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Supportive Care Communication Strategies to Improve Cultural Competence in Shared Decision-Making

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Abstract

Historic and the ever-increasing current migration into Western countries have greatly changed the ethnic and cultural patterns of patient populations. As healthcare beliefs of minority groups may follow their religion and country of origin, inevitable conflict can arise with decision-making at the end of life. The principles of truth telling and patient autonomy are embedded in the framework of Anglo-American medical ethics. In contrast, in many parts of the world, the cultural norm is protection of the patient from the truth, decision-making by the family, and a tradition of familial piety where it is dishonourable not to do as much as possible for parents. The challenge for health care professionals is to understand how culture has enormous potential to influence patients' responses to medical issues such as healing and suffering, as well as the physician-patient relationship. The paper provides a framework of communication strategies that enhance cross-cultural competency within nephrology teams. Shared decision-making also enables clinicians to be culturally competent communicators by providing a model where clinicians and patients jointly consider best clinical evidence in light of a patient's specific health characteristics and values when choosing healthcare. The development of decision aids to include cultural awareness could avoid conflict both proactively, and more productively address it when it occurs), and enable decision-making within the framework of the patient and family cultural beliefs.

Key Words

End of life, advanced kidney disease, decision-making, ethics, communication skills

This Moving Point series of articles describes the principles and challenges of providing person-centred care for patients with advanced kidney disease at the end of life. Communication between practitioner and patient (including their wider family/social support) is key to achieving these aims. As discussed by Davison and Jassal (1) this includes sharing prognosis, determining symptoms and providing care aligned to the preferences and goals of the individual patient (1). These principles of truth telling and patient autonomy are embedded in the framework of Anglo-American medical ethics. In contrast, in many parts of the world, medical practice is based on family decision-making and medical beneficence. These differences can inevitably lead to conflict between patients, families and clinicians and therefore the need to develop strategies to reduce cross-cultural miscommunication (3). This paper aims to help clinicians become culturally aware and competent and thereby improve their communication with patients and families.

The American clinical practice guidelines on dialysis initiation and withdrawal from the Renal Physicians Association (RPA) (3) states that “they reflect the ethical principle of respect for autonomy because clinicians, family members, and others have an ethical duty to accept the decisions regarding medically indicated treatment made by competent patients and, in the absence of competence, to formulate decisions that would respect patients’ wishes, or if wishes are unknown, advance the best interest of their patients”. Historic and the ever-increasing current migration into Western countries have, however, greatly changed the ethnic and cultural patterns of patient populations. This is particularly true when considering advanced kidney disease, which is much more common in many ethnic groups compared to white European populations (4). As an example, around 50% of patients on renal replacement therapy in London are from ethnic minorities, predominantly South Asian and Afro-Caribbean (5).

Migration: magnitude of the issue

Throughout human history, individuals, families, and groups have emigrated from their native homes to other places globally for many reasons: the prospect of education, economic, or social advantage; the need to escape war, political torture or other conflicts; or the desire to reunite with other family members. At one point in 2005 there were an estimated 191 million immigrants across the globe: approximately 64 million of these immigrants arrived in Europe and 44 million in North America, a tripling of the immigrant populations in these regions compared to twenty years earlier (6). Spain, Germany and the United Kingdom were the European countries with the highest immigration, receiving more than half of all immigrants in 2008 (7). Increasing diversity is a reality, as witnessed by the daily news bulletins about dramatic increases in global economic and political migration. This means that there is an enlarging proportion of people who do not live in their own native country or culture.

In many parts of the world, the cultural norm is protection of the patient from the truth, decision-making by the family, and a tradition of familial piety where it is dishonourable not to do as much as possible for parents (8); examples are given in Table 1. With evidence that the ethics of minority groups may follow their religion and country of origin (9), conflict with Anglo-American medical ethics structure may arise from both patients' and physicians' perspectives as both have their own languages, explanatory illness models, religious beliefs and ways of understanding the experience of suffering and dying (10, 11).

The impact of diversity during end stage renal disease and at the end of life

Culture is but one of several typologies of difference that has been used to signify diversity among individuals and groups. Narrowly defined from an anthropological perspective, culture can be thought of as that which refers to the *"...patterns, explicit and implicit, of and for* behavior acquired and transmitted *by symbols,"* language, and rituals (8). Seen as a 'recipe' for living in the world, this conceptual framework for culture explains the means of transmitting these 'recipes' to the next generation (9). The challenge for health care professionals in an increasingly diverse society is to understand how culture has enormous potential to influence patients' responses to medical issues such as healing and suffering, as well as the physician-patient relationship. As a direct result, those from migrant communities may possess little knowledge of, or have exposure to, palliative care[1]. For example in the United Kingdom, (16) and more recently among people living with end stage kidney failure in Canada, (17) those from black, Asian or minority ethnic groups were identified as being statistically less likely after taking all other factors in account, to understand the value of palliative care. Specific to kidney disease, USRDS date shows that rates of dialysis withdrawal in minority ethnic groups are lower compared to the white population (18). It is also important to note that migrant

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[1] Palliative care has been defined as an approach that improves the quality of life of patients (adults and children) and their families who are facing problems associated with life-threatening illness. It prevents and relieves suffering through the early identification, correct assessment and treatment of pain and other problems, whether physical, psychosocial or spiritual. Addressing suffering involves taking care of issues beyond physical symptoms. Palliative care uses a team approach to support patients and their caregivers. This includes addressing practical needs and providing bereavement counselling. It offers a support system to help patients live as actively as possible until death (15)

communities may also have different cultural values regarding life and death compared to the Western approach to dying which includes palliative care.

Identifying preferences for medical care in advance of untoward or terminal circumstances can be a difficult and emotional process. The decision-making model of advance care planning derived from bioethics practices assumes that choices made by the individual can be arrived at through rational processes that are unchanged by time, shifting social consequences, or disease and illness progression. Such a model may only appeal to certain subsets of groups, thus limiting the utility of instruments used for advance planning (living wills or durable powers of attorney for health care) (19,20). For some groups, speaking about the dying process or planning for death may represent a transgression of a strong cultural taboo and could create additional distress. Other patients, unfamiliar with or mistrustful of the legal system may misconstrue the purpose or nature of formal advance care planning documents. In all cases, rather than abandon the goals of advance care planning, strategies should be sought that facilitate understanding. For example, a generic discussion to identify a health care proxy need not be cast as a discussion of death, but rather an opportunity to determine desired roles of various family members and support persons. Discussions about patient preferences for end-of-life care should be culturally and linguistically appropriate and reflect sensitivity to patient values and beliefs.

Relevant knowledge and greater awareness of palliative care is therefore critical, particularly as growing evidence suggests that a significant number of people from ethnic communities, who disproportionately include those on low incomes, miss out on high quality palliative care and end of life care. This situation exists even in the UK despite palliative care being free-at-the-point of delivery from the National Health Service (NHS) and the independent charitable sector. Possible explanations for these disparities include (i) different referral patterns to specialist palliative care and lack of understanding amongst professionals about exactly which patients to refer and when; (ii) gate-keeping by services, (iii) complex linguistic and communication barriers; (iv) different preferences including for more aggressive or curative care at the end-of-life, or a cultural mistrust of end-of-life care; and (v) strong religious and familial support systems (21-23). Additionally, people from minority ethnic communities may also experience overt and inadvertent racial discrimination at an individual and institutional level (24). Identifying and eliminating vertical health inequality (inequality among households or individuals) and horizontal health inequality (inequality among culturally defined (or constructed) groups) in the delivery of high quality palliative and related care therefore represents a critical mandate. More sophisticated standards for monitoring and ensuring the cultural sensitivity and cultural competency within the palliative medicine workforce and more widely should be employed, as should strategies to increase community-based partnerships.

Avoiding and coping with conflict

Both the United States (US) RPA guidelines (3) and the General Medical Council (GMC) (25) in the UK give some guidance about avoiding conflict. Both are based on the premise that individual patients should be aware of their prognosis to make decisions regarding their care. The GMC states clearly that physicians do not have to provide treatment that they consider non-beneficial and that information should only not be given to a patient if he/she refuses (and has capacity to do so) and not on the request of the family unless it is believed that giving information would cause the patient serious harm (defined in document to mean "more than that the patient might become upset or decide to refuse treatment"). The GMC also suggests that where there is conflict with patient/family wishes or other medical colleague decisions, options are to consider seeking advice from a more experienced, perhaps senior, colleague, or obtaining a second opinion, or holding a case conference. Ultimately, seeking legal advice and resorting to the UK courts as final arbiter may be required, but awareness of cultural differences during patient/family discussions and guidance related to potential ethical conflicts should avoid this route (26).

In contrast, the US RPA guidelines are dialysis-specific. They also address the issue of conflict between clinicians and patients/families regarding demands for dialysis that the clinician deems medically inappropriate. The cultural conflict of giving information (or not) to individual patients is not addressed. The suggested solutions to conflict are specifically a trial of dialysis (but this needs clear endpoints), second opinions, consultation with the hospital ethics committee or ethics consultants and ultimately potential transfer to another institution or physician to provide dialysis. If none are willing to accept the patient, the family/legal representative can be informed that dialysis will be withdrawn unless there is a court injunction to the contrary.

In reality, neither the UK GMC nor the US RPA guidelines avoid conflict. Nephrology teams, therefore, need to develop cultural awareness and cross-cultural communication strategies, including use of decision aids, to enable shared decision-making within the framework of the patient and their family cultural beliefs. This approach should pro-actively reduce conflict (2) and productively address it when it occurs.

Cross-Cultural Communication Strategies

Culture defines the way people make sense of the world and influences how individuals view the illness experience and approach decision-making. Despite the importance of culture in healthcare, traditional medical training is deficient in cross-cultural communication education Strategies' to improve skills and knowledge in cultural competence –and better communication relevant to the care is required (27). For example, cross-cultural communication includes strategies that acknowledge individual cultural traditions; avoid generalizing a patient's beliefs or values based on cultural norms; and take into account one's own beliefs, values and experiences (28). Clinician culture is multifaceted and largely shaped by the biomedical influences which include knowledge and experience that accompanies becoming a physician as well as the influence of a given healthcare system in which one practices (10). A recent qualitative study of US and UK academic medical centers examined the influence of institutional culture on do-not-resuscitate decision-making at end of life (29). The way physicians in training approached decision-making was directly influenced by whether the hospital policies prioritized patient autonomy versus best interest. For instance, physicians training in a hospital that prioritized autonomy would be more likely to neutrally offer resuscitation regardless of whether they believed resuscitation to be clinically appropriate.

To address these challenges, cross-cultural communication strategies must be reflective and individualized (2, 30). The first step to cross-cultural competency involves becoming aware of the inherent beliefs, values and biases within ourselves as clinicians and the influence of the healthcare system in which one practices. When clinicians become conscious of their own beliefs and values, they may become more receptive and open to those of the patients especially when differences exist. Figure 1 visualizes the complex cultural influences within the patient and clinician relationship.

The second step involves effective communication strategies that are evocative, non-judgmental and respectful. The RISK reduction assessment is a helpful strategy to learn and support the particular cultural influence and beliefs of a given patient and family. This assessment includes: **R**esources for patients and families to navigate health care system; **I**ndividual circumstances and migration experience; **S**kills available to patient and family to navigate the health care system and cope with the disease itself; and **K**nowledge about the ethnic groups health beliefs, values, practices and cultural communication etiquette (2). Teal and Street developed a cultural competent communication model from existing models that incorporate critical elements of cultural communication. This model highlights five key communication skill sets: non-verbal skill, verbal skill, recognition of potential cultural differences, incorporation of and adaptation of cultural knowledge, and negotiation/collaboration (31).

Ask-Tell-Ask is a helpful communication strategy to engage in cultural competent communication (32). This framework encourages a two-way conversation in which the clinician first asks for the patient and/or family's input rather than reflexively disclosing information. The usefulness of this strategy extends beyond giving information to include asking about cultural experience, decision-making preferences, prior experiences with healthcare and exploring values and preferences. Table 2 includes examples of open ended-questions to better understand the cultural preferences and values of a given patient and family (2, 31,32).

Once the clinician has an understanding for the kinds of information desired and ways to communicate this information, how the information is told is equally important. Patients and families may have language barriers and low health literacy further complicating their ability to process and act on critical medical information (33). Clinicians should use clear language with only 1-3 pieces of information without medical jargon. The final ask allows the patient and family to 'teach back' what they've heard to ensure the clinician gave information in a way that was easily understood: *" To ensure, I did a good job giving you information, can you tell me what you will take away from our discussion today?"* This question is non-judgmental and invites the opportunity for the patient and family to 'correct' information or perceptions that the clinician may have shared. Additionally this final "ask" invites the patient and family to share any concerns or lingering questions.

Shared decision-making

Shared decision-making is seen as useful in enabling practitioners to be culturally competent communicators (31) by providing a model where clinicians and patients jointly consider best clinical evidence in light of a patient's specific health characteristics and values when choosing healthcare (34). In practice, it requires patients, professionals and healthcare systems to think differently about the delivery of, and engagement with, evidence-based care. Both practitioner and patient are expected to collaborate proactively in this decision-making process by; exchanging information about the illness, diagnosis and treatment from their areas of expertise; making explicit values and preferences in the context of care pathways and/or lifestyle; reasoning together the best option for the patient; agreeing and implementing the choice that aligns best with clinical evidence and patient preference (35).

Patients, professionals and healthcare infrastructures can be enabled to engage in shared decision-making (34,36). Interventions enabling people to collaborate more effectively within this complex system are informed by findings from the applied social sciences, medical communication, evidence-based practice, and health professional training. Different types of interventions are used to support people in different stages of making a decision and reasoning with others (36). For example: evidence-based prompts for professionals to make accurate choices in the context of care pathways and patients to make informed decisions in the context of their lives ([1&2] figure 2); health professional training, patient decision coaching and consultation prompts for more effective communication between patients and professionals ([3] figure 2); training and decision aids for others involved in implementing care in people's lives (e.g. other health professionals and/or family) (figure 2). When developed using systematic methods to identify patient, professionals and healthcare needs and preferences, these resources are culturally relevant (37) as they make explicit the options, attributes, values and evidence of importance to all people involved in making, and implementing, healthcare choices (see figure 2).

Evaluation of shared decision-making interventions within predialysis education programmes suggest they are acceptable to staff and patients, and can be implemented across different healthcare systems. For example: shared decision-making training and prompts for use by health professionals to structure predialysis education consultations (38); and patient decision aids supporting patients' engagement with predialysis programmes (39). Further, there are a range of patient-centred approaches used by others in the delivery of self-care, advance care planning and palliative services that provide techniques (e.g. goal setting training) and prompts (e.g. patient reported outcome measures) to help professionals deliver and negotiate evidence-based care in a culturally appropriate way (40,41).

Conclusion

There is increasing awareness in both lay and medical circles that for many patients modern medicine fails to achieve the quality and dignity of death that most people would want when asked. To achieve this, it is essential to enhance communication between healthcare teams, patients and families. The framework for doing this has mostly been developed round the Anglo-American model of truth-telling and patient autonomy as essential components of the decision-making process. Many of our patients and families make decisions using different frameworks and this may be further exacerbated by an underlying distrust of healthcare teams delivering care in culturally and linguistically different ways. The resulting conflict often disadvantages the individual patients concerned with failure to share prognosis, wishes and goals. Increasing cross-cultural competency with resulting enhanced use of shared decision-making should avoid some of this conflict and improve the quality of medical care for patients throughout the continuum of their illness.

Conflicts of Interest

There are no conflicts of interest

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Table 1: **Examples of ethics of truth-telling related to culture and country**

Country / Cultural group	**Attitudes towards truth-telling**
China	When fatal diagnosis or prognosis, physician informs family and hides it from patient – up to family to decide whether, when and how to disclose truth to patient. Families usually decide to conceal such information – and physicians are willing to follow such decisions and cooperate with families in deceiving patients (12).
African American	Only God has knowledge and power over life and death and physicians cannot have access to this type of knowledge. Christian religious view held by many in African American community holds that suffering is redemptive – it is to be endured rather than avoided. Forgoing life support to avoid pain and suffering therefore might be seen as failing test of faith (10).
Italy	Trend of partial and non-disclosure persists. This arises within families independently of patient requests – though some evidence that physician preferences are moving towards full disclosure (13).
Spain	Tradition of partial and non-disclosure. Majority of doctors state that they would inform patient only in certain circumstances or if requested by patient (13).
India (Hindu)	Tradition of non-disclosure and relatives protecting individual from knowledge in case he/she gives up hope and dies prematurely. This is exacerbated by belief that modern medicine often provides hope, however unrealistic, that a cure is possible (14).

Table 2: **Cultural competency communication skills and examples** (2, 25, 26)

Communication task	**Communication strategy**	**Example**
Understand the patient's experience	Rapport building Ask about the patient as a person	Can you tell me about your life? Where were you born and raised? How has your experience been coming to a new country?
	Invite curiosity	As your clinician, what would be helpful for me to know about you and your life?
	Assess how the patient interprets her condition	What do you think has caused your kidney problems?
Giving information	Assess for health knowledge needs	What is your understanding of your condition?
	Ask what kinds of information desired	Some people want to know everything about their medical condition while others may not. Do you have a preference?
	Give information concisely, without medical jargon and check in for understand	To ensure I did a good job in giving you the information, can you tell me what you'll take away from this visit?
Determine level of patient engagement in medical decisions	Assess who makes decisions in household	How would you like decisions to be made about your health care?
Understand the patients beliefs and values	Ask about what's important to patient and loved ones	As we talk about how best to care for you, what you are hoping for? What concerns you most?
	Address spiritual concerns	Faith can be a source of strength. Can you tell me about your faith?
Address trust concerns	Be transparent, avoid judgement and defensiveness	Some people are uncomfortable discussing their health with a clinician from a different background. Please feel comfortable sharing with me your concerns.
	Explore experience	When it comes to your health, have you ever felt that you've been treated unfairly?

Address resource/ needs	Actively inquire about ways to support patient and family Actively assess for concerns about the plan	What kinds of supports would be helpful to you and your family? What concerns do you have about this plan?

Figure 1: Cultural aspects that influence the clinician-patient interaction

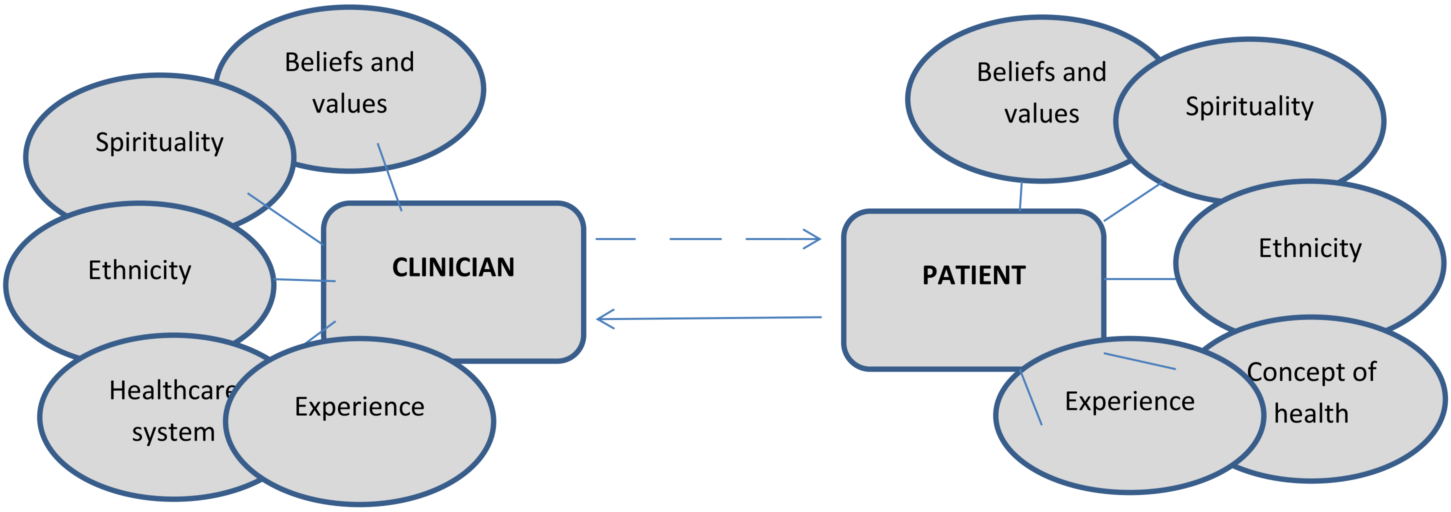

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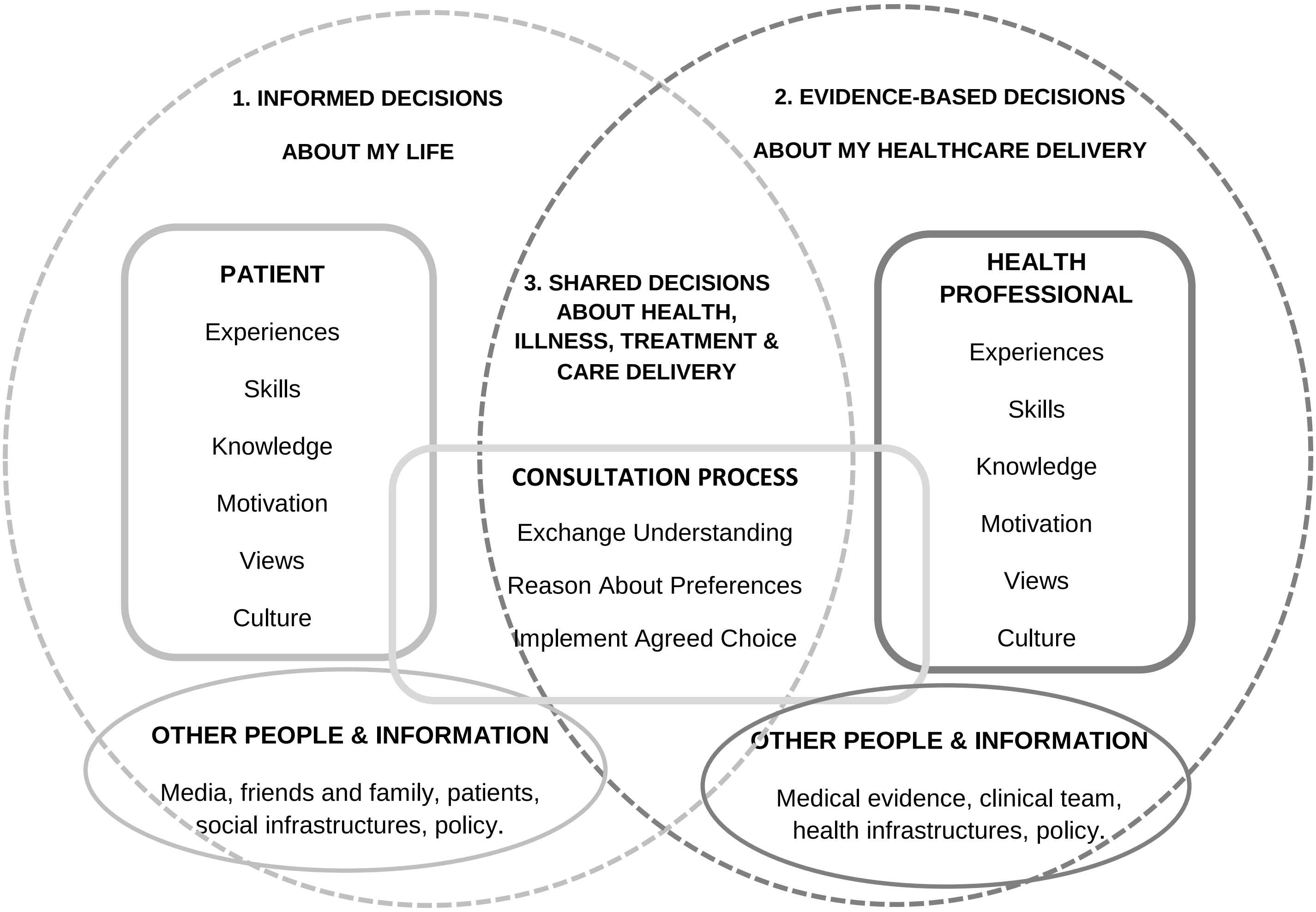
Figure 2: Function informed, evidence-based and shared decision support for patient (1), professional (2) and consultation (3). (Variant first published in Breckenridge et al 2015) (30)



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