



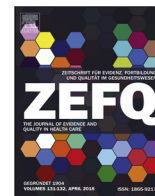
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Z. Evid. Fortbild. Qual. Gesundh. wesen (ZEFQ)

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Schwerpunkt/Special Issue „International Shared Decision Making Conference 2022“

Shared decision-making in Malaysia: Legislation, patient involvement, implementation and the impact of COVID-19



Partizipative Entscheidungsfindung in Malaysia: Gesetzgebung, Patientenbeteiligung, Implementierung und die Auswirkungen von COVID-19

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ARTICLE INFO

Article History:

Received: 22 March 2022

Received in revised form: 13 April 2022

Accepted: 24 April 2022

Available online: 21 May 2022

Keywords:

Malaysia

Multicultural

Shared decision-making

Patient decision aids

Implementation

Patient and public involvement

ABSTRACT

Shared decision making (SDM) activities in Malaysia began around 2010. The rise in the numbers of patients with chronic disease in Malaysia underscores a growing need for doctors to practice patient-centred care and SDM as more Malaysians come into regular contact with health decision-making scenarios. Recent guidelines for medical professionalism have emphasized that options and risks be discussed in consultations, especially for procedures with risk of adverse outcomes. Although SDM is not legally required, principles of SDM are applied in legal judgements on informed consent. Research on SDM has grown to include the adoption of patient and public involvement in research, an increased emphasis on incorporating local cultural values in SDM, and implementation of SDM in Malaysia's health system and organizational culture. While COVID-19 hindered the progress of SDM research, one positive development was that vaccination choices heightened public consciousness about personal decisional autonomy and the need to discuss pros and cons with doctors before making a medical decision.

ARTIKEL INFO

Artikel-Historie:

Eingegangen: 22. März 2022

Revision eingegangen: 13. April 2022

Akzeptiert: 24. April 2022

Online gestellt: 21. Mai 2022

Schlüsselwörter:

Malaysia

Multikulturalität

Partizipative Entscheidungsfindung

Entscheidungshilfen

Implementierung

Patienten- und Öffentlichkeitsbeteiligung

ZUSAMMENFASSUNG

Die ersten Aktivitäten im Zusammenhang mit partizipativer Entscheidungsfindung (PEF) gehen in Malaysia auf das Jahr 2010 zurück. Die steigende Anzahl von Patienten mit chronischen Erkrankungen in Malaysia unterstreicht die zunehmende Notwendigkeit, dass Ärzte eine patientenzentrierte Versorgung und PEF praktizieren müssen, weil sich immer mehr Einwohner in Malaysia regelmäßig mit Situationen konfrontiert sehen, in denen sie gesundheitliche Entscheidungen treffen müssen. Neuere Leitlinien für professionelles Handeln in der Medizin betonen, dass Behandlungsoptionen und -risiken im Rahmen der ärztlichen Konsultation erörtert werden müssen; dies gilt insbesondere für Maßnahmen, die mit einem Risiko für unerwünschte Behandlungsergebnisse behaftet sind. Auch wenn PEF gesetzlich nicht vorgeschrieben ist, finden die Grundsätze der partizipativen Entscheidungsfindung in Gerichtsurteilen im Zusammenhang mit Patienteneinwilligungserklärungen (Informed Consent) Anwendung. Forschungsaktivitäten zu PEF umfassen mittlerweile auch die Einführung einer Patienten- und Öffentlichkeitsbeteiligung in der Forschung, eine verstärkte Berücksichtigung lokaler/regionaler kultureller Werte in PEF sowie die Implementierung von PEF im malaysischen Gesundheitswesen und in der Unternehmenskultur. COVID-19 hat den Fortschritt der PEF-Forschung zwar behindert, doch ist als positive Entwicklung zu verzeichnen, dass die Impfentscheidungen das öffentliche Bewusstsein in Bezug auf die persönliche Entscheidungsautonomie und die Notwendigkeit, Vor- und Nachteile einer medizinischen Maßnahme mit den behandelnden Ärzten zu besprechen, bevor eine gesundheitsbezogene Entscheidung gefällt wird, geschärft haben.

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SDM in Malaysia- growth in research and guidelines

Since SDM research was first initiated in Malaysia in 2010, there has been an increase in activity and focus on SDM. This is exemplified by a growing body of published studies on the subject and an increasing number of PDAs from Malaysia in fields as diverse as mental health [1,2], primary care [3], pharmaceutical consultations [4], surgery [5] and genetics [6]. From a policy perspective, guidelines now emphasize in more detail how doctors are expected to communicate risks during consultations with patients [7].

Implementation context for SDM: Malaysia's dual-sector health system and socio-cultural diversity

Malaysia is a higher-middle income country facing a double-disease burden of communicable and non-communicable diseases, supported by a dual public-private healthcare system [8]. While the incidence of obesity, cardiovascular diseases and cancers are rising [9], the number of infectious diseases, such as tuberculosis and HIV, remains high [10,11]. Most of these chronic conditions, where patient-centred care and shared decision making are most needed, are often managed at the public sector, which is heavily subsidised, under-staffed and over-burdened. On the other hand, private sector is generally better equipped and staffed, but it incurs a significantly higher cost and can be afforded by only those from higher-economic group [12]. This has a significant implication on the implementation of patient-centred care and shared decision making, which requires adequate consultation time, competent healthcare providers to explore and address patient's needs, and providing healthcare options to patients [3].

Besides the dual sector health system, another key context is Malaysia's culturally and linguistically diverse multi-ethnic society. Malaysia is a multi-cultural country comprising three main ethnic groups (50% Malay, 20% Chinese, 10% Indian, 10% others). Linguistically, each of these groups speaks their own language, with the national language being Malay. This diversity impacts consultation and communication processes and researchers in Malaysia have identified five cultural components which are important mediators in the practice of SDM: language issues in information exchange and negotiation; paternalism in the healthcare-professional-patient relationship; heavy family involvement in health decision making; religious beliefs about health in patient values; and complementary medicine as a treatment option [13,14]. These domains, though not exhaustive, may guide clinicians to engage patients in SDM according to the cultural context of the practice.

Policy and legislation- Improvement in Good Medical Practice guidelines

Since the last review for SDM in Malaysia was published in 2017 [14], the Malaysian Medical Council (MMC), the professional body governing doctors, published an updated in 2019 to the Good Medical Practice guideline on the moral, ethical and professional obligations of the medical profession in Malaysia [7]. The following are new sections relevant to SDM. Under the section of "Doctor-Patient Relationship", the provision of medical treatment options and the relevant risks was explicitly recommended as "3.1.7.6 Give the relevant options when discussing treatment, and the limitations and possible complications." Furthermore, in relation to discussing risks and benefits of options, in the section on "Consent" it was recommended that "4.4.4 Before major invasive procedures are

undertaken, the patient must be told the possible post-operative complications... a patient should be informed about possible post-operative complications".

A legal review published in 2020 to determine if Malaysian law was sufficient to address shared decision-making requirements reported that there are no direct legal prepositions which require shared decision making to be practiced by medical institutions [15]. However, when courts apply the doctrine of medical informed consent to support patient-centric care, this often indirectly includes shared decision-making principles (such as patients' active participation in medical decisions). In instances where information about risks and benefits is under dispute, the Federal Court ruled in 2017 that "it is now the court (rather than a body of respected medical practitioners) which will decide whether a patient has been properly advised of the risks associated with a proposed treatment." [16]. It is hoped that this position could provide a push factor for doctors to be more vigilant about providing risk information in a patient-friendly manner. In reality, Malaysian laws which promote shared decision-making as standard-of-care are still lacking as the legislation is very much focused narrowly on informed consent.

Patient and public involvement in Malaysia

In Malaysia, the involvement of patients and public in SDM research has evolved from patients as participants to patients as partners/ research team members. Initially, SDM projects included public and patients as advisory panel members to guide the development and implementation of the PDAs. Over the years, the concept of patient and public involvement (PPI) in research projects has gained more emphasis and become an integral part of the research process. A PPI workshop was organised by a research project group in October 2018 at the Faculty of Medicine, University of Malaya, involving public-school children with asthma, their parents and teachers [17]. The event provided a platform for researchers and stakeholders to exchange ideas on how to ask research questions relevant to patients and community, facilitate research activities and better disseminate and implement research findings. This workshop was the first of its kind hosted in Malaysia and affirmed the need for a more systematic approach to engage community in research in Malaysia [17].

Research agenda on PCC/SDM- cultural values, implementation research

Implementation research on SDM in Malaysia has focused on two agendas; the need to understand how cultural values can be better integrated into shared medical decisions, and secondly, the need to develop implementation strategies that fit local healthcare scenarios.

Cultural values in PDAs

PDA research in Malaysia has seen a growing emphasis on how to include culture-related values in locally developed PDAs. There has been a growing development of culturally-informed PDAs in Malaysia which address cultural issues relevant to decision making in the local setting including religious concerns, roles of the spouse and family members in medical decisions, and the use of alternative or complementary medicine [18]. For example, a PDA on helping BRCA gene carriers decide about risk-reducing ovarian surgery, incorporated spousal roles, marital concerns and religious views on genetic risk as some carriers valued the husband's appro-

val and guidance from religious authorities in navigating their cancer risk [6,19]. However, in Malaysia's multi-ethnic society, the plethora of different belief systems and traditional treatments makes it a challenge to incorporate information from all perspectives without producing PDAs that are too wordy and future research agendas should aim to explore if there are viable solutions for this.

Implementing SDM in Malaysia's healthcare setting

There is a lack of studies on implementation strategies in Malaysia, but one study has tested a broad range of implementation strategies in an academic primary care clinic to implement an insulin-choice PDA. In this study, a total of eleven strategies were selected to address thirteen implementation barriers. Some of the barriers targeted are similar to those commonly reported elsewhere in the literature (e.g. time constraints, lack of awareness of SDM and PDA, patients' low literacy levels) while some were unique such as a lack of continuity of care and doctor-nurse role boundaries [20]. The study findings underline the fact that success of implementation strategies are heavily tied to the health system and culture. For instance, in this setting there is a lack of interprofessional delivery of healthcare, and hence the idea of delivering PDA via the nurses was rejected, even though they were considered by the stakeholders to be the most well-suited to deliver the PDA. In the end, the delivery of the PDA to patients had to be conducted by doctors during clinical consultations; the logistical challenges in this setting contrasts with literature from other settings where delivery of PDAs by doctors during consultation is less effective compared to delivery through other allied health professionals [21]. Another effective strategy was "Mandate change" where the clinic head issued a letter to encourage doctors to use the PDA. This was particularly relevant in the Malaysian context due to the hierarchical structure of the healthcare system. However, it later emerged that some doctors adopted the PDA as they were afraid of being penalised if they did not obey the letter. In a setting where PDAs are novel and continuity of care was lacking, the strategy that focused on systematic documentation of PDA usage in patient medical records facilitated implementation as the record of PDA use enabled continuous SDM engagement for patients between doctors. One of the less effective strategies was providing feedback on PDA distribution to doctors to enable them to see their patterns of PDA use. Doctors reported feeling stressed receiving the report due to feeling monitored and pressured especially if their quantitative adoption was less compared to others. Studies elsewhere have shown that more qualitative feedback (e.g. patient's positive feedback, satisfaction, knowledge and decision quality) has positive effects on SDM and PDA implementation [22].

Challenges in conducting SDM and PDA implementation research

Much of the work in implementing PDAs is still very much research-driven and the path towards long-term implementation is still unclear. Implementation requires resources for staff, materials, training, and data collection that are not available in most Malaysian healthcare organisations. Furthermore, there is a need for more research on selection of implementation strategies to suit Malaysia's unique health system and cultural setting.

Impact of COVID-19: Obstructed research, raised public awareness about medical choices.

The COVID-19 pandemic had both negative and positive effects to patient-centred care and SDM in Malaysia. During the COVID-19 pandemic, most of the hospital facilities restricted access to non-essential personnel. Hence, most of the SDM research projects

had to convert face-to-face data collection to virtual interviews or surveys. Numerous PDA feasibility studies are on hold due to the challenges of conducting an online video conference or voice interview with patients who are emotionally labile (e.g. patients with cancer). However, the COVID-19 pandemic has brought some positive impact to patient-centred care and SDM practice in the country. Specifically, the government COVID-19 vaccination programme adopted a more patient/public-centred approach after initially meeting with resistance and fear of vaccines. To address these fears, the government produced multi-lingual information materials about the pros (protective benefits) and cons (side effects) of COVID-19 vaccination with relevant scientific evidence. The public was encouraged to discuss these pros and cons with their doctor before signing an informed consent for vaccination [23,24]. In the development of the COVID-19 vaccination programme guideline, a consultation session with a doctor was embedded in the delivery flow process of the programme [23]. This scenario has enhanced public awareness of their autonomy to make a shared decision with their doctor before the decision to receive a vaccination; formal signing of informed consent for vaccination has never been practised widely before this. However, it is currently unclear whether this has impacted SDM practice outside of vaccination consultations.

Conclusion

The rise in the numbers of patients with chronic disease in Malaysia underscores a growing need for doctors to practice patient-centred care and SDM as more and more Malaysians come into regular contact with health decision-making scenarios. Recent guidelines for medical professionalism have emphasized that options and risks be discussed in consultations, especially for procedures with risk of adverse outcomes. Although shared decision making is not legally required, principles of shared decision making are applied in legal judgements on informed consent. Research on shared decision making has grown to include the adoption of patient and public involvement in research, increased emphasis on how to incorporate local cultural values in SDM, and implementation of SDM within Malaysia's health system and organizational culture. While COVID-19 hindered the progress of SDM research, one positive development was that vaccination choices heightened public consciousness about personal decisional autonomy and the need to discuss pros and cons with doctors before making a medical decision. Based on this review, some key steps can be taken to increase SDM adoption in Malaysia. These include 1) continued engagement at a policy level on the importance of SDM for patient care so that legislation and professional guidelines mention SDM specifically, 2) influencing a cultural shift from medical paternalism to a more patient-centred culture through continuous education and training, 3) conducting more research on implementation of SDM in diverse settings such as rural populations or specific cultural groups to improve the understanding of the nuances required for implementation in Malaysia and 4) increasing patient awareness towards SDM by implementing guidelines and practices that enable patients to play a more active role in health decisions.

Funding

This work is supported by the University of Malaya Research University Grant- Faculty Program (GPF006C-2018).

Conflict of interest

All authors declare that there is no conflict of interest.

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