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The Knowledge Platform on Sexual and Reproductive Health & Rights

RAHMY

RESPECTFUL, ABUSE-FREE, HUMANIZED MOTHERHOOD THROUGH YOUTH-EMPOWERMENT

Introducing Shared Decision Making for Respectful Maternal Care:

The case for Egypt

"Every woman has the right to the highest attainable standard of health, including the right to dignified, respectful health care throughout pregnancy and childbirth, and the right to be free from violence and discrimination." **(1)**

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ACRONYMS AND ABBREVIATIONS

COVID-19	Coronavirus or COVID-19 pandemic
EMR	Eastern Mediterranean Region
OV	Obstetric Violence
PCC	Patient-centered Care
RAHMY	Respectful, Abuse-free, Humanized Motherhood through Youth-empowerment
RMC	Respectful Maternal Care
SDM	Shared Decision Making
SRHR	Sexual and Reproductive Health and Rights
UNFPA	United Nations Population Fund
WHO	World Health Organization

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OBJECTIVE

This paper aims to introduce the concept of Shared Decision Making, explore various barriers to its implementation locally through the perspectives of providers and patients, and finally offer recommendations to policymakers, health providers, and patients to improve Respectful Maternal Care.

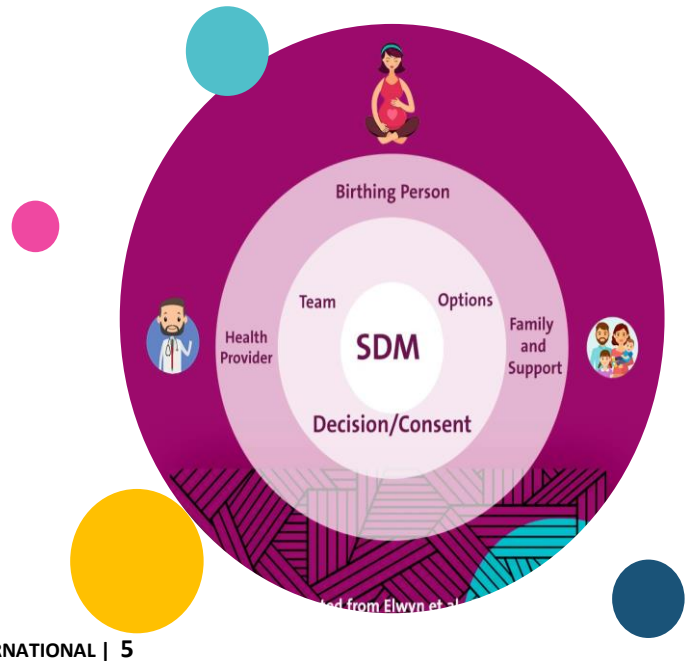
This document is prepared by Merette Khalil, MPH; obstetric violence specialist, health systems researcher, gender-equity and SRHR advocate, founder and CEO of YourEgyptianDoula, and principal investigator of this research project, RAHMY.

I. MITIGATING OBSTETRIC VIOLENCE THROUGH SHARED DECISION MAKING

Obstetric violence threatens the provision of high-quality, evidence and rights-based, respectful maternal care (RMC).[1] Globally, studies show as high as 98% of women experience at least one form obstetric violence, with young women almost two times more likely to experience physical abuse in childbirth (1–4). A recent study from the Eastern Mediterranean Region (EMR) concluded that obstetric violence is prevalent – with 6 out 7 types reported by women across two-thirds of countries included in the study. Physical abuse and non-dignified care were the most common forms of obstetric violence in the region (5). For example, in Egypt, obstetric violence is manifested through the routine overmedicalization in hospital-based deliveries, non-confidential, non-consented, dehumanizing care, and one of the highest C-section rates globally (many done unnecessarily) (6,7). The problem is that obstetric violence is often invisible; it is embedded within health systems and normalized by sociocultural norms; resulting in its underreporting by women and their families, continuation as 'standard' intrapartum care by health workers, and general passivity towards human rights violations by policymakers and managers (5).

A regional review of women's narratives revealed that intrapartum care is hierarchical, technocratic, overmedicalized, and common with unconsented and overused routine interventions, information asymmetry and limited decision-making power (5). Further to this, recent UNFPA data confirmed the gender inequalities and barriers to reproductive decision-making autonomy unveiling gaps in the region (8). Moreso, in the EMR, decision-making power on sexual and reproductive health and rights (SRHR), including maternal health, remain with men, religious leaders, and doctors while meaningful youth engagement and participation remain lacking and exacerbated by the COVID-19 pandemic (9–11). Recent studies from Egypt indicate large gaps in knowledge and awareness about SRHR, increasing risks for gender-based violence, loss of body autonomy and decision-making power with greater disparities among rural, less educated, poorer, younger women and girls while those intersectional identities are more vulnerable (6,12–14).

The World Health Organization (WHO) identified patient-centered care (PCC) as a key aspect to improve the quality of (maternal) care within an intregrated holistic health systems approach (15,16). This approach is widely utilized in many western health systems, yet there is limited regional evidence related to its implementation, especially in SRHR, as it is stigmatized and considered a taboo topic. Studies show that SRHR is neglected for youth (especially young women) who are often forgotten and underprioritized (10,17). Operationalizing PCC requires a collaboration between the patients, their community, the care team, and the environment towards shared and informed-decision making (18).



[1] See RAHMY: Obstetric Violence Factsheet including the definition, seven typologies, their corresponding human rights, and the most common forms reported in the Region

Shared Decision Making (SDM) utilized teamwork and discussion between the patient, their family or support system, and the health providers to identify roles, values, present options, preferences, pros and cons, check or clarify understanding, make or explicitly defer decision, and arrange follow-up (19–22). Various models exist to conceptualize the SDM process; in line with global reviews on implementing SDM for RMC, the Elwyn et al's three-step model is selected as the guiding framework for this project due to its simplicity and inclusion of family and support persons in the decision making process (19,23).

SDM is disruptive to the traditional provider-led approach of maternal health as it levels the power dynamics between patruients and their physicians (19). SDM is valuable for SRHR, as it empowers patients to understand their rights to bodily autonomy and enables them to make informed decisions about their own bodies and health. SDM is beneficial in promoting RMC as results in better maternal and child health outcomes, higher satisfaction in birth experiences, and fewer depressive symptoms (21,23,24).

Within the region,[2] Webair highlights the importance of being culturally-sensitive and responsive to patients' prefer ences, values, and needs. According to this cultural context, we adapt Elwyn et al.'s three-step model: 1) team talk, 2) options talk, 3) consent talk, to introduce SDM as a PCC approach to mitigate the hierarchical and technocratic care manifested as obstetric violence and ultimately improve RMC.[3]

II. FACTORS AFFECTING SHARED DECISION MAKING IN MATERNAL CARE:

REFLECTIONS FROM YOUNG EGYPTIAN MOTHERS AND DOCTORS

The application of PCC and SDM is novel in many of the Region's health systems, including Egypt, and are attributed to various factors affecting the service delivery supply (physician/health systems) and demand (patient/community).[4]

A. SUPPLY-SIDE FACTORS:

Health workers play an essential role in RMC, yet, the lack of understanding, operationalization, and accountability of SDM and PCC threaten their provision of high-quality RMC (25–29).

High workload, cultural (socially and medically), and health systems barriers were reported to impede SDM and RMC from the supply side.

Young physicians reported that patient illiteracy (associated with lower socio-economic status), lack of consistency in antenatal visits, and high workload resulted in short prenatal

[2] Geographical differences are noted between what the author defines as the Middle East compared to the WHO definition Eastern Mediterranean Region

[3] See YourEgyptianDoula's bilingual SDM4RMC Tips for patients, providers, family/support persons, adapted from Elwyn et al.

[4] This section triangulates the findings of a narrative review on barriers and enablers to SDM for RMC in Egypt and globally, along with qualitative findings from 2 sources to capture and validate both supply and demand side youth voices within maximum variation sampling until saturation was reached. Eight key-informant interviews were conducted with young obstetricians (OBGYN residents, referred to as health providers) from 4 governorates, capturing rural and urban voices, 80% of this sample was male, which was reflective of the male-dominated obstetric health system in Egypt. Additionally, four focus group discussions with 12 participants in each group were conducted with young mothers of different ages (15-35) of historically margenalized communities, in an urban-slum of Cairo, and rural-community in the Northern Delta. All participants provided their informed consent prior to participation.

appointments contributing to limited information sharing. This was in line with findings from a global Delphi study where SDM was more utilized pre-natally than during and after birth (23). This same study further highlighted the importance of open and respectful communication of evidence and contingency planning where health professionals were responsible to prepare women antenatally for unexpected and urgent decisions in birth (23).

Among the major barriers is the culturally-embedded hierarchy which places male physicians above female partuients, often resulting in many women feeling intimidated to ask questions, obtain sufficient information, and make informed-decisions (5,7). This creates an uneven power dynamic between the provider and patient. Interestingly, Webair's regional analysis reported that among doctors' top percieved barriers to PCC is patients wanting providers to decide for them (18). Across the region, as in Egypt, medical decisions are often unilaterally made by the physician within generally paternalistic and profit-oriented models posing a threat to SDM and RMC (18,30).

Moreover, similar to global findings, within Egyptian hospitals, the culture around informed consent is a significant barrier affecting RMC and service delivery (31). The qualitative findings of this study suggest that physicians generally had a high awareness and could define various elements of 'medical ethics' and RMC such as privacy (especially between male physicians treating female patients), talking gently and patiently and discussing preferences and decisions in antenatal visits. However, participants also noted limited implementation of SDM during childbirth. Young doctors also reflected that SDM and informed-consent are not applied in practice especially during the birth itself, highlighting that consent in birth is merely either paperwork that must be complete and signed by the husband prior to admission or verbally obtained from the husband in the case of medical procedures. Notably, a study on the causes for Egypt's high C-section rates found that a substantial number of surgeries took place in the absence of strong medical justification with physicians contributing this to convenience incentive, lack of supervision, training in public hospitals, and limited familiarity with clinical guidelines (13). Moreso, studies conducted in hospitals in southern Egypt reported that about 50% of doctors and nurses knew about the list of patient rights (32); however, about 75% of patients did not know about this charter, and 98% stated that the medical team did not inform them about available treatment choices (33). These findings conclude that the lack of knowledge, application, and accountability around medical ethics pose a threat to RMC in Egypt.

Regarding health systems barriers, young doctors reported that in many public hospitals, the lack of essential supplies and under-equipped facilities threaten their ability to provide RMC. These findings are in line with those reported by health workers in other developing countries such as Kenya, Ethiopia, and Nigeria (27,34,35).Facility-level infrastructural barriers and overcrowding were reported to impede SDM; this was further confirmed by a systematic review that found the noisy and non-confidential settings in hospitals inhibited meaningful discussions (36). Additionally, one of the biggest threats to RMC in Egypt is the lack of women-centered care and limited capacities of nurses and midwives (7). Globally, studies highlight the essential role of midwives in delivering women-centered care, showing empathy, participating in shared decision making, and safeguarding women's dignity (29,37,38). Interestingly, one study found that women who experienced midwifery care reported greater autonomy and satisfaction regarding their decision-making in maternity options, compared to those than women under physician care(24). The lack of investment in nursing and midwifery, poor coordination, limited collegiality, and weak

organizational support for multidisciplinary care teams further threatens PCC nationally and regionally (18).

B. DEMAND-SIDE FACTORS:

In a regional review, barriers to PCC identified by patients included: time constrains, doctors feeling superior, lack of empathy and respect, lack of privacy and confidentiality, use of medical jargon, provision of services by a provider of the opposite sex, and lack of adequate training (18). These factors mirror many of those reported by women as contributing factors to obstetric violence across the region (5). Moreover, the status of inclusive, rights-based, respectful, and PCC is even more dire for youth, women, LBGTQIA, refugees, lower educational and socio-economonic backgrounds, and other marginalized identities (9,17).

Among the key barriers to SDM are women's limited reproductive autonomy, insufficient information for informed consent, and loss of control.

The most critical barrier to SDM for RMC is women's limited reproductive autonomy. The qualitative findings of this study indicate that women, described the involvement of many other decision-makers regarding their SRHR, including but not limited to their physicians, their husbands, their mothers, mothers-in-law, and female relatives (including in-laws). Many women, representing poorer socio-economic quintiles, compared their experiences as first-time mothers where their sources of information were usually their mothers and female family members, followed by their doctors, to subsequent pregancies where they relied on their previous experiences. This is confirmed in literature from Egypt (39) and other developing contexts. For instance, in a study from Sub-Saharan Africa, Darteh et al. concluded that rural residence, young age, low/no level of education, muslim religion, lack of occupation and limited partner's

education were found to be associated with lower women's decision-making about sexual intercourse, condom use and reproductive health decision-making index (40). UNFPA 2021 data revealed that globally nearly half of women in almost 60 developing countries were denied their bodily autonomy (8). Another systematic review found that women in developing countries often have limited autonomy and control over their health decisions with factors, such as young age, lower socio-economic status, and poor education, affecting women's health care decision-making autonomy (41).

The lack of sufficient information for decision making and informed-consent were frequently reported across the qualitative data confirming what is documented in national and regional literature (5,7). Moreover, a study by Metwally et al. highlights the gender-gap in information especially for young women (31). When interviewing patients in three different types of Egyptian hospitals (governmental, university and private), this study found that the legal guardians of adolescents took decisions on their behalf without consulting them. Additionally, 85% of the female sample stated that while going through the informed consent process, they received minimal

to no information, as opposed to their male counterparts who reported receiving sufficient information (31). As reported in this study's focus group discussions, about half of participants noted that limited time during appointments did not allow for questions or exchange of information during their antenatal appointments. Other women reported feeling embarrassed, not knowing what questions to ask during appointments, or intimidated by their providers to inquire for more information due to the stigma of SRHR issues. Conversely, a global review revealed that among the top enablers in implementing PCC were exchanging information and deeming the patient-clinician relationship as essential; women prioritized access to information above any other enabling factor (42).

Qualitative narratives surrounding decision-making during birth were generally traumatic, recounted non-consented care along with most of the seven typologies of obstetric violence. Many women shared stories of insufficient pain management, loss of control and autonomy, feeling dehumanized, and being abandoned confirming the high prevalence of obstetric violence in both private and public hospitals in Egypt. These experiences were similar to the narratives are reported regionally (5,43). More than 60-70% of participants had undergone C-sections and only about a third were informed that it was necessary due to a medical condition. Many women reported that while they felt some agency to discuss their preferences antenatally, during giving birth, they felt objectified with interventions happening to their bodies and decisions taken on their behalf without their consent; confirming literature findings (7). Additionaly, for about a quarter of participants, qualitative findings highlighted distrust towards medical staff due to previous negative experiences. One systematic review on SDM in birth points to the importance of providers' role in respecting bodily autonomy and integrity, providing sufficient information, and enabling informed choices as essential to RMC and PCC (44).

Finally, among other barriers, a study from rural Egypt found that approximately a quarter of women reported that gaining family permission, allocating time to go to health facilities, or concern about lack of female physicians (personal/cultural barriers) was a barrier for them (12).

In conclusion regarding the stages of SDM, both supply and demand sides point to general acceptance and application of the first stage (team talk). Generally, teamwork is utilized between obstetricians, parturients, and their partners in antenatal care. Both sides also recognize the importance of the second stage (options talk) to empowered and informed birth; yet are limited by information asymmetry, inadequate reproductive health literacy, and high workload and short appointment times. The final stage of SDM (consent talk) is poorly implemented and requires the most urgent action. Operationalizing and monitoring the informed consent process in childbirth and strengthening women-centered care are essential to ensuring rights-based and respectful maternal care.

Improving SDM, RMC, and PCC require multi-level and multi-pronged interventions. The following recommendations aim to pushback against a culture that normalizes obstetric violence and hierarchical care, increase awareness about patients' rights, including their right to informed consent, improve service delivery through women-centered care teams and service delivery, and increase overall advocacy for the right to respectful and high-quality maternal care.

III. RECOMMENDATIONS ON OPTIMIZING SHARED DECISION MAKING FOR RESPECTFUL MATERNITY CARE

AT A NATIONAL LEVEL, a strategy to improve rights-based and respectful maternal care must be instituted to improve the quality and outcomes of maternal and child health and address obstetric violence and its various typologies. This must include strategic interventions to address the rampant C-section rates, train health workers on delivering women-centered, gender-sensitive, rights-based maternal care. Creating compulsary continuing education and capacity building on utilizing SDM for RMC would improve patient-centeredness in maternal services provision. These trainings should be taken up by all cadres of maternal health workers (ranging from community midwives and health educators to specialists and consultants in obstetrics) in both private and public settings. National efforts to increase public awareness on SDM and RMC through educational and advocacy should also be prioritized, in collaboration with educational institutions, civil society organizations, non-governmental actors, medical syndicates, media, and others.

AT THE FACILITY-LEVEL, accountability mechanisms, such as patient feedback mechanisms, must be in instituted. Hospitals play a key role in disseminating the SDM approach to both patients and providers, this can be through be digital dissemination through social media channels, physical handouts/flyers, or visual representation of the SDM approach in common places that remind and oblige parties to discuss and explain the approach, its process, and benefits in ensuring patient-centered and rights-based service delivery. Hospitals would benefit from training their staff on the benefits of SDM as a first step in implementing PCC, beyond SRHR but further for other specializations. Moreover, hospitals would further benefit from scaling up their human resources through investing in and building the capacities of nurses and midwives to deliver women-centered care through multidiscplinary team-based appraoches. As part of these efforts, hospitals may further utilize telemedicine and digitial health to recruit and mobilize community health workers who may disseminate and educate women and their communities on their rights in childbirth, the SDM process, and elements of RMC.

AT THE COMMUNITY AND PATIENT LEVEL, awareness raising and culture change are required to protect bodily autonomy, advance reproductive decision-making power, and eliminate obstetric violence. Within this context, it is necessary to raise awareness about women's rights in childbirth, including the rights to bodily autonomy and informed consent as essential elements to quality of maternal care. Moreso, introducing the concepts and practices of reproductive and bodily autonomy, SRHR, SDM, RMC, and PCC must be prioritized. Educational resources, such as the knowledge

products of this project, should be made available and accessible to equip expecting parents, their families, and support persons on utilizing this tool and approach to improve respectful and rights-based maternal care. This advocacy and education must target partuients, their partners, their families, their communities, including local champions such as social media influeners, male decision-makers and heads of households, and religious leaders, among others. SDM, RMC, and PCC must be taught within a comprehensive curriculum which empowers women, especially youth, with information and skills to enable every person's fulfillment of their SRHR in a wholistic and patient-centered manner that respects their values, autonomy, and rights.

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