctors; women rarely seen as independent decision-makers.                    |
| 17 | Ahmed S, Yi H, Dong D, Zhu J, Jafri H, Rashid Y, Ngan OM, Ahmed M. Interpretations of autonomous decision-making in antenatal genetic screening among                                                    | 2018 | Qualitative Study with interviews | Women in China, Hong Kong, and Pakistan regarding antenatal genetic screening. | Pakistani respondents favor a shared choice led by husbands; greater delegation to doctors compared to Hong Kong.                                                  |

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|    | women in China, Hong Kong and Pakistan                                                                                                                                                                                                 |      |                                                                              |                                                                                                                                                                                                     |                                                                                                                                                                                                                                                                                                                                                                                                                                     |
| 18 | Mir, Ghazala, and Aziz Sheikh. "Fasting and prayer don't concern the doctors... they don't even know what it is': communication, decision-making and perceived social relations of Pakistani Muslim patients with long-term illnesses. | 2010 | Ethnographic study involving in-depth interviews and participant observation | A 3-year ethnographic study used interviews, observation, and contact with patients, carers, and HCPs. 104 adult patients with long-term conditions were interviewed at 13 community organizations. | Religious identity significantly shapes experiences with illness, yet is often avoided in healthcare discussions. Patients feel uneasy raising religious issues, while providers may underestimate their importance. Consequently, Pakistani Muslims, already feeling marginalized in UK society, experience poorer health and face challenges managing chronic conditions due to neglected religious considerations in healthcare. |
| 19 | Aslam, Fawad, Omar Aftab, and Naveed Z. Janjua. Medical decision making: The family–doctor–patient triad.                                                                                                                              | 2005 | Opinion article                                                              |                                                                                                                                                                                                     |                                                                                                                                                                                                                                                                                                                                                                                                                                     |

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| 20 | Memon, Rakhshi, Muqaddas Asif, Bushra Ali Shah, Tayyeba Kiran, Ameer B. Khoso, Sehrish Tofique, Jahanara Miah et al. "Clinicians' experiences of obtaining informed consent for research and treatment: a nested qualitative study from Pakistan. | 2024 | Qualitative Study with interviews | 20 clinicians/researchers involved in obtaining informed consent for research and treatment in Pakistan. | Four distinct themes emerged which were (1) Family deciding for patients, (2) Benefits of involving family in consent process, (3) Gender disparity in consent process, (4) Challenges experienced by clinician-researchers during consent process in Pakistan |
|----|---------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|------|-----------------------------------|----------------------------------------------------------------------------------------------------------|----------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|