

## Patient Centred Decision Making in Healthcare in Malaysia

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### Abstract

This is a conceptual paper to analyse the patient-centred decision-making approach adopted in healthcare in Malaysia. This study reviews literature on the history of patient-centeredness and the requirement of shared decision-making and its consequences in healthcare practice. It aims to evaluate the crucial elements of shared decision-making particularly the factors that affect the voluntariness and informed consent in medical practice. This paper reviews the existing literature surrounding the phenomenon of shared decision-making for medical treatment in the healthcare, particularly giving importance to the patients' views and how it plays a role in shared decision-making. This study provides an overview of the perplexing concept of shared decision-making and the various concerns that have surrounded the topic leading to its recognition. Hence in Malaysia, there is no specific law that governs the provisions for shared decision-making approach in the healthcare practice. This study aims to explore the Malaysian Medical Council Guideline on Consent for Treatment of Patients by Registered Medical Practitioner (MMC Guideline on Consent) and the current Malaysian laws to determine whether they are sufficient to address the element of informed consent requirement in shared decision. Finally, lack of empirical evidence is recognised in this paper and several suggestions are made for future research and recommendations for the enactment of new provisions pertaining to medical treatment.

**Keywords:** patient-centred approach, shared decision-making, informed consent

### 1. Introduction

For about two decades, a practice that has become known as patient or person-centred care (PCC) and the associated notion of shared decision-making (SDM) have been making headway in Western health care research, organisation, policy, and business. This emphasis has been visible as a general initiative,<sup>100</sup> but is especially salient

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<sup>100</sup> Ezekiel Jonathan Emanuel; Linda Emanuel, 'Four Models of the Physician-Patient Relationship', JAMA; Apr 22, 1992; 267, 16; Research Library p. 2221.

regarding chronic or durable conditions, care of the elderly and demented, as well as other areas involving long-term, home-based and/or quality of life-oriented care.<sup>101</sup> To some extent, this trend has evolved into an alleged 'culture' or 'movement', embodying a special ideology or mission.<sup>102</sup> Shared decision-making is a joint process that permits patients and their providers to decide healthcare treatment choices, taking into consideration the best medical evidence, along with the patient's preferences and values. This process offers patients the support they need to make the best personalised care decisions, while permitting providers to feel confident in the care they prescribe.<sup>103</sup> SDM is part of PCC and is progressively thought to be the best standard of medical care by the community, doctors, and policy makers.<sup>104</sup> Involving patients in decision-making helps increase their experience and awareness in healthcare and decrease cost and utilisation of healthcare services. Patients might change their health behaviour following involvement in decision-making.<sup>105</sup> Emphasis on decision-making has brought about the evolution of shared decision-making (SDM), where doctors and patients share values and information, and patients have a dynamic role in deciding healthcare choices.

SDM takes into consideration the results from existing evidence-based practices, in addition to the patient's values, desires, and preferences. Patient-centred care is a commonly utilised concept in modern healthcare structure. The drive towards patient-centred care is noteworthy and advancing these services is becoming a key focus of many global healthcare systems.<sup>106</sup> Healthcare leaders and patients' advocates argue that the current model of healthcare has an inclination to be (1) too disease-centred (concentrating mainly and only just on pathologies and frequently needless technology solutions that provide inadequate concern to the individual's experiences during sickness, autonomy, and particular interests of patients), or (2) highly system or staff-centred and unsuitably positioned to help the interest of the organization and experts who deliver service.<sup>107</sup>

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<sup>101</sup> David Edvardsson, Elizabeth Watt & Frances Pearce, 'Patient experiences of caring and person-centredness are associated with perceived nursing care quality' (2016) *Journal of Advanced Nursing* 217.

<sup>102</sup> Mary Jane Koren, 'Person-centered care for nursing home residents: the culture-change movement' (2010) 29(2) *Health affairs (Project Hope)* 312.

<sup>103</sup> Richard Wexler, 'Six Steps of Shared Decision Making' (2012) *Informed Decision Making Foundation* <[https://www.mainequalitycounts.org/image\\_upload/SixStepsSDM2.pdf](https://www.mainequalitycounts.org/image_upload/SixStepsSDM2.pdf)> accessed 1 July 2019.

<sup>104</sup> Chirk Jenn Ng et al, 'An overview of patient involvement in healthcare decision-making: a situational analysis of the Malaysian context' (2013) 13 *BMC Health Services Research* 408 <<http://www.biomedcentral.com/1472-6963/13/408>> accessed 7 July 2019.

<sup>105</sup> Angela Coulter, Crispin Jenkinson, 'European patients' views on the responsiveness of health systems and healthcare providers' (2005) 15(4) *Eur J Public Health* 355 <<https://www.ncbi.nlm.nih.gov/pubmed/15975955>> accessed 6 July 2019.

<sup>106</sup> Rinchen Pelzang, 'Time to learn: understand patient-centred care' (2010) 19(14) *Br J of Nurs* 912 <<https://www.ncbi.nlm.nih.gov/pubmed/20647984>> accessed 1 July 2019.

<sup>107</sup> Vikki Ann Entwistle, Ian S. Watt, 'Treating Patients as Persons: A Capabilities Approach to Support Delivery of Person-Centred Care' (2013) 13(8) *Am J Bioeth* 29 <<https://www.ncbi.nlm.nih.gov/pubmed/23862598>> accessed 1 July 2019.

## 2. Patient-Centred Care

The discussion of SDM would not be comprehensive without drawing attention to patient-centred care (PCC) particularly because SDM is considered to be one of the fundamental components of many PCC models.<sup>108</sup> Patient-centred care can be explained as ‘treating the patient as an exclusive individual’.<sup>109</sup> Angela Coulter, in “The Autonomous Patient: Ending Paternalism in Medical Care”, defines patient-centred care as, “Health care that meets and responds to patients’ wants, needs, and preferences and where patients are autonomous and able to decide for themselves”.<sup>110</sup>

The word “patient-centred care” originated in the US in 1988 by the Picker/Commonwealth Program for Patient-Centred Care with the aim of highlighting to healthcare providers, staff, and systems to change and modify their emphasis from diagnosis and management of disease to the needs and desires of patients and families.<sup>111</sup>

PCC shows respect for the patient, as a person and is very much about considering the patients’ point of view and circumstances in the decision-making process. It also denotes a doctor-patient encounter characterised by openness to a patient’s needs and preference, utilising the patient’s informed wishes to guide activity, communication, and information-giving, and shared decision-making.<sup>112</sup> It is a way of seeing health and illness that affects an individual’s general well-being and an effort to empower the patient by increasing his/her role in their health. The basic functions of patient-centred care are to make patients more informed and provide reassurance, comfort, support, acceptance, confidence, and legitimacy.<sup>113</sup>

In PCC, a person’s specific health requirements and desired health outcomes are the motivating force behind all health care decisions and quality measurements. Patients are

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<sup>108</sup> Mary Atkinson Smith, ‘The Role of Shared Decision Making in Patient-Centred Care and Orthopaedics’ (2016) 35(3). *OrthopNurs* 144 <<https://nursing.ceconnection.com/ovidfiles/00006416-201605000-00003.pdf>> accessed 1 July 2019.

<sup>109</sup> Richard W. Redman, ‘Patient-centred care: an unattainable ideal?’ (2004) 18(1) *Res Theory Nurs Pract* 11 <<https://www.ncbi.nlm.nih.gov/pubmed/15083659>> accessed 3 July 2019.

<sup>110</sup> Julian Tudor Hart, ‘*The Autonomous Patient: Ending Paternalism in Medical Care*’ (2002) 95(2) *JRSM* 623 <[https://www.researchgate.net/publication/25094978\\_The\\_Autonomous\\_Patient\\_Ending\\_Paternalism\\_in\\_Medical\\_Care/link/5530eb4c0cf2f2a588ab5c81/download](https://www.researchgate.net/publication/25094978_The_Autonomous_Patient_Ending_Paternalism_in_Medical_Care/link/5530eb4c0cf2f2a588ab5c81/download)> accessed 1 July 2019.

<sup>111</sup> Picker Institute, ‘Picker Principles of patient-centred care’ (2016) <<https://www.picker.org/about-us/picker-principles-of-person-centred-care/>> accessed 1 July 2019.

<sup>112</sup> Anne Rogers, Anne Kennedy, Elizabeth Nelson and Andrew Robinson Rogers, ‘Uncovering the limits of patient-centredness: implementing a self-management trail for chronic illness’ (2005) 125(2) *Qual Health Res* 224. <<http://citeseerx.ist.psu.edu/viewdoc/download?doi=10.1.1.922.8851&rep=rep1&type=pdf>> accessed 1 July 2019.

<sup>113</sup> Pelzang, (n 7).

considered partners with their health care providers, and these providers treat patients not only from a clinical viewpoint, but also from a mental, emotional, social, spiritual, and financial viewpoint.<sup>114</sup> Similar to other value-based healthcare systems, PCC comprises a change in the way providers practice and healthcare systems are planned and achieved. PCC also characterises a change in the outdated practices of patients and their relatives from one of submissive “order taker” to one of dynamic “team member.”<sup>115</sup>

The fundamental philosophy of PCC requires the caretaker to appreciate the patient as an individual rather than as a group of illness. PCC uses a combination of activities including engagement, observation of the patient’s beliefs and values, having an empathetic presence, and taking care of physical and emotional needs to provide care to patients.<sup>116</sup> Patient participation is enabled by working with patients’ beliefs and values through providing information and mingling freshly formed perceptions into care activities which in turn reinforces one of the significant philosophies of PCC, namely shared decision-making.<sup>117</sup> PCC accepts that the patients are capable of deciding their particular expectations and desires and that they are capable of making choices and decisions concerning what they need and desire.

### 3. The Concept of Shared Decision-Making

Shared decision-making is considered as one of the characteristic components of patient-centred care that allows and encourages patients to contribute actively in their health-related management.<sup>118</sup> It is presently a widely acknowledged feature of patient-centred care in this modern age of healthcare standards worldwide.

According to Glyn Elwyn and Marie-Anne Durand, shared decision-making is “an approach where healthcare professionals and patients make decisions together using the best available evidence about the likely benefits and harms of each option, and where patients are supported to arrive at informed preferences”.<sup>119</sup> Basically, SDM is merely assisting another individual make an informed decision, whatever choice or behaviour change they face. That may not appear too difficult, but the process itself can be intricate. This is particularly true in circumstances where patients and clinicians have

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<sup>114</sup> Anon, ‘What Is Patient-Centred Care?’ (2017) NEJM Catalyst <<https://catalyst.nejm.org/what-is-patient-centered-care/>> accessed 3 July 2019.

<sup>115</sup> *Ibid.*

<sup>116</sup> Pelzang (n 7).

<sup>117</sup> Moira Stewart, ‘Towards a global definition of patient centred care’ (2001) 322(7284) BMJ 444 <<https://www.ncbi.nlm.nih.gov/pmc/articles/PMC1119673/pdf/444.pdf>> accessed 3 July 2019.

<sup>118</sup> Chong Guan Ng, Syahrir Zaini, ‘Shared Decision Making in the Treatment of Depression’ (2012) 27(2) Malaysian Journal of Psychiatry 23.

<sup>119</sup> Glyn Elwyn, Marie-Anne Durand, ‘Mastering Shared Decision Making: The When, Why and How’ (EBSCO Health Notes, 20 Feb 2018) <<https://health.ebsco.com/blog/article/mastering-shared-decision-making-the-when-why-and-how>> accessed 1 July 2019.

significantly different levels of experience, knowledge, and know-how. Healthcare is a good example where choices and options offered are very unfamiliar and full of uncertainty.

Charles, *et al*, defined a set of features in SDM affirming “...that minimum two partakers, the clinician and patient be involved; both members exchange information and take steps to build a compromise about the favoured treatment; and an arrangement is agreed on the treatment to execute.”<sup>120</sup>The generally accepted 4 ethical principles necessitates SDM to be the benchmark in most medical practices.<sup>121</sup> SDM is vital for valuing autonomy in empowering patients to make reasoned and informed choices and for beneficence by comparing the benefits of treatment against risks, as well as cost and non-maleficence in keeping away harm. The fourth principle of justice (allocating cost, benefit, and risk fairly) might also be boosted if patients elect to have fewer procedures.<sup>122</sup>It would also be more equitable if less educated individuals are engaged to a similar degree as those educated.

One way to reflect on SDM is to classify decisions into those that require discussion against those where that level of investment might not be needed.<sup>123</sup> Typically, these decisions are circumstances where the risks are higher. Further, making the incorrect choice could be painful, irritating, costly or lead to regret. Decisions in healthcare are usually of this nature and especially where there are treatments or investigations to be considered. Nevertheless, the problem is that most individuals are often ignorant of two significant issues.<sup>124</sup> Firstly, people are unaware that there are other possibilities that exist, or no one informs them that choices exist. Overall, healthcare professionals and organisations are not proficient in making patients aware that options do exist. Secondly, even if patients do become aware that choices that exist, often after searching the internet, there has been a tendency to be unenthusiastic among healthcare professionals to encourage and support a process of deliberation. Patients who bring their own findings to clinic appointments are frequently met with scepticism, and there are several reasons for this reluctance.

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<sup>120</sup> Cathy Charles, Amiram Gafni, Tim Whelan, ‘Shared decision-making in the medical encounter: what does it mean? (or it takes at least two to tango).’ (1997) 44(5) SocSci Med 681 <<https://www.ncbi.nlm.nih.gov/pubmed/9032835>> accessed 4 July 2019.

<sup>121</sup> Tom L. Beauchamp and James F. Childress, *Principles of Biomedical Ethics* 5<sup>th</sup>ed, Oxford University Press 2001.

<sup>122</sup>Anne M Stigglebout, *et al*, ‘Shared decision making: really putting patients at the centre of healthcare’ (2012) 344 BMJ 28 <<https://www.bmj.com/content/344/bmj.e256.full>> accessed 9 July 2019.

<sup>123</sup> Glyn Elwyn, Amy Lloyd, *et al*, ‘Collaborative Deliberation: A model for patient care’ (2014) 97(2) Patient EducCouns 158 <<https://mayoclinic.pure.elsevier.com/en/publications/collaborative-deliberation-a-model-for-patient-care>> accessed 1 July 2019.

<sup>124</sup>Elwyn, Durand (n 20).

It is important that healthcare professionals understand the concepts relevant to SDM so that they would be capable of applying them while taking care of patients. The academic model of therapeutic decision-making is separated as 4 types depending on the part played by the staff providing medical service namely, paternalistic, informed, agent, and shared.<sup>125</sup> Among these 4 types, the shared concept is well distinguished against the others since the exchange of knowledge in both directions happens in the shared type only.<sup>126</sup> This shared concept of medical decision-making is consistent with the type of bi-directional exchange of knowledge between patient and clinician as emphasised in the definition of shared decision-making above. Over a period of time, many ideas associated with physician-patient relationships have been persistently echoed in shared decision-making. Significant concepts associated with physician-patient relationships can be summarised by the ensuing four groups.

Firstly, building excellent physician-patient relationships involve good communication.<sup>127</sup> Good communication in healthcare is important as unpredictability is impossible to be entirely left out in the process of decision-making. Trusting relationships should be formed between clinician and patient by means of effective conversation techniques for good communications to happen. Clinicians will be more able to appreciate patient issues and visibly recognise patient preferences once a reliable bond is initiated. Trust is the basis on which SDM is achieved.<sup>128</sup>

Secondly, patient autonomy must be maintained for good communication.<sup>129</sup> The concept of autonomy is linked mutually to customer-centred values in the social order and medical ethics for patients' safety. It has been stressed to resolve difficulties appearing in medical practices indicated by paternalistic decisions. Once autonomy is assured, patients tend to exert their power to choose freely and agree to the outcome of decision-making.<sup>130</sup>

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<sup>125</sup> Jong-Myon Bae, 'Shared decision making: relevant concepts and facilitating strategies' (2017) 39 *Epidemiol Health* 1 <<https://www.ncbi.nlm.nih.gov/pmc/articles/PMC5733387/pdf/epih-39-e2017048.pdf>> accessed 7 July 2019.

<sup>126</sup> *Ibid.*

<sup>127</sup> Jurgen Kasper et al, 'Turning signals into meaning – 'Shared decision making' meets communication theory' (2012) 15(1) *Health Expect* 3 <<https://www.ncbi.nlm.nih.gov/pmc/articles/PMC5060601/pdf/HEX-15-03.pdf>> accessed 4 July 2019.

<sup>128</sup> Betty Chewing, *et al*, 'Patient preferences for shared decisions: a systematic review' (2012) 86(1) *Patient Educ Couns* 9 <<https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4530615/pdf/nihms-279704.pdf>> accessed 7 July 2019.

<sup>129</sup> Bae (n 26).

<sup>130</sup> Myfanwy Davies, Glyn Elwyn, 'Advocating Mandatory Patient 'Autonomy' in Healthcare: Adverse Reactions and Side Effects' (2008) 16(4) *Health Care Analysis* 315 <<https://www.ncbi.nlm.nih.gov/pubmed/17975729>> accessed 7 July 2019.

Thirdly, assured of their autonomy, patients enthusiastically take part in decision-making.<sup>131</sup> The reassurance of patient participation will occur when the clinician presents appropriate suggestions as he sums up the current issues and attempts to describe the benefits and drawbacks of every available option. Fourthly, for a patient to willingly agree to a decision, the process must be patient-centred, emphasising on the patient's characteristics namely the clinician recognises the patient's individual needs and desires and makes a decision.<sup>132</sup>

#### 4. Shared Decision-Making Process

Shared decision-making process encompasses three interrelated stages, namely 1) patient engagement stage, 2) discussion stage, and 3) decision stages.<sup>133</sup> The three stages involve several interworking principles that support the overall idea of SDM, with patient engagement being the initial stage of the process. After the patient engagement stage is initiated, there is a continuous progression into the discussion stage, with the decision stage being the final emphasis. Once the decision stage has been reached the shared decision-making process might move back and forth from the discussion and patient engagement stages. These stages work together to promote empowerment and activation among patients and encourage effective communication between patients and healthcare providers. These stages encourage partnership and create beneficial collaboration among healthcare providers and stakeholders in a way that positively improves patient care experiences.<sup>134</sup>

#### 5. Patient Engagement Stage

A survey by the National eHealth Collaborative in the US in 2012 revealed that patient engagement is a crucial element in the transformation of healthcare and SDM but their answers varied significantly regarding the definition of patient engagement. The answers included descriptions such as patients utilising online educational material to learn more

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<sup>131</sup> Yves Longtin, *et al*, 'Patient Participation: Current Knowledge and Applicability to Patient Safety' (2010) 85(1) *Mayo Clin Proc* 53 <[https://www.researchgate.net/publication/40819547\\_Patient\\_Participation\\_Current\\_Knowledge\\_and\\_Applicability\\_to\\_Patient\\_Safety](https://www.researchgate.net/publication/40819547_Patient_Participation_Current_Knowledge_and_Applicability_to_Patient_Safety)> accessed 4 July 2019.

<sup>132</sup> Michael J. Barry, Susan Edgman-Levitan, 'Shared Decision Making — The Pinnacle of Patient-Centred Care' (2012) 366(9) *N Engl J Med* 780 <[http://projects.iq.harvard.edu/files/shared\\_decision\\_making/files/sdm\\_pinnacle\\_of\\_patient\\_centered\\_care.pdf?m=1446225643](http://projects.iq.harvard.edu/files/shared_decision_making/files/sdm_pinnacle_of_patient_centered_care.pdf?m=1446225643)> accessed 5 July 2019.

<sup>133</sup> S. Chow, G. Teare, G. Basky, 'Shared decision making: Helping the system and patients make quality health care decisions' (2009) *Saskatoon: Health Quality Council* <[https://hqc.sk.ca/Portals/0/documents/Shared\\_Decision\\_Making\\_Report\\_April\\_08\\_2010.pdf](https://hqc.sk.ca/Portals/0/documents/Shared_Decision_Making_Report_April_08_2010.pdf)> accessed 7 July 2019.

<sup>134</sup> Mary Atkinson Smith, 'The Role of Shared Decision Making in Patient-Centred Care and Orthopaedics' (2016) 35(3) *OrthopNurs* 144 <<https://nursing.ceconnection.com/ovidfiles/00006416-201605000-00003.pdf>> accessed 1 July 2019.

about their health, patients communicating with healthcare providers concerning changes in their health, patients scheduling appointments online with their healthcare providers, patients sending e-mails to their healthcare providers to ask questions, and patients discussing health-related questions face to face with their healthcare providers. The absence of a standardised and formal explanation of patient engagement generates challenges when it comes to executing and improving the process of patient engagement.<sup>135</sup> Patient engagement may also be well-thought-out as a form of information exchange between patients and their healthcare providers.<sup>136</sup>

Participation in engagement allows individuals to be involved in activities that permit them to attain the greatest benefit from healthcare services offered to them and also allows them to balance precise and comprehensive information with their preferences, needs, and capabilities.<sup>137</sup> Patient engagement within the SDM process helps to involve patients in their personal care to promote further positive patient outcomes and self-involvement in care management. Patients who are engaged in this method are more likely to take proactive steps in managing their individual health on a regular basis.

## 6. Discussion Stage

The SDM process progresses with the discussion stage, which is a focused and thorough derivative of patient engagement. This stage involves verbal communication between the healthcare worker and the patient. It may be regarded as a form of counselling that emphasises on available treatment options, patient preference, and healthcare professional recommendations. The discussion stage is a two-way form of communication between the treating physician and the patient. Preceding this discussion stage, the treating physician might evaluate existing literature pertaining to a precise disorder or course of treatment to support evidence-based practice. The patient may review information collected during the course of patient engagement and prepare a list of preferences based on the disorder-related information he has obtained. The healthcare provider must empower the patient to enquire about the efficacy of available and suggested treatment options, to include the risks and benefits during the discussion stage.

The healthcare worker may play a part in this stage through decision support that includes the use of counselling and decision aids to further inform and educate patients.

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<sup>135</sup> Ian Worden, 'The path to increased patient engagement lies in the definition' (2013) <<https://docplayer.net/11134630-ian-worden-mba-mhi-pmp-healthcare-cio-and-patient-engagement-advocate.html>>accessed 7 July 2019.

<sup>136</sup> Chow, Teare, Basky(n 34).

<sup>137</sup> Centre for Advancing Health, 'A New Definition of Patient Engagement: What is Engagement and Why is it Important?' (2010) <[http://www.cfah.org/pdfs/CFAH\\_Engagement\\_Behavior\\_Framework\\_current.pdf](http://www.cfah.org/pdfs/CFAH_Engagement_Behavior_Framework_current.pdf)> accessed 7 July 2019.

The usage of decision aids may help to improve health literacy, increase patient satisfaction, improve patient experience, encourage patient empowerment, and positively support the complete SDM process. Health coaches can teach and mentor patients so that they will have the necessary skills, knowledge base, and understanding needed to empower and encourage patients to make decisions grounded on their own desire and preferences.<sup>138</sup>

## 7. Decision Stage

Patients and provider collaboration are encouraged by the decision stage by supporting a mutual agreement connected to the plan of treatment.<sup>139</sup> The commencement of the decision stage might involve discovering the availability of recommended or desired treatment choices. The decision stage may then advance into negotiating specifics of the plan. This stage may further consist of choosing when and where to receive treatment relating to the plan of care. The physician might not at all times be in agreement with the patient throughout the decision stage. However, the aim of this decision stage is to develop the plan of care so that it demonstrates the patient's value, preference, and desired health outcomes.<sup>140</sup>

## 8. Shared Decision-Making and Informed Consent

SDM depends on the basic principle of both patient autonomy and informed consent. The model accepts the fact that patients have their own values that influence the understanding of risks and benefits in a different way from the way a physician interprets them. Informed consent is at the centre of shared decision-making,<sup>141</sup> i.e. without an understanding of the benefits and shortcomings of all treatment options, patients cannot participate in making decisions. Often there is usually more than one option, with no clear distinction of which option is the best. SDM varies from informed consent in that patients make their decisions based on their values and beliefs, as well as on being fully informed.

There have been recent criticisms within the medical community of the traditional method of informed consent and calling for a replacement of those methods with a SDM

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<sup>138</sup> France Légaré, Dawn Stacey, Nathalie Brière et al, 'A conceptual framework for interprofessional shared decision making in home care: Protocol for a feasibility study' (2011) BMC Health Serv Res 11 <[https://www.researchgate.net/publication/49798586\\_A\\_conceptual\\_framework\\_for\\_interprofessional\\_shared\\_decision\\_making\\_in\\_home\\_care\\_Protocol\\_for\\_a\\_feasibility\\_study](https://www.researchgate.net/publication/49798586_A_conceptual_framework_for_interprofessional_shared_decision_making_in_home_care_Protocol_for_a_feasibility_study)> accessed 7 July 2019.

<sup>139</sup> Chow, Teare, Basky (n 34).

<sup>140</sup> Chow, Teare, Basky (n 34).

<sup>141</sup> Simon N Whitney, Amy L McGuire, Laurence B McCullough, 'A typology of shared decision making, informed consent, and simple consent' (2004) 140(1) Ann Intern Med 54 <<https://www.ncbi.nlm.nih.gov/pubmed/14706973>> accessed 4 July 2019.

style.<sup>142</sup> SDM can be defined as a discussion in which patients and doctors work in collaboration to appreciate the circumstances of the patient and to decide how to address their wishes ideally while the definition of informed consent is basically a twin process where, clinicians disclose the benefits, risks and choices of a planned procedure or treatment and patients agree to or reject the suggestion. Informed consent prerequisites came from laws associated with battery, and therefore represent a fixated attempt to shield patients from whatever occurring to their bodies in the absence of their knowledge.<sup>143</sup> Informed consent was not proposed to recognise the values of distinct patients and their exceptional circumstances.

Whereas SDM is envisioned to be utilised across diverse circumstances in which patient preferences have a noteworthy role in considering the possible harms and benefits of a decision, informed consent prerequisites are applicable with few exclusions only to invasive procedures and treatments.<sup>144</sup> As a consequence, the law does not require clinicians to deliberate with patients what diagnostic tests or monitoring strategies to use in situations where a procedure is not being done. By contrast, SDM is proposed to be utilised for any situation where patient values and preferences should play an important part in balancing the harms and benefits of a medical decision. This comprises the discussion on a full range of procedures and treatments, as well as investigation plans or attentive waiting, each time these are reasonable choices.

SDM can also be differentiated from the informed consent process by how and what information is given to patients. Informed consent mostly involves “disclosure to patients” and not “discussion with patients” inferring that the informed consent process can be accomplished by a one-way information discussion. Furthermore, informed consent disclosures frequently happen when a treatment option has already been selected, whereas SDM dialogue needs the way onward uncertain prior to the discussion and that the most suitable course of action arises via this discussion. This reveals that in SDM choices are deliberated without presuming that one choice merits more consideration whereas others take an alternative role. With respect to the amount of information mandatory for informed consent, what is followed is frequently stated to be either a “reasonable physician” standard or a “reasonable patient” standard.

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<sup>142</sup> Erica S. Spatz, Harlan M. Krumholz, Benjamin W. Moulton, ‘The New Era of Informed Consent Getting to a Reasonable-Patient Standard Through Shared Decision Making’ (2016) 315(19) JAMA 2063 <<http://ignacoriesgo.es/wp-content/uploads/The-new-era-of-informed-consent.pdf>> accessed 8 July 2019.

<sup>143</sup> *Schloendorff v. Society of New York Hosp.*, 105 N.E. 92, 93 (N.Y. 1914).

<sup>144</sup> Rachel A Lindor, Marleen Kunneman, Matt Hanzel, *et al*, ‘Liability and Informed Consent in Context of Shared Decision Making’ (2016) 23(12) AcadEmerg Med 1428 <<https://onlinelibrary.wiley.com/doi/pdf/10.1111/acem.13078>> accessed 8 July 2019.

The *Bolam* test<sup>145</sup> in England was applied to determine what should be disclosed. The test holds that the law imposes a duty of care between a doctor and his patient, but the standard of that care is a matter of medical judgement. The test was further acknowledged in *Sidaway v Bethlem Royal Hospital Governors & Ors*<sup>146</sup> though not unanimous, with judges employing different emphasis on the patient's right to make informed treatment decisions as opposed to the doctor's professional judgment in disclosing information. Under the "reasonable physician" standard, doctors must inform the benefits, risks, and alternatives to treatment that a reasonable doctor under similar situations would disclose. What these benefits, risks, and alternatives constitute is decided principally by similarly skilled doctors and is commonly established by the testimony of other clinicians as stated above. In the "reasonable patient" standard, doctors must inform the benefits, risks, and alternatives to treatment that a reasonable patient would find material to his or her decisions.<sup>147</sup> Even under this standard, the law has deliberately evaded needing clinicians to deliberate what the individual patient before them would want to know, in its place concentrating only on a "reasonable" or representative patient, based on a fear that deliberating the needs of every individual patient would excessively burden the clinicians.<sup>148</sup> Distinct to the two standards of informed consent, that focuses on the one-way delivery of information, shared decision-making needs a discussion and emphasises explicitly on the information required for an individual patient.

In *Montgomery v Lanarkshire Health Board*, the established concept that the disclosure of information by clinicians when procuring an effective consent for treatment must be decided on the foundation of what a reasonable group of medical opinion approves should be told and made aware in the situation.<sup>149</sup> Despite considerable deliberation about the exact implications of *Montgomery*, there is an overall agreement that, post-*Montgomery*, consent necessitates a process of shared decision-making based on discussion between clinician and patient about the benefits and material risks of the presented choices including the choice of no treatment. The discussion required here maintains the viewpoint of the clinician as well as increases the importance of the perspective of the patient. This is emphasised in the *Montgomery* two-limbed test of a material risk. This is well-defined as a risk that is considered material, either from the viewpoint of a reasonable person in the patient's position or from that of the particular patient concerned. The legal opinions supporting this test recognise that the clinician and

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<sup>145</sup> *Bolam v Friern Hospital Management Committee* [1957] 1 WLR 582.

<sup>146</sup> [1985] AC871.

<sup>147</sup> *Canterbury v. Spence* 464 F.2d. 772, 782 (D.C. Cir. 1972).

<sup>148</sup> Jaime S. King, Benjamin W. Moulton, 'Rethinking Informed Consent: The Case for Shared Medical Decision-Making' (2006) 32 Am.J.L. & Med 429 <<https://pdfs.semanticscholar.org/e3b1/663dc4a4de0ded0ae63bd54c64939d94cdeb.pdf>> accessed 8 July 2019.

<sup>149</sup> [2015] UKSC 11.

patient may view the benefits and risks of treatment choices differently in terms of their own values.

The justification mentioned in *Montgomery* meant for this novel test of materiality focuses on the fundamental ethical position the law rightfully now confers reverence for patient autonomy in procuring consent. The Montgomery decision offers new horizons to expand patient-centred care within the doctor–patient relationship by recognising the change of a more patient-centred method to the law of informed consent. Montgomery upsets well-known medical views around negotiating, acquiring, and recording the act of informed consent, and it brings into clearer attention the inevitable requirement for doctors to make sensible, well-reasoned decisions amid ethical values. The Montgomery decision is decisively complementary to good medical practice as it is presently understood. This adapting process is totally reliant on the doctor initiating discussion and a beneficial cooperation where knowledge and information can be spontaneously exchanged between patient and doctor.

## 9. Ethical Principles of Shared Decision-Making

As the familiarity of the ethical consequences of physician-patient relationships becomes more refined, clinicians must fit in these teachings into reality. Many clinicians have yet to achieve the equilibrium between complete patient autonomy and beneficence in clinical practice. Many doctors still underrate disclosure and misjudge the variability in patient wishes. Patients often obtain either insufficient medical data to establish an informed decision or too few doctors' views to feel confident in their choice. To fulfil their ethical duties towards the patients, healthcare professionals must have a structured medical decision-making that satisfies the importance of both ethical values namely autonomy and beneficence. SDM can achieve this purpose by promoting patient autonomy, while also leaving room for clinician beneficence.

Recognition for autonomy and beneficence are two vital principles that oversee medical ethics.<sup>150</sup> Beneficence compels clinicians to do “good” for the advantage of their patients, respect for autonomy necessitates them to ensure that patients have adequate information to make a well informed and autonomous decision.<sup>151</sup> Though this autonomy and beneficence can satisfy one another, they may often conflict, necessitating their relational importance to be recognised.

Historically, beneficence has been assumed in terms of the patients' “medical” benefit, rather than promoting their best interests on a wider level. As a result of their

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<sup>150</sup> Beauchamp and Childress (n 22).

<sup>151</sup> *Ibid.*

sophisticated training and knowledge of medicine, clinicians took the responsibility of acting as agents for their patients, deciding the best treatment choices to fulfil the primary goal of improved health. The beneficence-focused, decision-making model forced patients to accept not only their clinician's treatment choices, but also their clinician's levels of risk aversion, values, and personal preferences. Frequently treatment results effect significantly more than the patient's health, such as their participation in their favourite activities, ability to work, and caring for their children. Beneficence unrestricted by concerns for patient autonomy quickly turns into paternalism.

SDM is a process of communication in which the clinician and patient utilise complete and impartial information on the benefits and risks associated with all feasible treatment alternatives and information from the patient that may make one treatment alternative more desirable than the others to arrive at a treatment decision. While this definition incorporates the traditional disclosure crucial for legal informed consent, it goes past the mere presentation of risks, facts, and alternatives. SDM comprises a heartier conversation, which involves both the patient and the clinician in assessing the patient's therapeutic goals and life preferences to come to an informed choice.

As a result, SDM encourages both autonomy and beneficence. While appreciated for any therapeutic decision, its approaches demonstrate most effective for use in preference-sensitive circumstances. Here, the patient and provider exchange information to better appreciate all the possibilities of the options the patient faces, and to deliberate about the patient's individual values as they associate the benefits and risks of each option. While the patient and clinician mutually take part in the treatment decision, SDM gives preference to patient autonomy over beneficence, but only sufficient to tip an otherwise even balance.<sup>152</sup> In cases of disagreement after discussion, the patient's preference should govern the treatment. By defending patient autonomy and accepting the importance of provider analysis and opinion, SDM offers the most effective technique of allowing clinicians to fulfil their ethical responsibilities to patients.

## 10. Shared Decision-Making in the Malaysian Context

Even in countries where SDM is formally recommended by the government, its execution has proved difficult. In countries that have inadequate healthcare resources and an overburdened healthcare system such as Malaysia implementing SDM is even more difficult. Unfortunately, we have inadequate knowledge of in what manner to inculcate the SDM concept into our existing healthcare practices. Not much is understood about

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<sup>152</sup> Benjamin Moulton, Jaime S. King, 'Aligning Ethics with Medical Decision-Making: The Quest for Informed Patient Choice' (2010) 38(1) L Law Med Ethics 85 <[https://repository.uchastings.edu/cgi/viewcontent.cgi?article=1324&context=faculty\\_scholarship](https://repository.uchastings.edu/cgi/viewcontent.cgi?article=1324&context=faculty_scholarship)> accessed 7 July 2019.

the decision-making preference and roles of patients and clinicians and, furthermore, it is not known if this Western concept of SDM is applicable to cultures where relatives and communities strongly impact healthcare decisions.<sup>153</sup> Various notions of harmony and family virtue, which spring from different religious or moral codes affect healthcare decisions in Malaysia.

There are also many gaps in the practice, research, laws, and policies associated with SDM in Malaysia. Clinicians do not include patients regularly in decision-making and still act in a paternalistic manner in making healthcare choices for patients. Cultural and language variety also makes the practice of SDM difficult in Malaysia. Doctors not only have to communicate in a language that may not be their mother tongue but also to recognise patients' personal and cultural values. Communicating risk, compromise, and reaching agreement involve high-level communication skills and calls for high language proficiency. Moreover, the public–private dual healthcare system results in practice disparities. Both issues make the implementation of SDM a challenging task.

In Malaysia, health literacy is low, which might contribute to the poor patient participation in decision-making.<sup>154</sup> Local health information quality is insufficient and mostly poor, and this is further hampered by the lack of translation into common languages which prevents cultivating health literacy and increasing health awareness. One of the key steps to empower patients to be involved in decision-making is “patient education”. Access to appropriate, understandable, and precise information boosts health literacy and encourages patients in selecting the most suitable option for their health. There needs to be simultaneous effort from government organisations, non-government organisations, professional bodies, and academic institutions to enhance the quality of, and access to, patient information.

The Malaysian Medical Council guideline describes that the relationship between a patient and a physician must be collaborative and be a partnership that facilitates free dialogue in which a physician's clinical knowledge and a patient's preferences and needs are mutually exchanged to decide the best therapeutic option. Although the Malaysian Medical Council recommends the practice of SDM, its execution remains challenging. The council needs to collaborate systematically with other stakeholders, namely the Ministry of Health, patient support groups, professional bodies, and academics, to come up with a plan to grow the awareness and the execution of SDM. Changes must be initiated in the healthcare system by incorporating SDM within its policies. Presently, there is no health policy in Malaysia that precisely looks into the matters concerning SDM.

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<sup>153</sup> Ng (n 5).

<sup>154</sup> *Ibid.*

## **11. Conclusion**

The SDM process will continue to become popular as patient-centred care continues to encourage patient engagement, in addition to provider and patient discussions that determine the plan of treatment. The aim and purpose of SDM is for patients to make high quality-decisions. To achieve this, healthcare professionals should be a partner who “shares” relevant information. SDM also helps to positively impact patient outcomes and experience. It is thus significant for SDM to be completely understood by healthcare professionals and patients before implementation. SDM is applicable to a broader range of clinical decisions and requires a more deliberate emphasis on the needs of the individual patient compared to informed consent although they may overlap in basic ways. The implementation and enablement of SDM should be ideally one of the basic foundations of federal healthcare policies as it has a positive effect not only on patients and physicians but also on government health systems.

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