

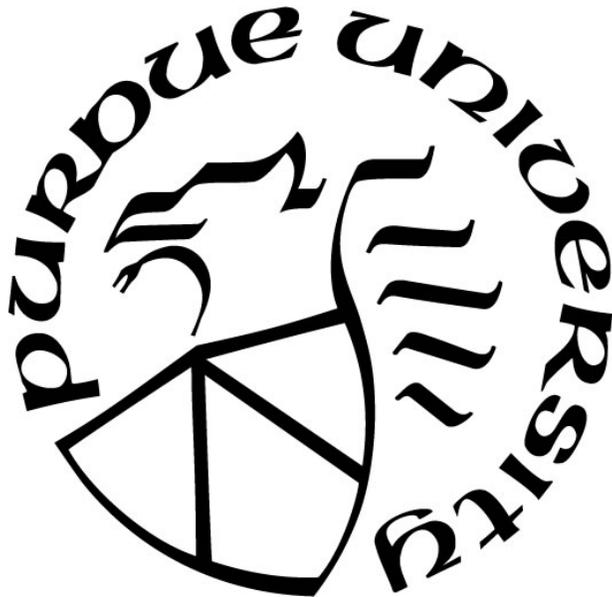
**REPRODUCTIVE HEALTH DECISION-MAKING: EXTENDING THE
SHARED DECISION-MAKING MODEL INTO THE COMMUNITY
SPACE**

by
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For my mom and dad, who have always supported my dreams and ideas, and who instilled in me the value of hard work, dedication, and creativity.

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ABSTRACT

Background: Shared decision-making (SDM) increases patients' involvement in their healthcare, extending the goal of patient-centered care provision. However, SDM is underexplored in women's reproductive health, where choices about contraception and pregnancy are frequently value and lifestyle-dependent. Furthermore, limited research exists on SDM outside of the patient-physician dyad, preventing insight into how non-physician community-based healthcare professionals (HCPs) engage women in practice. Finally, little research takes a social-ecological approach to SDM, despite interaction of multiple levels of influence in women's reproductive healthcare decision-making. Therefore, the purpose of this study was to explore women's and HCPs' experiences with SDM, including the various factors associated with how women make their reproductive healthcare choices.

Methods: This study consisted of three distinct, but interconnected phases. Phase 1 consisted of 6 focus groups (Sept-Dec, 2019) with women aged 18-45 living in Indiana who sought community-based or private healthcare for women's reproductive healthcare needs. Phase 2 included 20 key-informant interviews with non-physician HCPs (i.e., NP, RN, CNM, doula, pharmacist, chiropractor) living in Indiana (September 2019-May 2020) who provided community-based women's reproductive healthcare. Focus groups and interviews were audio-recorded, transcribed, and analyzed using an expanded grounded theory framework. Constant comparative analysis identified emergent themes in both phases. Phase 3 consisted of an online survey. Women (18-45 years) living in Indiana who sought reproductive healthcare completed the survey (N=432). Multiple linear regression, chi-square analyses, and structural equation modeling were utilized to identify ecological factors associated with pregnancy and contraceptive shared decision-making.

Results: *Phase 1)* Participants (n=22) wanted to be invited into healthcare discussions. Additionally, they wanted conversations to proceed organically, where HCPs listened to their needs, and supported and validated their choices. Though these behaviors did not always occur, they provided recommendations to enhance these experiences. Additionally, participants described quality of time was more important than quantity of time during appointments. Prior negative healthcare experiences specifically tied to HCP-interactions decreased women's healthcare

engagement. Additionally, social support system experiences were influential on women's choices. Race also emerged as impactful toward decision-making, including Black women feeling less respected in care and making choices about their reproductive healthcare to ensure their voices were heard, such as enlisting Black doulas. *Phase 2)* HCPs noted patient-centered care was important to community-based care. They also noted the importance of contextualized decision-making approaches to ensure they could meet women's varied needs. Results identified that outcome-oriented SDM concepts, including patient buy-in and investigative listening, were important for increasing SDM. HCPs suggested SDM improved healthcare experience beyond one visit. *Phase 3)* Structural equation modeling revealed access, social support, and patient-HCP relationship had significant relationships with contraceptive and pregnancy SDM. These models demonstrated good global and component fit, suggesting the importance of context in women's health choices. Further, regression results demonstrated SDM was associated with higher reproductive healthcare quality. Additionally, utilizing community-based healthcare for reproductive health was associated with decreased contraceptive SDM scores.

Conclusion: Findings from this study provide practical considerations for extending SDM work in women's reproductive health. In particular, results supported shifting SDM beyond the patient-physician dyad to include non-physician HCPs and HCPs in community-based healthcare settings. Women frequently access these services when seeking reproductive healthcare; thus, findings improve our understanding of the practical considerations researchers, policy-makers, and HCPs must make when promoting SDM in these settings. Furthermore, results revealed SDM use across multiple touchpoints, including community-based services, is imperative for women to achieve partnership in their healthcare. Thus, SDM provides a broader opportunity to enhance patient involvement across the spectrum of women's reproductive healthcare. Incorporating women's contextual needs and preferences improves HCPs' insight into women's experiences to further personalize care. Findings emphasize the importance of decisional space that include the various factors, agents, healthcare settings, and options that exist in reproductive health decision-making as these can shape women's choices, and, subsequently, their SDM experiences. This mixed methods study allowed thorough insight into multiple stakeholder groups engaged in healthcare decision-making; thus, the results offer guidance on the verbiage, resources, and strategies to engage in SDM and strengthen patient involvement reflective of women's lifestyle needs and

HCPs' existing workflow. Findings drive SDM practice into community-based healthcare and position it as the standard of care across healthcare settings.

CHAPTER 1: INTRODUCTION

Women living in Indiana face unique women's health disparities. For instance, more than half of Indiana's 92 counties are designated as primary care professional shortage areas, which reduces access to primary care and, frequently, women's health services.^{1,2} In addition, 37 of the 92 counties have no obstetrician/gynecologist (OBGYN), and 2.26 OBGYNs serve 10,000 women;³ thus, access to specialty women's healthcare is limited. Indiana also experiences 49% unintended pregnancy rates compared with 46% nationally.⁴⁻⁶ Family planning service access is one reason for high unintended pregnancy rates in Indiana, as approximately 437,000 women between the ages of 13 and 44 years are in need of family planning.⁵ Additionally, publicly funded family planning clinics met 26% of Indiana women's family planning needs, including for services and contraceptive products, compared to 29% nationally.⁵ Prior research suggests women experience difficulties accessing women's healthcare in locations with limited healthcare services, such as rural settings.⁷⁻¹⁰ As such, community-based healthcare provide important services in these health professional shortage areas.^{5,11-14} In Indiana, approximately 15% (300,000) of women aged 19-64 years and 17% of women aged 15-49 years were enrolled in Medicaid in 2018.^{15,16} Women receiving Medicaid and those living in health professional shortage areas benefit from services offered by community health centers, which serve approximately 52% of Medicaid-covered patients, and 44% of women between the ages of 15-44,¹⁷ filling an important gap in women's reproductive health service provision.¹⁸

Indiana maternal mortality is higher in Indiana than in the US (48.6 deaths/100,000 live births compared to 20.7 deaths/100,000 nationally), including from causes related to pregnancy, childbirth, and the 6-week postpartum period.¹⁹ Indiana's pregnancy-related mortality rate was 48.6 deaths per 100,000 live births in 2018, positioning the state as the 3rd worst in the country for maternal mortality, with 43 counties designated as high or moderate risk for maternal mortality due to limited or scarce resources.¹⁹⁻²¹ Despite decreased maternal mortality risk in some Indiana counties, maternal mortality still remains a critical issue across the state.²¹ Though maternal mortality rates are higher in Indiana than nationally, data suggests women in Indiana still seek prenatal care prior to the third trimester, which is similar to U.S. prenatal care-seeking rates.¹⁹ Additionally, Cesarean (C-section) rates in Indiana and nationally are similar.¹⁹ Because women are seeking prenatal care and experiencing similar C-section rates in Indiana, this indicates there

may be other factors contributing to high maternal mortality, including care quality, healthcare access, and social-ecological differences that negatively affect women in the state, compared to national data. High maternal mortality among Black women and younger women in Indiana support care quality discrepancy arguments.¹⁹ Thus, differential healthcare quality and patient involvement may be related to social determinants of health and social-ecological factors that must be addressed to improve negative health outcomes for women.²²

Shared decision-making (SDM) set forth by Charles et al.²³ and, later, Elwyn et al.²⁴ via the three-talk model (*team talk*, *option talk*, *decision talk*),²³⁻²⁵ provides a patient-centered approach to increase patient involvement and individualize care. It demonstrates that patients have a role in their healthcare, including how their values and preferences relate to healthcare choices. *Team talk* demonstrates that patient and HCP are working together to make a healthcare decision, and may include verbiage such as “Let’s work as a team to make a decision that is best for you”, while *option talk* compares alternatives using risk/benefit communication that is understandable to the patient.²⁴ *Decision talk* is the final stage and includes getting informed preferences related to what the patient values and the information that was shared by the provider to make a final preference-sensitive decision.²⁴ This model stemmed from a departure in the theoretical underpinnings surrounding the medical encounter, reconfiguring medical care from paternalistic to shared.²⁶ This reconfiguration positioned patients as equal partners in decision-making by encouraging patient-centered care via a bidirectional exchange of expertise and experience between HCPs and patients.^{23,27} Integral to this process is patient preference elicitation, as medical and healthcare decisions often involve a complex interplay of health and personal factors related to individual preferences.^{23-25,28} The three-talk model recommends patient role discussions in treatment decision-making, exchanging option, risk, and benefit information, and eliciting preferences to support a shared decision; thus, effective SDM involves the patient and HCP working together to ensure that the final decision reflects what a patient values, and that they understand all of the relevant option information so they feel prepared and involved in their health.²⁴ SDM extends the Institute of Medicine’s goal to improve patient-centered care,⁸ and was a key focus area in the Patient Protection and Affordable Care Act.²⁹ Previous literature identified benefits of increased patient involvement in healthcare decision-making.^{23,30-32} One study found patient-centered communication allowed patients increased autonomy over their health decisions, in turn improving patient health outcomes.³³ It was also associated with reduced follow-up tests

and referrals, increasing efficiency.³³ Though patients may express uncertainty regarding who makes the ultimate health decision, the participatory nature of SDM offered benefits, including increased satisfaction, option knowledge, and decision confidence.²⁷

Extant literature suggests SDM implementation barriers exist;^{34–38} physicians held positive attitudes toward SDM,^{39,40} but were not trained in SDM^{27,39} and expressed concerns about the length of time required for SDM engagement.^{27,35,40–42} However, appointment times did not necessarily increase with SDM use and SDM may, instead, facilitate more positive and satisfactory patient experiences.²⁷ Though some patients may prefer HCP-driven decision-making,^{41,43} prior research suggests most desire to engage in decision-making.^{27,28,44,45} Yet, inconsistencies existed regarding perceptions of involvement in practice.^{27,46,47} Studies assessing SDM use during clinical consultations found HCPs often scored low on SDM behaviors, indicating SDM absence or minimal skill level.^{48,48,49} HCPs may inconsistently present patients with choices, reducing engagement behaviors,⁵⁰ and may need further training to effectively execute SDM.^{27,39} In particular, further training should incorporate non-physician HCPs such as nurses (RNs), nurse practitioners (NPs), physician assistants (PAs), and pharmacists, among others, as these HCPs represent an important opportunity to increase patient involvement and SDM in healthcare decision-making.^{51,52} In particular, 63% of people living in states that did not limit the scope of practice of non-physician HCPs had access to primary care practice, compared to 34% in restrictive states.⁵³ These HCP's, therefore, increase access to primary care services and, subsequently, women's healthcare services provided in primary care settings.

Women's reproductive health decision-making (i.e., contraception, pregnancy, labor/delivery, women's wellness) offers an opportunity for SDM, as choices women make are often preference and value-sensitive and are unlikely to be honored if they are not active participants in the decision-making process.^{54–56}

SDM in Contraceptive Decision-Making

Approximately 50% of all United States pregnancies are unintended.^{57,58} Half of these are due to contraceptive non-use while the other half result from incorrect or inconsistent use,⁵⁹ illustrating barriers to sexual education and effective contraception use. Women may be unfamiliar with various contraceptive options and efficacies, highlighting a need for increased contraceptive option discussion.^{60,61} Additionally, women may not know or understand that some contraceptive

options are more effective than others. For example, hormonal contraceptive pills are 91% effective compared to long-acting reversible contraceptive (LARC) which are 99% effective.^{59,61-63} Further, women remain uninformed that LARC (e.g. the intrauterine device [IUD] or subdermal implant) is the most effective contraception and retain misconceptions and concerns about safety and efficacy.⁶⁴⁻⁶⁶ Women may not regularly discuss available contraceptive options with their HCPs.^{64,67} Prior research indicated women may be unaware of available contraception because HCPs strongly recommended or prescribed one or two methods rather than presenting and discussing the range of contraceptive options.⁶⁸⁻⁷⁰ Lack of contraceptive knowledge and options may be associated with women being unable to choose the method most appropriate to their needs, which may relate to method dissatisfaction^{71,72} and subsequent discontinuation, leaving women at increased risk of unintended pregnancy.⁷³ Discontinuation due to dissatisfaction underscores a need for improved patient involvement to better align preferences and chosen contraceptive method.

SDM offers an opportunity to reduce unintended pregnancy rates while allowing women to choose contraceptive methods aligning with their needs and goals.^{72,74,75} HCPs play an important role in the decision-making process during contraceptive consultations.⁷⁶⁻⁷⁸ Despite the essential role they play in this decision, HCPs may not regularly discuss a range of contraceptive options,^{64,67,68,79,80} describe the necessary behaviors associated with various forms of contraception (e.g., consistent use of daily methods versus nondaily methods),^{73,81-83} or agree with women's preferences.^{84,85} Patients indicating high-quality interpersonal relationships with HCPs were more likely to maintain their chosen contraception and adopt more effective contraceptive options with improved satisfaction.⁸⁶⁻⁸⁸ A study of contraceptive counseling among 11 European countries found 47% of women chose a method besides the oral contraceptive pill when HCPs discussed other available options.⁸⁹ Thus, individualized counseling addressing components of SDM, such as options and patient preferences, was related to contraceptive choice^{78,90,91} and may be associated with improved continuation and satisfaction.

Contraceptive decision-making involves an interplay of factors including relationship-building, trust, information provision, and patient autonomy.^{71,92} Though limited research exists regarding contraceptive decision-making within the context of the SDM, Dehlendorf et al.⁷¹ found SDM occurred in less than a quarter of contraceptive consultations, with most visits consisting of informed choice and information provision only on methods women specifically asked about

during the clinic visit, precluding a discussion of methods women may be unaware of. Additionally, extant literature⁷⁶ indicated women also valued HCP input that was sensitive to their preferences. Engaging in SDM improved satisfaction in method choice when compared with both patient and HCP-driven decisions.⁷² Patient-centered communication was found to improve women's IUD attitudes, perceptions of HCP empathy, and knowledge when compared with doctor-centered communication.⁹³ One study⁹⁴ found 36% of their sample preferred a different contraceptive method than the method they were using, frequently tied to barriers such as limited knowledge of alternative options. However, a review conducted by Inoue et al.⁹⁵ documented reasons for method discontinuation did not reflect women's specific experiences, and instead, relied heavily on the HCPs' report, resulting in ambiguity surrounding women's actual reasons for discontinuation. Increased patient involvement may improve satisfaction and acceptability because the chosen method better reflects women's health and lifestyle priorities.^{71,72,94,96-98} SDM discussions focusing on method attributes and women's preferences may, therefore, improve method-lifestyle fit and provide an additional opportunity to reduce unintended pregnancy associated with incorrect, inconsistent, or non-use related to dissatisfaction and knowledge gaps.⁷⁹

SDM in Maternity Care

Relatively little research has investigated SDM in pregnancy and childbirth contexts.⁵⁴ Most research has focused specifically on Down syndrome screening,^{99,100} illustrating women and HCPs desired engagement in SDM in these clinical settings, despite some SDM use discrepancy. Extant research also acknowledged SDM fluidity as decisions can change with women's pregnancy, labor, and birth preferences and expert-identified health needs.^{55,101} SDM represents an important contribution to maternity care models,¹⁰² particularly considering poor maternal outcomes in the United States have increased.^{102,103} Therefore incorporating women's voices in maternity care is critical, including increased discussion of options and decisional respect. Integrating women's experiences and needs in birth decision-making represents opportunities to improve patient involvement and address gaps in current maternal care practice.^{103,104}

Research suggests SDM in maternity care should incorporate women's autonomy, build trust, invite women to ask questions, and provide accurate understandable information.^{101,105,106} Further, institutional changes and early delineation of women's preferred role in decision-making may be critical to ensure all women receive equitable care and involvement opportunities. One

study¹⁰⁵ identified sharing high-risk pregnant women's birth stories enhanced compassion and listening. SDM may promote positive birthing experiences, enhance the quality of obstetric care, and improve outcomes with greater patient involvement and HCP understanding.¹⁰⁷ However, barriers, including institutional policies that constrain SDM in practice and beliefs that patient decisions are incorrect remain in maternity care.¹⁰⁸ There is also reduced consensus regarding the role HCPs should play in directing or supporting women.¹⁰¹ Though additional research is necessary linking SDM with final decision and outcomes, maternity care patients may benefit from SDM and experience greater satisfaction in their decisions.^{27,33}

The Holistic Patient Experience and SDM

Social Support

Contextual factors are often present during clinical consultations^{109,110} and should be considered when engaging in SDM. Medical decisions frequently include social support members outside the patient and HCP. The role of these social support members in decision-making (e.g., family, friends, and partners) has received little attention in the SDM literature.^{86,87,111–113} Charles et al.²³ initiated the potential importance of social support in SDM when suggesting *at least* two people must engage in the consultation. Critical contributions of this work included recognition that more than two people—people outside of the patient-physician dyad—may engage in decision-making, referred to as *distributed decision-making*.^{23,25,42,112,114} *Distributed decision-making* emphasizes that medical decisions are frequently made over time and *distributed* across multiple people, including friends and family.¹¹² Because individuals form perceptions of available healthcare options and treatments beyond communication with HCPs, via other people in their social support spheres, media, history, among others,⁴² it is essential to understand how others factor into healthcare choices.^{23,112} Thus, understanding the effect of social support on decision-making may be important to providing the most effective patient-centered care.

Interpersonal communication about contraception with family members and friends may provide one discussion point when making contraceptive decisions.¹¹⁵ For example, though participants described family and friends' opinions as important to their contraceptive decisions, HCPs often shortened those discussions, missing the relevance of social networks to

contraceptive choice.^{110,113} In a qualitative study conducted by Anderson et al.,¹¹⁶ results indicated women placed heightened value on friends' and female family members' IUD recommendations. The experiences and opinions of others, especially when information was negative, contributed to participant acceptance or rejection of the IUD. Additional studies demonstrated women considered information and support from family, friends, and partners as significant to contraceptive choices.^{115,117} One study found participants mentioned social influence in 42% of consultations, illustrating the pervasiveness of social context within contraceptive counseling.¹¹⁰ Valente et al.¹¹⁸ and Choi et al.¹¹⁹ identified increased association between method recommendation/use among friends and family members and personal contraceptive choice. Greater understanding of the role of social network in contraceptive consultations may improve knowledge and contraceptive concordance and allow the HCP opportunities to address myths and misinformation.^{65,110,120} Further, exploring social support within specific women's reproductive health clinical contexts may elucidate additional SDM features to better address patient needs.^{23,25,110,112} Despite work conducted in contraceptive choice, little research examines social support in SDM surrounding pregnancy and birth.^{55,101,121}

Race/Ethnicity

Race and ethnicity may relate to SDM, serving as a barrier toward greater patient involvement in care. Whitley¹²² noted a critical need to consider race and ethnicity as a starting point rather than an addition to the SDM model, especially given serious racial and ethnic disparities. Prior research suggested Black patients experienced infrequent participation in medical decision-making, with their participation occurring at much lower rates than their White counterparts.¹²³ Yet, many patients rated participation as positive and important when making health decisions.¹²³⁻¹²⁵ In contrast, Levinson et al.¹²⁶ found Black and Hispanic/Latino patients had a greater preference for HCP-driven medical decisions. One reason may be that some research has reported that HCPs rarely promote participation in healthcare among Black and Hispanic/Latinos.¹²⁶ Prior studies found that physicians demonstrated greater patient-centeredness behavior among patients who they thought communicated better; however, they often perceived Black patients as less effective communicators and, subsequently, engaged in less patient-centered communication during consultations with Black patients.^{123,125,127} In fact, Lin et al.¹²⁸ found racial/ethnic minorities received less information on the rationale for choosing a specific treatment

option. One qualitative study found Black participants identified HCP bias, discrimination, and dominance served as race-related barriers to SDM, while also suggesting Black patients may defer to physicians, provide less information about their health experiences, and may not adhere to treatment regimens as patient factors related to decision-making.¹²⁹ Though these barriers were also described across patients,¹³⁰ they may be exacerbated in racially diverse patients' experiences.^{125,129,131} Studies suggested consistent discrimination against Black individuals through generations may have long-lasting effects on their health outcomes, including maternal outcomes.^{132,133} Patient-centeredness and cultural competency models in healthcare may assist in improving health disparities and healthcare quality by incorporating related features such as: understanding patient context, discussing patient values, and demonstrating respect toward patients.

Relatively little research addresses the race/ethnicity and SDM in maternal care. Prior research examining Black women's reproductive health experiences noted a dichotomy between fatalism (e.g., preferences not to know about their health) and desire for engagement and autonomy,¹³⁴ illustrating a need to understand how Black women desire to engage in health information-seeking and decision-making. Attanasio et al.⁵⁴ found Black women were less likely to report high SDM in maternity care visits, particularly when Black women delivered by C-section. Thus, race and mode of delivery reduced the likelihood of SDM use, suggesting these women may experience less involvement in their birthing decisions and illustrating a need to understand race in SDM within reproductive health contexts.⁵⁴

Prenatal care provides opportunities to monitor the health and well-being of women, with delays in care serving as barriers.¹³⁵ Black women and Hispanic/Latinas are less likely than White women to initiate, access, and maintain prenatal care.^{136,137,138} Qualitative data demonstrated Black women were frequently unaware of pregnancy status and experienced stigma when seeking prenatal care,⁹ building on prior work demonstrating HCPs may judge patients due to personal factors.¹⁰⁸ Though attitudes and plans for vaginal birth did not differ by race/ethnicity in prenatal care, underserved women were less likely to deliver via their preferred mode.¹³⁹ Thus, women of color may not realize their preferred birth preferences discussed during prenatal care¹⁴⁰ or may experience greater pressure to adopt HCP-suggested birthing options during labor and delivery.^{54,140} Perceptions of prenatal care quality, especially among Black women, remains

limited; however, one study noted shared interest in patient-centered prenatal care among Black patients and HCPs.¹⁴¹

Negative Prior Healthcare Experiences

Negative prior healthcare experiences may be negatively associated with future healthcare consultations through anticipation of similar adverse experiences.^{142,143} Although relatively little research has explored a negative history of reproductive healthcare and its relationship to future consultations, this association has been explored in other chronic illnesses, including HIV^{144,145} and irritable bowel syndrome.¹⁴² Particularly, negative prior patient-HCP interaction reduced disclosure to other HCPs and timely access to health services.^{145,146} Additionally, a negative healthcare experience may be associated with changing HCPs and limited trust in HCPs and the healthcare system.¹⁴³ Further, prior negative experiences can affect the patient-HCP relationship, with HCPs blaming individuals for their illness or perceiving them as difficult and non-compliant.^{142,147} One study found traumatic birth experience was associated with fewer pregnancies and longer spacing.¹⁴⁸ Additionally, women who have experienced negative contraceptive counseling, limited contraceptive choices, or are members of historically marginalized groups who have experienced contraceptive coercion expressed discomfort with healthcare, and reduced contraceptive option offerings during appointments.^{80,149–151} In a national sample, Black and Hispanic/Latina women who perceived discrimination during maternity healthcare appointments were less likely to ask questions during prenatal care, reducing patient-HCP communication quality.¹⁵² Additionally, women of color who had experienced three forms of perceived discrimination (e.g., race/ethnicity, insurance type, and differing patient-HCP opinions) were less likely to follow up for postpartum consultations.¹⁵³ Decreased health system engagement following a negative healthcare consultation demonstrates a vital area of research in SDM. Understanding how these experiences relate to patient engagement may delineate opportunities to address additional barriers to SDM.

Social-ecological Approaches to Decision-Making

The social-ecological model allows movement from the individual level of analysis to higher system levels.^{154–156} In this model,¹⁵⁶ determinants for behavior range from individual (e.g.,

genetics, physiology), relationships, living conditions, neighborhoods and communities, to institutions, and social and economic policies that exist within individuals' life course. Specifically, Whitley¹²² argued that for SDM to be effective, race must be at the forefront of the model, rather than an afterthought. Race provides an interaction of social-ecological levels, including individual, societal, and cultural. The interpersonal level may also affect decisions, as relationships with family, friends, partners and HCPs, may be associated with acceptability of health decisions. Recent research^{111,112} suggests there is limited data regarding others' roles in decision-making in the SDM model; however, social interaction, especially in trusted relationships, may relate to the type of decision a patient makes as well as real versus perceived options.^{112,116} The interpersonal level also incorporates patient-HCP interactions on decision-making. This relationship is related to multiple factors from both the patient and HCP perspective,¹⁵⁵ which may be associated with relationship quality and subsequent health choices. These relational experiences may affect patient knowledge and engagement levels, facilitating or impeding the process. At the community level, multiple variables may relate to decision-making. Decisions to attend follow-up reproductive health appointments may relate to inaccessibility,⁹ due to both geography and HCP shortages, as well as negative perceptions of healthcare stemming from prior negative patient-HCP interactions.¹⁴³

The final layer smrests on social, cultural, and environmental factors surrounding individuals' health outcomes. Prior to the early 2000s, little policy existed regarding patient-centered care. However, in 2003, the Institute of Medicine developed guidelines¹⁵⁷ with a specific focus on using patient-centered care to improve health outcomes and quality. These related to significant concepts identified within the SDM model and other patient-centered care approaches, demonstrating a changing culture in healthcare that asserted the role of the patient as a critical aspect of decision-making. Changing social norms have facilitated increasing opportunities for patients to make health decisions, including by increasing the range of options that are feasible and appropriate. The changing focus toward increased patient-centered care was also captured in the Patient Protection and Affordable Care Act.²⁹ The New Haven Recommendations¹⁵⁸ have also delineated strategies for patient involvement for hospitals and healthcare facilities to increase support of patients and their social support systems to make decisions with HCPs. Changing social norms and policy has worked to increase patient engagement at the lower levels and may be related to patient decision experience. The social-ecological model¹⁵⁶ may be particularly important to

enhancing SDM, as notable gaps persist regarding how individuals' social and personal contexts influence their health choices.

Recent calls to incorporate the social-ecological model into patient engagement and SDM efforts^{158,159} illustrate a *critical need* to examine patient experiences and how those experiences can shape healthcare decisions and available choices.¹¹⁴ Incorporating patient experience has occurred to determine effects of race/ethnicity in primary care settings^{123,129} and cancer care,^{160,161} gender effects in patient-HCP interactions,¹⁶² and health literacy.^{42,159,163} However, a gap exists regarding social-ecological frameworks within women's reproductive health consultations and SDM.¹⁶⁴ Though extant research identified that context matters in women's reproductive health decisions,^{110,134,164,165} empirical studies have not incorporated a social-ecological approach to SDM in reproductive health. These factors have also been under-explored in the current SDM model.²⁴ Incorporating SDM and the social-ecological model¹⁵⁶ represent a critical next step in improving patient-centeredness by addressing the multi-layered domains present in women's lives.

Women frequently seek reproductive health services through community health centers and programs, especially in primary care and OBGYN health professional shortage areas, such as those found in Indiana. Indiana offers various community-based health services to address women's reproductive health in resource-poor settings. These services include programs such as the Nurse-Family Partnerships,¹⁶⁶ which aims to improve infant and maternal health by partnering women enrolled in the program with a registered nurse during and 2 years after pregnancy. Women enrolled in this program have experienced successful outcomes, including 89% of babies born full-term, 89% of mothers initiating breastfeeding, and 68% of mothers employed at 24%.¹⁶⁶ Additionally, Indiana offers a range of community health center women's health services, including contraceptive counseling and prenatal and pregnancy wellness care services that function on a sliding scale, and incorporate check-ups and classes to improve reproductive health.¹⁶⁷ Additional innovative services in Indiana include the community paramedicine program, Project Swaddle,¹⁶⁸ which provides in-home primary care, consultations, and prenatal/pregnancy care via paramedics to women living in rural Indiana counties or who face other access difficulties, increasing access to high-quality healthcare and reducing disparities in healthcare access and health outcomes. More recent programs include the OB Navigator program, signed into law in 2019,¹⁶⁹ which aims to create a network of services and support for women and babies. This aim

is accomplished through home visits from an OB navigator who assists women in finding services and provides personalized guidance to pregnant mothers. These programs reduce delays in care and demonstrate the critical nature of community health provision in Indiana. However, few studies have examined SDM outside of the patient-physician dyad, despite calls to do so.^{52,170–172} Though these programs assist in successfully increasing care access, the process of patient involvement and decision-making is underexplored. Therefore, understanding SDM within these community-based contexts is significant as it can assist in identifying how to increase patient involvement and what is effective when engaging patients in community-based care.

Pharmacists,^{173,174} RNs and NPs,^{52,172} and case managers¹⁷⁵ are critical and trusted caregivers who play an important role in SDM practice. Further, encouraging SDM and patient involvement as social change requires involving all stakeholders, including non-physician HCPs. Enhancing SDM in community health, such as home care and community health centers,¹⁷² may improve patient understanding of options and allow greater decisional involvement.^{176–178} Thus, exploring the context of practice in community health settings,^{172,179} including multiple dimensions (e.g., individual, social, community, institution, and policy) that surround available health choices, access, and decision-making is necessary, particularly in women's reproductive healthcare. Thus, the social-ecological model¹⁵⁶ paints a broader picture of opportunities for improving decision-making to better reflect women's lived experiences.¹¹¹

Purpose

Little research has examined SDM occurrence during women's reproductive health consultations, including those related to contraception and pregnancy. Additionally, little research has explored reproductive decision-making in community health settings and between women and non-physician HCPs. Finally, gaps exist regarding how context affects women's reproductive health SDM, including race/ethnicity, friends and families, and negative healthcare experiences. This gap demonstrates the importance of understanding how patients' context and ecological factors are related to decision-making, and aligns with calls to incorporate social-ecological factors into SDM,^{110,158,159} particularly as women's reproductive health choices are often driven by preferences and lifestyles. Thus, decisional space^{180,181} that incorporates the actors (i.e., patient, HCP, patient's social support structures), settings (i.e., community-based healthcare, services),

contexts and preferences, and available health options is important for furthering SDM to meet women's multi-faceted reproductive healthcare needs.

Given these gaps, this study utilized a mixed-method design to identify the ecological factors impacting women's reproductive health decision-making in community health in Indiana. An additional goal is to investigate reproductive health decision-making facilitators and barriers, specifically related to SDM use in community health settings among non-physician health professionals (e.g., NPs, certified nurse midwives (CNMs), RNs, doulas, clinical pharmacists, and prenatal and postpartum chiropractors). Specifically, this study recruited women who have sought reproductive care in community health settings for Phase 1 (focus group discussions) and 3 (web-based survey). Phase 2 consisted of in-depth, key informant interviews with non-physician HCPs who provide women's reproductive health in community health settings, programs, or agencies. Findings from this study extend the SDM model to better account for contextual factors in women's reproductive health decisions to enhance SDM reflective of women's lives. This may improve SDM utility and clarity among community-based HCPs. Additionally, findings offer recommendations and strategies to increase SDM in community health settings to further support patient involvement beyond the patient-physician dyad that prioritizes all the factors involved in women's decisional spaces.

Research Questions

RQ 1: What factors do women consider when making reproductive health decisions, including socially contextualized and constructed factors existing in women's decisional spaces?

RQ1.2: How are these considerations associated with women's reproductive health decisions?

RQ 2: What are the barriers and facilitators to SDM, including the factors, agents, and available options, in women's reproductive health in community health settings?

RQ 3: What contextual factors are associated with women's self-reported involvement in their reproductive healthcare decisional spaces?

RQ3.1: What is the relationship between ecological factors and the SDM model?

CHAPTER 2: WOMEN'S VOICES: EXPLORING CONTEXT AND PRACTICAL STRATEGIES FOR WOMEN'S HEALTH SHARED DECISION-MAKING IN COMMUNITY HEALTH SETTINGS

This is an original manuscript of an article in review at Springer in [BMC Women's Health].

Abstract

Background: Shared decision-making represents an opportunity to increase patient involvement in their healthcare, and may be particularly important in women's health where decisions are frequently preference-sensitive. However, limited research exists on how women's contexts impact their decision-making choices and what their practical needs may be. Therefore, the purpose of this study was to explore the ecological factors impacting decision-making, including how these relate to the existing shared decision-making model.

Methods: As part of a larger mixed methods study, we completed 6 focus groups (Sept-Dec, 2019) with women aged 18-45 living in Indiana who had sought community-based or private healthcare for women's reproductive healthcare needs. Women's decision-making processes were explored using techniques from grounded theory.

Results: Participants indicated a desire to be invited into the healthcare discussion, in which healthcare professionals listened to their needs, and supported and validated their choices. Though this did not always occur, they provided recommendations from positive experiences to identify what they would want during a women's healthcare appointment. Additionally, participants described quality time was more important than quantity of time spent during consultations. Prior negative healthcare experiences specifically tied to interaction was associated with their decision-making perspectives and healthcare engagement, as were family/friends and race. Finally, participants suggested any interaction with healthcare could influence whether patients perceived healthcare as positive or negative, specifically citing community-based reproductive healthcare.

Conclusions: Findings offer recommendations for healthcare professionals to engage in shared decision-making, including practical opportunities to fulfill women's patient involvement and relationship needs. Additionally, findings demonstrate new insight into continuing to develop the shared decision-making model in reproductive healthcare.

Introduction

Women in Indiana experience access disparities, as more than half of Indiana's 92 counties are designated primary care professional shortage areas,¹ reducing access to primary care and women's health services. Further limiting access to specialty women's healthcare, 37 of the 92 counties have no OBGYN, and 2.26 OBGYNs serve 10,000 women.³ Reduced access may have detrimental effects on women's healthcare. Indiana has a 49% unintended pregnancy rate compared with 46% nationally.^{5,6} In addition, Indiana is the 3rd worst state in the country for maternal mortality, especially for Black women who have a 3x greater risk of dying during childbirth than white women.²⁰ Community-based care is critical to reproductive healthcare provision, especially among uninsured and underinsured women.^{5,17,18} Therefore, community health settings are important touchpoints for reproductive health provision across the state, as these represent the various ways women may interact with, or touch, the healthcare system.^{182,183} Enhancing patient experience at these healthcare touchpoints, including in varied settings and during patient-healthcare professional (HCP) interactions, has been suggested to improve care quality.^{182,183} This may allow HCPs to increase their patient involvement behaviors to meet patient needs,¹⁸³ especially in low-resource settings where women may seek care from multiple settings. Thus, considering healthcare engagement as touchpoints in the patient journey may allow enhanced patient involvement across the spectrum of women's healthcare.¹⁸⁴⁻¹⁸⁶

Shared decision-making (SDM) is a patient-centered approach focused on communicative partnership between patient and HCP, sharing medical option information and patient preferences, and supporting patient decisions to enhance patient involvement.²⁴ Current components include *team talk* to build partnerships, *option talk* where all options are discussed, and *decision talk* where a mutual decision occurs.²⁴ *Preference elicitation* that incorporates patient needs is critical to SDM.²⁴ Though highlighted as an important component to healthcare quality,^{187,188} SDM has struggled with slow widespread adoption¹⁸⁹ and remains a topic of debate. Recent opinion pieces demonstrated competing perceptions of SDM utility^{190,191} and scholars are still defining the key SDM components,^{24,189,192} including how to implement SDM effectively in clinical practice.¹⁹³

While SDM may not be fully characterized, exploring opportunities to understand and implement SDM may offer important benefits to patients (i.e., increased patient involvement, satisfaction, knowledge, and decision confidence),¹⁸⁸ including practical additions to the model to improve patient care.¹⁹⁴ Though different decision-making needs exist depending on the context

of the healthcare appointment,¹⁸⁹ women's reproductive health decisions are frequently preference- and value-sensitive.^{72,152,195} Continued investigation into the role of SDM in women's reproductive healthcare (e.g., contraception, women's wellness, pregnancy),^{56,72,196} is necessary to improve patient care quality.^{56,72,101,106,197} Women's contextual factors may be particularly influential in how women make decisions^{110,196} in SDM. Recent work has called for incorporating the social-ecological model into SDM efforts.^{158,159} Though extant research identified that women's reproductive health decisions are related to lifestyle needs and contexts,¹¹⁰ few studies have incorporated a social-ecological model approach to SDM in reproductive health. Further, discussion of context is underdeveloped in the current SDM model;²⁴ therefore, including the social-ecological model within SDM may improve care quality and HCPs' ability to counsel women at the intersection of lifestyle and healthcare.¹⁹⁶

Contextual factors may relate to social support in women's reproductive health.^{112,198,199} Friends, family members, and social norms can affect decisions about contraception and other reproductive health matters.¹⁹⁹ However, incorporation of social support into the SDM model in women's healthcare has received limited attention.¹¹² An additional factor that may influence how women make health decisions is race, with prior research arguing race should be central to all SDM work.¹²² Contraceptive care suggests the importance of race, as women in marginalized communities found long-acting reversible contraception problematic because of historic contexts of coercion.^{85,149,150} One national sample found Black and Hispanic/Latina women who perceived discrimination during prenatal appointments were less likely to ask questions, reducing patient-HCP communication quality.¹⁵² Thus, race may influence how and why women make certain reproductive health choices. An additional contextual factor includes prior healthcare experiences.¹⁴² One study explored the impacts of negative prior healthcare experience on primary healthcare engagement and found 32% of patients had experienced a perceived negative healthcare interaction, which was associated with changing HCPs, discounting HCP recommendations, and limiting healthcare-seeking.¹⁴³ However, little research has explored a negative history of reproductive healthcare and its relationship to future care quality and patient involvement. Women who have experienced negative contraceptive counseling, limited contraceptive choices, and traumatic birthing experiences and interactions expressed discomfort and distrust with healthcare.^{80,149,150} Understanding how these experiences relate to women's healthcare decision-making may represent additional ways to enhance SDM across patients.

The primary purpose of this study was to understand women's SDM perspectives in reproductive health consultations, including the ecological factors that may influence how they make their decisions. A secondary purpose of the study was to explore practical opportunities to improve SDM in women's healthcare, including in community health settings.

Methods

This study explored women's SDM experiences, with a specific focus on the contextual factors women perceive influence their reproductive health experiences. Qualitative methods provided a robust understanding of women's experiences and needs related to healthcare decision-making and involvement. Focus group discussions offer insight into group dynamics, and can be particularly impactful when exploring shared experiences among participants.²⁰⁰ Because women's reproductive health decisions may depend on lifestyle and context, focus groups provided an effective way to understand how women construct reproductive health decision-making in the broader context of their lives.²⁰⁰

We completed 6 semi-structured focus groups with 2-9 participants each (n=22) in September-December 2019. Women aged 18-45 years who had ever sought reproductive healthcare in community health centers and programs in Indiana were included in the study. Purdue University's institutional review board approved this study.

Convenience sampling for focus group recruitment occurred via flyers distributed at community health centers and community locations (e.g., community centers, libraries), emails through community health service listservs, and shareable social media advertisements. In-person recruitment with onsite sign-up sheets and email follow-up also allowed interested women to commit to a day and time for focus groups. Community partners assisted recruitment efforts in three Indiana counties (Tippecanoe, Montgomery, Marion), which were selected based upon demographic and geographic makeup (i.e., race/ethnicity, rurality), established connections, and convenience. Theoretical and snowball sampling, which includes referrals from participants for other eligible women, improved data robustness and ensured community member inclusion.²⁰¹ Following each focus group, participants completed an anonymous demographic survey, which was collected and stored in a locked file cabinet to ensure confidentiality.

Focus Groups

Focus groups were conducted in locations convenient to the participants and researchers (e.g., reserved, private conference room in a community location). Each discussion lasted approximately two hours, and all participants received a \$25 Walmart gift card to compensate their time. Each focus group was led by a moderator (the first author), who has extensive experience in qualitative data collection and analysis, and a co-moderator trained in graduate-level qualitative methodology. All focus groups proceeded using a semi-structured protocol, allowing participant experiences and social dynamics to drive the conversation.^{200,201} Further, a semi-structured protocol allowed researchers to explore unique perspectives, novel experiences, and shared knowledge. This focus group guide approach permitted moderators to probe on topics and responses related to the research questions and facilitated group sharing and development of ideas.

The guide was developed from extant SDM and reproductive health decision-making literature.^{24,54,196} Focus groups illuminated the factors women felt affected their reproductive health choices and decision-making process. Focus groups began by asking general questions about participants' health to build rapport and facilitate inter-participant discussions.²⁰¹ Researchers then transitioned into discussions about reproductive health experiences and decision-making. Focus groups continued until data reached theoretical saturation when study categories and themes are stabilized and reinforced rather than further explained with incoming data.²⁰²

Data Analysis

The co-moderator took notes and memos during all focus group discussions to record insights and non-verbal information. Focus group discussions were transcribed verbatim, including observer comments and interpretations to maintain reflexivity. Techniques from grounded theory provided the framework for data analysis in which emerging findings were grounded within the data.²⁰² This approach underscored participants' personal experiences,²⁰² allowing for data contextualization and broader pattern identification within and between participant experiences. Participant words, phrases, and experiences provided *in vivo* codes to analyze the data.²⁰² Expanded grounded theory allows for incorporation of existing theory to assist in data initiation and analysis; therefore, the SDM and social-ecological¹⁵⁶ models provided codes for analysis. Additionally, an initial reading of all data allowed for further code refinement to address the

research aims. HyperRESEARCH 4.5.0, a qualitative data management software, assisted the coding and analysis process through data input and organization. The first author (SM) completed iterative line-by-line open and axial coding to reduce data to its most basic meanings and build conceptual categories and themes.²⁰² Open coding describes the creation and application of tentative codes to portions of data based upon meaning established by participant words.²⁰² Axial coding identifies relationships among codes and to broader categories, patterns and theories.²⁰² A constant comparative approach within and between transcripts allowed researchers to identify emerging themes. Co-authors discussed emerging themes and addressed inconsistencies via consensus.

Results

The average age of participants was 25.8 ± 5.31 years (R:20-35). Twelve participants (54.5%) self-identified as White, while 7 (31.8%) self-identified as Black or African American. Most participants had completed some college or a 4-year degree ($n=13$; 59.1%), while 5 (22.7%) indicated completing a graduate degree. Ten participants (45.5%) were employed, while 11 were students (50.0%). The majority of participants held private insurance ($n=17$; 77.3%) and 3 (13.6%) received insurance via Medicaid. The majority of participants ($n=19$; 86.4%) were single. Eight participants (36.3%) were not currently using a contraceptive method, and 4 were using the birth control pill (18.2%), intrauterine device (IUD) (18.2%), or condoms (18.2%), respectively. Six (27.3%) had been pregnant. Four themes and subthemes emerged. Each quote is followed by focus group number.

Contextualizing the Decision-Making Process

Initiating Patient Involvement

Participants described a desire to be invited into decision-making partnerships by women's health HCPs. One participant said, "it was just helpful for her [HCP] to walk into the room and... she started the conversation, because I don't know how I would have started that (FG2)." Another participant discussed an improvement in comfort and experience with birth control consultations when the conversations were HCP-initiated, "some of my doctors like won't do that. And they'll want you to bring it up. It just makes you feel more comfortable [when they do] (FG2)." Others

described open-ended questions that facilitated sharing. One participant said, “it was like an open conversation. He was like ‘I don't know what your plans are’... It wasn't an outright, ‘Well what do you want to do’ (FG3).” Rather than directing the conversation, the HCP initiated open-ended discussions to better gauge desired level of engagement in healthcare conversations. Attentiveness and “willing to work” (FG4) with a patient was critical to healthcare experience, particularly “helping me problem solve and troubleshoot (FG5).” Participants described conversational openness as increasing opportunities for sharing other needs during appointments. One participant said,

And like, we're just here because we have to come see you to get a refill on our birth control.... And they just assume that you're good to go. It's like maybe that's why I came but I also had other concerns and they just didn't ask and then it's hard to bring up...(FG2).

This participant described the importance of establishing patient-HCP partnerships to understand women’s needs in addition to the visit purpose. Thus, initiating conversations surrounding lifestyle needs and concerns beyond the visit purpose may enhance SDM.

A Listening Environment

Participants identified the necessary role of listening in women’s healthcare. One participant emphasized listening lending itself to better understanding a woman’s priorities, “it's like thinking more intuitively and being a step ahead rather than just being on the laptop typing away just like asking the general questions (FG2).” A participant emphasized these characteristics in HCPs, “they are attentive listeners. So instead of me just telling you my condition, you pay attention to the adjectives that I use and ask for more information (FG4).” Another participant suggested additional ways to demonstrate listening, “I feel encouraged if she's looking at me in my eyes... ‘So what I hear you saying is,’ repeating things back (FG5).” Listening facilitated feelings of partnership. One participant described listening and responding using phrases like “‘I understand why you're frustrated or why you're in pain,’ or ‘I'm sorry you're not feeling so good.’ It's that general empathy (FG4).”

However, participants also described this process going wrong. The absence of listening impacted women, “and then sometimes they'll cut you off while you're explaining it (FG4)” decreasing opportunities for SDM. Participants preferred “organic (FG2, FG6)” conversation. In one focus group conversation, participants suggested, “even if they just nod their head, say ‘Yeah.’

I feel like I never really get that and then it's like, do you really care or are you just trying to get the information you need into the computer (FG6).” One participant shared one way to overcome this:

Because I've had HCPs who have been behind a screen but I've still been able to do that because they have acknowledged, ‘Hey, I'm sorry, I need to be on my computer so that I can take good notes to put in your chart for when you come back and see me next.’ And I feel that helped a lot, acknowledging that this is a barrier to our communication, but also making it about me talking to the HCP, not a patient talking to a HCP (FG6).

Acknowledging barriers but prioritizing listening helped this participant feel valued. Simple gestures facilitated positive communicative experiences.

Decision-making Processes

Sometimes decision-making was related to outside factors that were important to women, including “what experiences other women I know [had] connected to whatever health decision I'm making (FG6).” Friends appeared important to participants when discerning appropriate choices for their lives. One participant discussed, “I was thinking about getting the IUD... So if you hear about it from your friends you're more likely to consider that as an option (FG2).” Another participant highlighted how friends can influence decisions, “friends’ experience has [an impact], the only reason I got an IUD in the first place [was my friend’s suggestion] because I'm somebody who shouldn't have anything inserted. Which maybe that's why [it wasn't the right choice for me] (FG6).” This participant chose a method because of a friend without determining if it would necessarily fit her personal needs, suggesting understanding these decision-making influences may be important to SDM, including influences that occur outside clinical settings.

Quality Time in Patient-HCP Interactions

Participants described time as a critical component of women’s health appointments. However, these perceptions were related specifically to how time was used versus desire for more time with a HCP. One participant described, “[the OBGYN appointment...is] fairly quick but I feel it’s sufficient because I get my questions answered (FG5).” Participants who felt involved in their healthcare seemed satisfied with the quality of time spent with the HCP. Thus, positive relationship superseded actual time spent.

Other participants described timeliness related particularly to HCP affect: “she's always tired, she's so busy and she always wants to throw drugs at my face [even though] we talked about this (FG3).” The HCP’s overall affect paired with lacking recall about her priority illustrated how HCPs can emphasize time constraints. Another participant described the language HCPs have used in the past, “they often are running late and they make a note of that ‘Oh, yeah, 40 minutes late today, it's just a rough day.’ So I feel kind of rushed (FG6).” Regardless of intention, this affected how the appointment proceeded. However, participants did not necessarily want to spend more time with HCPs “a lot of times I'm in as much of a hurry as [HCPs]... (FG4).” Thus, patients and HCPs share similar goals. One focus group centered on solutions to address time constraints:

Maybe like two minutes [of rapport building]. Two minutes, it doesn't need to be long... It's little things like eye contact, stuff that you don't necessarily think about but that's the only time that they're going to be able to make eye contact before they're on their laptop or clipboard (FG2).

This was reiterated:

It is important to walk into a room and develop that rapport. But it's also important to remember that you do have patients waiting for you besides the one you're with, so being personal with them, but also not letting conversation carry on and on. So I think two minutes, it's a good time. It's enough to go back and forth (FG2).

Briefly demonstrating patient value may assist in building positive relationships, without requiring excessive appointment times. Changing how time is spent can enhance patient involvement and SDM through simple strategies.

The Impact of Negative Healthcare Interaction on Healthcare Decision-Making

Consequences in Women’s Healthcare

Negative past healthcare experiences often related to negative patient-HCP communication experiences. One participant shared, “hearing a lot of people say ‘Doctors don't care,’ or ‘They'll only do so much’ ... you almost feel defeated..., it's like, what's the point of going and telling them... (FG3)?” Participants offered that these prior experiences had consequences for their engagement with healthcare. One participant shared, “it makes you not want to go to the doctor anymore (FG1).” Another participant emphasized, “if [the HCP] is not giving me what I need or if I don't feel like she's listening to me, I have no problem going to the next person (FG3).” She suggested she would

stop receiving care from a HCP who did not engage in SDM. One participant described, “you don't really think about your women’s health journey much until someone asks you and I've been through experiences that made me reluctant to go [to the doctor] ... snarky comments from doctors, so not coming back (FG4).” She noted the interactive components of judgment and poor relationships impeded her ability to engage.

In addition, others who had negative experiences discussed sharing less information with HCPs. One participant said, “I definitely omit a lot of information... I'm not going to tell them my entire history, [only] the surface (FG6).” Another described, “I've never had a doctor who's validated my bad experiences with hormonal birth control...I don't tell them about [how it affects me] anymore because they're like, ‘Oh, really? That shouldn't be the case’ or ‘That's strange.’ (FG6).” She reduced information-provision because HCPs dismissed her reasons for desiring non-hormonal contraception. Further coping mechanisms included pushing back during appointments. One participant said, “I wish it didn't take many visits and frustrations to feel like you can push back. I only do that because of being there and having to and I kind of wish I didn't (FG6).” In addition to push-back, some participants said “it makes me question more, what does this mean, what does that mean (FG1),” to increase control and involvement during appointments. Another participant demonstrated, “this [HCP] didn't do this and I want to make sure it happens the next time. So me taking more ownership the next time I see somebody (FG3).” Thus, challenging HCPs during appointments, rather than feeling invited to be a partner in decision-making, arose.

Race in Women’s Healthcare

The focus groups with primarily Black women in attendance brought up other instances of negative experience related to race, including historical and current contexts of race in women’s reproductive healthcare.

In the middle of slave times... it's not a good history with African Americans and the doctors and a lot of people won't go until it's almost too late. So, it probably has something to do with that. And I know we've moved on, but maybe habits haven't because of ... a history of feeling not cared for and then anticipating that (FG3).

She described Black women’s feelings toward healthcare stemming from historical standpoints, facilitating stigma anticipation and reduced SDM opportunities. Another participant described, “I've dealt with more microaggressions from white male practitioners than I have from other

demographics (FG4).” Concerns about inequality were particularly salient when discussing childbirth. One participant said,

I feel like I've seen it a lot, as Black women we're not listened to. When my sister was looking for a gynecologist to deliver my niece and nephew, I was strategic about getting her a Black female doctor and that's the same now with me. I'm going to have a Black doula because I was really affected by the recent conversations around when we go into the hospital versus when our White counterparts go into the hospital (FG5).

She made choices related to concerns surrounding how Black women are treated in healthcare, including choosing a Black doula to ensure decisional respect. She continued, “I was like ‘Oh you're a doctor?’ and she was like ‘No I'm a doula.’ And she's Black. And then she started equipping me, she gave me a lot of education and I said ‘Will you be my doula’ (FG5)?” This advocate opened opportunities for this participant to be a partner in decision-making. Another participant reiterated these concerns,

My sister mentioned her biggest fear is to give birth and die giving birth. And she said it comes from doctors who take the strength of the African American woman for granted because of our history, so when we say things it doesn't have as high of a weight as some of the other women that are giving birth (FG3).

The knowledge of how and why black women die during childbirth represented real decisional influences in current and future pregnancy choices. One participant suggested the need for HCPs to support Black women in childbirth,

Even if you don't look like me, I need you to understand where I'm coming from, and when you think of childbirth... [it's] the closest thing to death. So I really need my doctor to be in sync, not ‘No you'll be fine’ (FG5).

Partnering with HCPs so they understood what Black women needed was critical to this participant's healthcare needs.

Touchpoints in the Patient Journey

Participants described a desire for healthcare to “meet you where you're at (FG4).” Thus, moments where HCPs, “... assume that other people know everything you do (FG2)” can pose problems. This suggested using previous skills, like initiating conversations and listening:

There's some people who need that information from a doctor and that's totally fine. There's some people who ‘I've been dealing with x y & z my whole life, I'm

pretty damn knowledgeable about what goes on with that.’ Kind of assessing before you go on the training wheels or not (FG4).

Establishing understanding provided opportunities for positive touchpoints along the patient experience. Thus, simple engagement like, “asking about your experience in the first place. I feel like they never ask what does it feel like to you or how does it impact your daily life? Which sounds like a good question a doctor can ask (FG6)” may ensure each touchpoint in patient-HCP communication is positive. In particular, doing so “would be nice! I don't think I've ever been asked that, what my priorities are (FG2).”

Person-centered touchpoint needs existed across the health continuum, from private healthcare settings to community-based services. One participant discussed the importance of touchpoints at the community level:

Because at the end of the day, I think sometime this may be a one-time touch for you [as the HCP] and they may not see you again. So I don't know if it's that one touch but I would think that in those [community-based women's healthcare] settings, you're dealing with certain populations that maybe already come with a certain level of trauma around health or healthcare or are scared... So I just think that, well with all people you should have that level of compassion, but especially when it comes to those settings and you're helping folks because they absolutely have nowhere else to go and they need you to help, that's when you need [involvement] the most but I don't think that's oftentimes the case (FG5).

HCP behaviors in each healthcare setting could help “or harm people's healthcare choices in the future (FG5).” According to participants, even a one-time positive or negative interaction can change patient perceptions and affect whether patients have the “personal energy to deal with the system (FG4).” One participant described this as, “I felt like I wasn't faithful to [women's community-based healthcare setting] and they didn't have to be faithful to me (FG3).” These interactions and relationships may influence those seeking care in the community, while SDM engagement may counteract existing perceptions. One participant illustrated:

It was a local clinic for people who didn't have insurance and I didn't have it at the time and my experience with the HCP was good, they were concerned, they asked you questions, they asked you about your reproductive health. ‘Do you want this?’ ‘No.’ ‘Are you sure? Because we can.’ It was a wealth of information that was given to me so that I can make a more informed decision about myself and taking the time to listen to me... the experience there was one of my better experiences (FG4).

Despite being a one-time healthcare visit, SDM behaviors created a positive patient experience.

Discussion

Women described various needs when engaging with HCPs, including a desire for HCPs to initiate involvement via listening, and to support preference-sensitive decision-making. In addition, social support played a role in women's reproductive health decision-making. Participants also noted the role of quality time as important to overall care quality. Negative prior reproductive healthcare experiences also impacted participants' healthcare engagement, with race serving as one component affecting choice. Finally, community-based care provided an important touchpoint for healthcare involvement. Participant-suggested SDM strategies included asking about women's reasons for the visit, building rapport by asking about women's lives, demonstrating listening via verbal and non-verbal cues, probing into contexts, and acknowledging experiences.

Participants indicated hesitancy to initiate conversations about choices during women's healthcare appointments due to uncertainty surrounding: 1) their role in the consultation, 2) how to express their needs, and 3) how open they could be with HCPs. Partnership establishment aligns with existing SDM research; however, participants' conceptualization differed from just establishing *team talk*.²⁴ Women wanted HCPs to introduce the visit purpose via question-asking based on what they offered at intake to increase overall comfort. They also this be done so women could share additional needs they did not initially offer, which may facilitate preference elicitation, a critical aspect of SDM. Prior research suggested women frequently bring their contexts into reproductive healthcare;^{110,203} thus, HCPs represent a critical layer to support these discussions during consultation via their communicative behaviors.²⁰⁴ Integrating these initial involvement techniques into the existing SDM *team talk* construct may spur engagement and trust. The approach may allow patients and HCPs to co-produce the interaction and decisional process²⁰⁴ and offer HCPs specific guidance to create a positive, sustained patient-HCP relationship.

Participants demonstrated listening was critical to feeling valued. Women suggested listening indicated HCPs valued the patient as much as the patient valued their care. This finding aligns with adding active listening to SDM²⁴ but elaborates on some practical barriers women experience. While displays of active listening, such as nodding and following-up with related questions, facilitated further engagement from the patient, participants frequently felt this was lacking. Thus, SDM should emphasize the practical ways to demonstrate listening. Feeling 'cut off' was particularly difficult when they were initially asked to share their health history and

current needs.²⁰⁴ HCP communication training could include ways to organically redirect conversation rather than appearing to ‘cut patients off’ to enhance the relationship-building components suggested as implementable aspects of SDM.^{51,194,205} If question-asking and listening when patients are invited to share does not occur, it could limit engagement, affecting the relationship and potential outcomes. Given that computer note-taking occurs frequently,²⁰⁶ demonstrative listening may be even more critical. Based on participant suggestions for what would assure them of HCP listening, HCPs should acknowledge the computer’s role, emphasize they are listening, and utilize non-verbal communication.

Distributed decision-making has been explored to some extent in SDM research as one component of *decision talk*.¹¹² Results suggested one factor impacting women’s choices was social support from friends and families, including before, during, and after consultations, extending *decision talk*. Valued social support systems helped patients break down information and identify preferred choices. Prior research described women’s reproductive health decisions can be influenced by others;¹⁹⁹ however, this influence is lacking in the SDM model but may inform HCPs why some women desire certain options over others. Inquiring into why women have these preferences may help HCPs better personalize care and ensure the decisions are health- and lifestyle-concordant, and reflect preference elicitation set forth in SDM.²⁰³

Quality time perceptions were important to the decision-making process among participants. Participants generally recognized the difficult balance between spending enough, but not too much, time with patients. Thus, quality, rather than quantity of, time was important. HCPs who built rapport and listened attentively to patients were perceived as spending more time, whereas those who asked a list of questions with little to no engagement were perceived as devaluing patients. Spending a minute or two on rapport-building, including asking about the patient’s life and priorities, was enough for participants to feel cared for and facilitate mutual respect. Thus, a feedback loop formed so that value and perception of time spent was associated with how positive or negative the experience was.

Negative women’s healthcare experiences arose frequently in participant conversations. Participants who felt devalued, disrespected, or alone carried that forward in their future interactions. Little research exists regarding SDM following perceived negative healthcare interaction experiences.¹⁴³ Findings from participant conversations extended the limited research available on the consequences of negative interactions, including avoiding care, switching HCPs,

or foregoing recommendations.¹⁴³ Data from this study suggested another critical consequence of frustrations surrounding healthcare interactions: withholding relevant information from HCPs. This consequence underscores an important component of SDM; for those who may have had negative experiences, rapport must be established in all appointments or HCPs may be unable to foster engaged care. Understanding the potential impact of these negative experiences may be especially critical in women's healthcare, as women's health needs are frequently interrelated, can impact lifestyle, and are affected by context.^{101,196,207} Thus, SDM may function to improve care quality in the present and future. Conversely, not embracing key components of SDM may have serious consequences for women's healthcare engagement.

The role of race in women's health experiences further emphasized patient involvement disparities, building on prior work.^{54,149,152,153} However, findings suggested knowledge of racial-ethnic discrimination, even if they had not personally experienced it in their healthcare interactions, affected women's future choices. These women were aware of high death rates in childbirth among women of color, and indicated this knowledge would facilitate decisions regarding whether or not to have children and who their HCP would be. Thus, these negative experiences are very real for women navigating their reproductive lives and are couched within marginalization and perceived HCP lack of concern for their well-being.^{85,150} HCPs who desire to engage in SDM must be aware of negative experiences, including racial discrimination, to facilitate respectful care when women feel vulnerable.

While it may be difficult to have conversations about negative experiences during a visit, acting as though all patients have experienced negative healthcare engagement in the past may assist in ensuring communicative strategies that respect patient agency and counteract prior experiences. Incorporating this model across all healthcare touchpoints along the patient journey, including, as participants noted, one-time interactions in community-based reproductive health settings, can improve the co-creation of value for both patients and HCPs.^{182,204} Patients may gain greater trust in the system and be more likely to attend follow-up appointments, follow HCP recommendations, reduce pushback, and share all necessary information. Keeping in mind that healthcare experience is connected, whether HCPs interact with a patient once or have a sustained relationship, may enhance care, demonstrating the value of SDM implementation.

Limitations and Future Research

Qualitative data provided in-depth insight into practical suggestions for supporting HCPs in provision of high quality care to women across the healthcare journey. However, results should be interpreted in the context of some limitations. Results may not be generalizable across different populations, including other geographic locations or sociodemographic groups, though these findings may transfer to other contexts and samples. Because of the social nature of focus groups, some participants may not have shared their experiences due to desirability bias. Complete confidentiality could not be guaranteed due to the social environment, and the sample was a convenience sample. Further analyses were completed by one coder, limiting interrater reliability. However, because interrater reliability is not a universally accepted component of qualitative data analysis, one coder is acceptable for rich insight and thick description.^{208,209} Future research should further identify what ecological factors impact decisions, beyond those identified in this study, and examine their role in the SDM process. Additionally, future research should explore the acceptability of the communication strategies suggested by participants in enhancing patient involvement in their women's healthcare.

Implications

HCPs serve a critical role in facilitating patient engagement by inviting patients into the decision-making space. Demonstrating listening, even when communication barriers exist, offers HCPs one way to ensure patients feel valued. Inquiring into contexts when these conversations arise, including asking why patients hold certain preferences or priorities, may allow HCPs to personalize care and support patients in making the best decisions for their lifestyles. HCPs should keep in mind patients may have prior negative healthcare interactions that impact their current views and behaviors. Thus, HCPs should facilitate positive engagement for all via communication strategies, such as building quick rapport, refraining from abruptly ending conversations, validating experiences, and demonstrating listening. HCPs are the touchpoints who can boost patient involvement and positive future interactions.

Conclusion

This study offered insight into how women make their reproductive healthcare decisions through a SDM framework. Findings suggest contextual factors such as race and negative prior healthcare experiences may impact how women make decisions and engage with healthcare and that these tie to overall healthcare interaction components, including listening. The study offers novel insight into how HCPs can better understand patients' experiences to enhance personalized care provision, while suggesting practical strategies to engage in SDM and support patient involvement that reflects lifestyle needs and fits within HCPs' existing workflow.

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In Review

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CHAPTER 3: SHARED DECISION-MAKING AMONG NON-PHYSICIAN HEALTHCARE PROFESSIONALS: ENHANCING PATIENT INVOLVEMENT IN WOMEN'S REPRODUCTIVE HEALTH IN COMMUNITY HEALTHCARE SETTINGS

This is an original manuscript of an article in review at Elsevier in [Patient Education & Counseling].

Abstract

Background: Shared decision-making (SDM) is an important approach to patient-centered care in women's reproductive healthcare. This study explored SDM experiences and perceptions among non-physician healthcare professionals.

Methods: We completed 20 key-informant interviews with non-physician healthcare professionals (i.e., NP, RN, CNM, doula, pharmacist, chiropractor) living in Indiana (September 2019-May 2020) who provided community-based women's reproductive healthcare. Interviews were audio-recorded, transcribed, and analyzed using an expanded grounded theory framework. Constant comparative analysis identified emergent themes.

Results: Professionals noted community-based healthcare as patient-centered care, requiring contextualized decision-making approaches. Results identified listening, buy-in, and engagement strategies for enhanced SDM involvement. Findings suggested the importance of outcome-oriented SDM concepts, including patient buy-in and investigative listening, to enhance SDM. Professionals redefined 'challenging' patients as engaged in their healthcare and discussed ways SDM improved healthcare experience beyond one visit.

Conclusion: Findings offered insight into actionable and practical strategies for enhancing SDM in community-based women's reproductive healthcare. The findings offer options to improve SDM by addressing barriers and facilitators among professionals. This extends SDM beyond the patient-physician dyad and supports broader application of SDM. Incorporating professionals' experiences into SDM concepts can enhance SDM in community-based women's healthcare practice, offering opportunities to support a culture of SDM across settings.

Introduction

Indiana women experience various health disparities,¹⁷ including 49% unintended pregnancy rates in Indiana compared with 46% nationally⁴⁻⁶ and rising maternal mortality rates (48.6 deaths/100,000 live births compared to 20.7 deaths/100,000 nationally).^{19,20} Furthermore, 37 of Indiana's 92 counties have no OBGYN, and on average 2.26 OBGYNs serve 10,000 women,^{1,3,169} limiting access to women's health services. However, community-based healthcare settings with non-physician healthcare professionals (HCPs) provide important services in healthcare professional shortage areas. In particular, 63% of people living in states that did not limit the scope of practice of non-physician HCPs had access to primary care practice, compared to 34% in restrictive states.⁵³ Non-physician HCPs may, therefore, increase care access, particularly in rural and low-income settings.^{53,210} Access and quality may be further enhanced by engaging in patient-centered care.^{5,11-14} Shared decision-making (SDM) represents one patient-centered care approach to identify patient needs and encourage patient involvement.²⁴ This communication model encourages two-way sharing of information, preference, and expertise between patients and HCPs.²⁴ SDM promotes patient involvement via three stages: *team talk* (making patients aware of their choices and eliciting their goals), *option talk* (comparing alternatives using risk communication), and *decision talk* (arriving at decisions that reflect informed preferences);²⁴ thus, patient goals and needs are integral to the entire decision-making process.²¹¹⁻²¹³

Encouraging SDM and patient involvement across disciplines and stakeholders, including non-physician HCPs, may facilitate widespread SDM uptake and co-creation of value, fostering consistent, quality care experiences for women across HCPs and settings.^{214,215} However, relatively little SDM research exists on patient-HCP interactions in community settings where the HCP is not a physician.^{12,14,130,216-220} One international review of SDM training found most research targeted physicians,²²¹ limiting insight into how non-physician HCPs (e.g., nurses [RNs], nurse practitioners [NPs], and doulas, etc.) engage in SDM.^{52,172,210,216,217,222-225} Prior research has found RN-patient interactions demonstrate considerable variance in SDM use.⁵² NPs with patient-centered communication styles saw improved health outcomes, including in patient satisfaction, adherence, and overall health.²²³ However, one study found a minority of NPs used a patient-centered communicative style, demonstrating potential gaps in how patient involvement is practiced.²²² Thus, further exploration of these HCPs' experiences may enhance SDM utility.

Incorporating HCPs outside of the patient-physician dyad offers a holistic approach to care building upon social-ecological approaches of patient involvement in community settings.^{159,226} Exploration of multiple stakeholder perspectives has occurred in some healthcare settings,^{217,227,228} but more work is needed in women's health to ensure stakeholders feel invested and represented in SDM provision.^{56,210,229,230} Therefore, the purpose of this study was to explore non-physician HCPs' experiences with providing community-based women's reproductive health services in community-based healthcare settings. In particular, we used qualitative interviews to understand SDM practice, including barriers and facilitators to patient involvement.

Methods

We conducted 20 in-depth, individual interviews with non-physician HCPs (i.e., RNs, NPs, CNMs, clinical pharmacists, doulas, chiropractor) who provide women's reproductive healthcare in Indiana in community health settings between September 2019 and March 2020. Inclusion criteria were: 1) working in a community healthcare setting, and 2) being a non-physician HCP. Theoretical saturation occurs when new information provides additional support for themes rather than novel insight, typically at 12 interviews.^{231,232} Thus, 20 interviews exceeded theoretical saturation for study concepts, and provided adequate information power.^{233,234} Informants were recruited via purposive and snowball sampling using email invitations and personal contacts with existing community partners. The study's protocols were approved by the university's Institutional Review Board (IRB).

Interviews

Interviews occurred at the convenience of HCPs and took place in-person or via phone, depending upon HCPs' availability and comfort. Prior to participation, all in-person HCPs provided written informed consent, including permission to audio-record. HCPs interviewing over-the-phone provided written informed consent via e-mail when possible, otherwise, they provided verbal informed consent to participate and be audio-recorded. All HCPs confirmed consent once audio-recording began. Interviews were recorded on the SoundNote application and lasted 49-91 minutes [69.6±12.0min].

Interviews followed a semi-structured approach to allow HCPs to present novel concepts and discuss their experiences and knowledge holistically.^{201,202} The interview protocol was developed from extant literature regarding SDM acceptability and feasibility in healthcare practice in community health settings and pilot tested with an NP who reviewed the protocol and provided feedback. Following each interview, informants completed a brief demographic survey to obtain individual characteristics. Informants did not receive an incentive for participating but did receive a thank you note.

Data Analysis

All interviews were audio-recorded and transcribed verbatim by the first author and an undergraduate research assistant. The first author also recorded comments and memos to aid in analysis and identify bias in line with qualitative methodology recommendations.²⁰² Techniques from grounded theory offered a constant comparative approach to data analysis.²⁰² This approach privileges informants' personal experiences,²⁰² allowing for data contextualization and broader pattern identification within and between informants' responses. An initial reading of all data provided *in vivo* codes to develop the codebook. Expanded grounded theory allows for incorporation of existing theory or frameworks to assist in data initiation and analysis; as such, concepts from the SDM model proposed by Elwyn et al.²⁴ supplied codes used to analyze interview findings. SDM codes specific to this phase included option discussion (e.g., side effects, effectiveness, benefits, lifestyle), patient involvement (e.g., decision-making invitation, patient preferences, listening, barriers), decision-making role (e.g., autonomous, paternalistic, shared), among others. Further, codes also incorporated barriers and facilitators to SDM practice in community-based reproductive healthcare. Following codebook development, the first author completed open and axial coding, with frequent meetings with the committee chair to discuss coding. Open coding occurred first and allowed for documentation of initial impressions, where key words and phrases were tagged to sections of data. Axial coding was then used to identify broader patterns within the data, as well as compare findings to extant literature and the SDM model. Coding allowed for identification of emergent themes. Any discrepancies were resolved via discussion and consensus. HyperRESEARCH 4.5.0, a qualitative data analysis software, assisted in data organization and management.

Results

Informant Characteristics

HCPs represented diverse clinical backgrounds and included NPs, CNMs, RNs, clinical pharmacists, doulas, and a chiropractor. For additional informant characteristics, see Table 3.1.

Themes and Exemplar Quotes

Themes and subthemes are presented below. Table 3.2. provides example quotes for each theme and subtheme.

Table 3.1. Informant Characteristics

	n=20
Gender	
Woman	19 (95.0%)
Man	1 (5.0%)
Age	39.7±12.7
Years in Women’s Reproductive Healthcare	9.5±8.7
Years Serving Current Community	11.2±10.3
Healthcare Organization Type	
Community-Based Program	10 (50.0%)
Health System	3 (15.0%)
University Affiliated	2 (10.0%)
Private Organization/Agency	5 (25.0%)
Professional Title	
Nurse Practitioner	7 (35.0%)
Registered Nurse	3 (15.0%)
Certified Nurse Midwife	2 (10.0%)
Nurse Practitioner/Certified Nurse Midwife	1 (5.0%)
Clinical Pharmacist	3 (15.0%)
Doula	3 (15.0%)
Pregnancy & Postpartum Chiropractor	1 (5.0%)
Specialty	
Primary/Family Practice	7 (35.0%)
Obstetrics/Gynecology	13 (65.0%)
Race Ethnicity	
White/Caucasian	18 (90.0%)
Latino/a	1 (5.0%)
Black/African American	1 (5.0%)
Education	
Associate’s Degree/Some College	3 (15.0%)
Undergraduate Degree	1 (5.0%)
Graduate Degree	16 (80.0%)
Location	
Urban	12 (60.0%)
Rural	8 (40.0%)

Listed as n (%) or Mean±Standard Deviation

Table 3.2. Themes, Subthemes and Exemplar Quotes

Theme	Subtheme	Exemplar Quote
Community-Based Care as Patient-Centered Care		<p>I have served the wife of surgeons who live in houses that look like castles and I also work with low-income women in Gary, Indiana, which is one of the poorest places in the country (Doula).</p>
		<p>I served 60% Medicaid, and then self-pay. And then I would see people that had insurance that specifically sought me out as a midwife to care for them (CNM).</p>
		<p>We work with people that are non-English speaking, non-native people to our area... We work with people that use substances, we work with people who have lower incomes, people who are homeless... a lot of them have a lot of the same things going on in their life that may be causing or contributing to their issues. So that's kind of the majority of the population that we see and work a lot with in our community (RN).</p>
	<i>Community considerations</i>	<p>There's a reason for being there. Then it's like an onion..., where you try to figure out what is going on with the patient. And sometimes... it's psychological. There's just many things that can be going on with someone (NP).</p>
		<p>A lot of times the story is much bigger than what's written on that chart (NP).</p>
		<p>I didn't really talk about [contraceptive] ring a whole lot because it's super expensive and only private insurance will cover it. So, Medicare and Medicaid don't cover it (NP).</p>
		<p>There are those that are without insurance and need to know [the cost of contraception too]. So, I know what Walmart does. And I know what Kroger's has available. And I know what the clinic has available for non-insurance (NP).</p>
		<p>It's such a low-income area that some of our patients walk, they do not have vehicles. They would not have access to healthcare if they did not have anybody out here (NP).</p>

Table 3.2. Continued

Patient-centered resources

We look at the patient as a total patient, and although we may not provide certain services, we try to plug them into other services that would meet their ongoing needs (NP).

Our staff took a bus tour, the two buses that come by our office. We took the whole route one day, so that we can explain to people where to get on the bus, which bus to transition to, and where our bus stop is. So, we really do try to think of things that we can do to like help our community and help people get to our office. So, whenever we think of something, we try to get trained in it (RN).

We created an IUD myths versus facts handout that addresses some of the most common things on Google..., all the crazy things you can find about IUDs on the internet. So, if patients are interested, I'll give them one (Clinical Pharmacist).

But here, we are great at helping people with resources. I think that we have the staff and the knowledge. I think we have more knowledge of the resources than I think everybody else does in other facilities too because working in public health, you kind of have to know, what are, not all the resources, I don't know everything, but some of the major resources for food, resources for housing, resources for substance treatment, or resources for mental health [because] those are the needs so if we're not addressing that need, and they have those needs, then we are setting them up for failure in other areas (RN).

And doulas have been a great resource as well [for improving access to parental and postpartum chiropractic care]. Because they're, they're in there too. They're listening. They're hearing what the problems are. They're trying to give their clients the experience that they want. So, I've spent probably like five years kind of cultivating the relationships I have now (Chiropractor).

And then I do these grounding activities with them too. Especially for the girls who have to go through [prenatal] exams, they're just having anxiety issues, and I'll give them [a plush] heart and say 'When you're having a hard time, you can hold this heart and think about good things. You know, every once in a while, hold your heart and think about some awesome experience you've had or something that makes you happy. And then when you go to those appointments, you can hold your heart and think about those good things while you're having that experience that's challenging. And then if you forget your heart, you can just imagine that you have it' (RN).

The mind body connection and labor, it's so hormonally, it's all mixed so, you really just need to be kind of free when you're stepping into that labor space. And so, I work throughout their pregnancy to let go of some of those things they may be carrying from the past experience (CNM).

Table 3.2. Continued

**Navigating the
Patient-HCP
Relationship**

*Establishing
partnerships
through SDM*

You're asking a patient 'Well, what do you think? What do you want to do today? What's your goal?' I'm not the boss. We are partners. And that's a hard concept to understand but it's really helped me (Clinical Pharmacist).

I do what I say I'm gonna do and I write out what I'm gonna do by the next visit or during the visit. They'll say 'Can I get any information on how I have a party for a gender reveal?' So, I'll come back with ideas for that (RN).

Just asking open-ended questions and talking about options and it being a partnership, open space for that discussion to flow back and forth [so the patient] gets the information and feels able to make a choice (CNM).

Chiropractic is cool, because... my job is to make you feel better. So, I just really try to create a space where I'm gonna present this information in an anatomical way that may be uncomfortable - no one's talking about your pelvic floor and intercourse [after delivery], but I'm gonna bring it up. So, you know, it's okay, from that perspective, that you bring it up because I already mentioned it (Chiropractor).

I think it's that we're cheerleaders. So just coming back and saying, 'You did a really great job at this' or 'I'm really proud of you for making that decision. And you did what's best for your baby' (Doula).

It would be better if there was some more education [formal training] to providers on how to approach patients, how to approach certain patient populations... if you're rural, it's so different, just [ways of] relating to the patient (NP).

In school, it's funny, they don't spend a lot of time with that, at all. You deal more with anatomy, physiology, and not communication, which is huge! That's most of what, in any relationship, that is the main thing in a personal relationship, communication and we spend the least time teaching it, it's crazy. So, you might get something on talking about open ended questions or motivational interviewing. But you have to know how to apply it (NP).

Table 3.2. Continued

[SDM and decisional support] is not part of the training I received sadly... the agency that I worked with, we would get together and do like learning sessions and I would share that with the other that you never ask why questions. Because why seems kind of defensive, like they have to justify themselves, always ask open ended questions, 'How do you feel about this (Doula)?'

I 100% learned from trial and error. I was taught in my pharmacy residency motivational interviewing, really letting the patient guide. I think as a pharmacist, [though] it's hard [because] we are very black and white and women's health is not very black and white at all (Clinical Pharmacist).

Coming in and talking about some key things for providers to consider [asking]. I think it's really great having people in clinics who are champions of SDM patient care, someone modeling [these behaviors for you] early on (Clinical Pharmacist).

If I need to draw a picture, I will, but usually I'm writing stuff out pretty simple for them to understand so they can remember...which I learned from my collaborative physician. Again, he's an old-school doctor and he would say 'This is the best thing that I found that works for these patients' (NP).

In residency, it was really just people I learned from that did that so I don't remember ever having like a formal training. But a lot of what I learned has been from preceptors that kind of had that same philosophy. So, I've just been fortunate enough to have some awesome people kind of teach me that way... which not everyone has (Clinical Pharmacist).

Asking the patient what is most important to them, I'm embarrassed to say, to me, that was novel (NP).

But coming in and talking about some key things for providers to consider [asking]. I think it's really great having people in clinics who are champions of SDM patient care, someone modeling early on (Clinical Pharmacist).

Culture on the provider side, if you have HCPs who are supportive of SDM and buy into these ideas (Clinical Pharmacist).

Team talk as patient buy-in

It's harder to get people to do [what you] want if they don't want to, so you have to make them want to...Because there's no point in coming up with this elaborate plan if it's not feasible (NP).

Table 3.2. Continued

When I'm building trust with them, there's more them wanting me to know more about them and understand them... but then after they trusted me, they would tell me their concerns, I didn't sometimes even have to ask (CNM).

Especially with the population we serve, they already are kind of defensive and rightfully so and that's the last thing I need, that's the last thing they need, they've had enough of that. They've had enough of judgment. They've had enough of all that, so I can't start out like that [asking them questions like I'm] interrogating them (NP).

I'm teaching them to ask questions. So, teaching them to really go through step by step with their doctor. You know, why are we doing this and then the doctor has to explain it to them. What happens if we don't is one of the main ones to like what are my other option, because doctors usually do things in a set way that they like that is easiest for them (Doula).

It allows them to feel a bit more ownership over the decision (Clinical Pharmacist).

I would say 90% of them are [interested in being part of decision-making]. And even when they're, they don't seem engaged. For instance, I have one mom, who I give her education and I say, 'Hey, do you want to know about that?' She's like 'Sure.' So, I try and start a dialogue. But that wasn't going to work, [she wasn't interested in dialogue] then later when I went with her [at an appointment], she goes, 'Wait a minute. That's not what my nurse told me.' Like oh, she was listening. I think it's really, if you have someone that's nodding and going 'mhm' they might not be learning any of it. So, it's interesting how people learn (RN).

And we'll talk about what they want to talk about with each visit. So, I've learned, when I was first practicing, I'm like, "Nope... we got to talk about birth control." This does not work for anyone, because then the patient's angry, like they don't want to talk to you about whatever you're supposed to be talking about. And then I'm frustrated because I feel like my time is being wasted. So, when I started letting the patient tell me what they wanted to talk about first and have a little bit more freedom to open up with me, I felt I was getting a lot better results from patients and getting more buy-in and trust. And longer and better relationships with people (Clinical Pharmacist).

Investigative Listening

HCP-suggested strategies

Learning to listen and talk less than my patient in appointments (Clinical Pharmacist).

How to talk to people and investigate them through how to listen, there's techniques for listening (RN).

Table 3.2. Continued

Reflect[ing] back well, 'How do you feel about that?' (RN).

It's sometimes just repeating back. 'Oh, you said this' and they'll share more. And it's just kind of learning over the years, how to get people to open up, it's something you can learn... You can shut somebody down really quickly if you want to, and you learn how to not shut them down (RN).

'Is that helpful to you?' and then really listening to their answer (NP).

And so even that, in that talk about the hierarchy of needs, because somebody who's like, aggressive or angry or upset or whatever, a lot of times you find their need, like, what is the need? Why are they you know, what's causing them to be upset like this, you know, maybe it's because they're homeless, maybe it's because they don't have any support. Maybe it's because they're hungry, like those kinds of things. So, it is kind of a broad thing that covers like all the areas that I've worked in, because it is something that I have been taught from the get go (RN).

A clinical care provider that I work with often sees doula care as an important part of the birthing process. [One client] had previous experience that made birth very traumatic for her. And the doctor used that information, which she got from me, with permission from the client to...navigate [her psychosocial needs in birth] ... her patients adore her, her C-section rate is nine percent, her vaginal birth after Cesarean success rate is 88% (Doula).

I think remembering personal details about patients is important. I'll remember some really obscure detail. But I've learned that habit and it really helps because the patients are like, 'Oh, you remembered.' And I find that it shows that I'm listening outside the scope of practice... I usually write all these things down to remember them (Clinical Pharmacist).

Yeah, through questions, not not always, what I try to teach people, is not asking them like, Why Why are you like this? Why are you upset? Why are you - asking like what can I do or what's going on or how can I help? instead of like, why? Like why sounds kind of accusing. If you're like why are you you know upset or why are you homeless, know like what led to this or like how, you know, how can I help you with that kind of thing (RN).

And then, I mean, a lot of times, it's a shared decision, I try to leave it open up to the patient as much as possible, and, you know, but at the end, they're likely going to ask my recommendation, so I might get them, you know, like, given XYZ this might be the best option for you (Clinical Pharmacist).

Table 3.2. Continued

So, we're, we're obviously not going to be making any decisions for them, we're just going to be there to help facilitate to make sure they're confident in their decision. I think that that's an important piece of it is, once you get to that point where you have to make a hard decision, like you still want to be the one making it rather than someone making it for you. We see that that emotionally, like, play a big role and how you feel afterwards (Doula).

If I get somebody that, you know, doesn't seem to be responding very much, but I know is in need of contraception because she's expressed that, I'll try to go over commonly asked questions from other patients. So, I kind of have in the back of my head like, even like random questions that I get from patients (Clinical Pharmacist).

And honestly, we don't know the changes with [postpartum], we don't know what's going on. So, if someone comes in, you're like, this is normal, they're like, 'Okay, I'm not crazy. Okay, now I can handle this.' Normal, you know, just like explaining to someone if you have these symptoms (Chiropractor).

'What is the most important thing to you that we can do today?' or 'What is the most important thing to you while you're here?' Like, 'What do you want to happen?' And I feel like it opens a lot more doors and I had never even considered it. The patient satisfaction scores have gone up and it's been very helpful (NP).

I think that that's kind of a big component is kind of finding what people need and not just assuming what they need and not just doing the same thing for every person because not every person needs the same thing and I think that some places have that problem where they kind of get into your routine (RN).

Asking open-ended questions and, and saying, 'It says you're here for birth control today. Was there a particular one that you're interested in? And why are you interested in that one?'—to see what they tell you first. Because if you go in there and you've got all this information to tell them and it overwhelms them, they may forget what they were going to say to you (NP).

I try to find out what's most important to the patient. So, you know, are they looking to light in their periods? Are they looking for the most effective pregnancy prevention? Are they looking to help acne or something like what are their goals with the contraception and then kind of give them the pros and cons of each (Clinical Pharmacist)?

Table 3.2. Continued

<p><i>Personality and intuition</i></p>	<p>I would say it was more just my personality...the question-asking and open-ended questions, but then it comes back to your own personality (NP).</p> <p>Personally, I've experienced [feeling lost]. And I see how people kind of, especially somebody, so many here [in this community], can get lost in the system (RN).</p> <p>Not so much for my training. I would probably say it's more specific to me, my personality, but I think that's just because, me as a patient, that's how I would want to be treated and respected. And my goal is for people to feel comfortable because if they feel comfortable, then they're going to share all the things and if they share with me all the things I'm not going to miss things because they're withholding information (CNM).</p> <p>I kind of think I did SDM in an intuitive way: What's your decisions here? What's your options? Let's go through each option, and how do you feel about each one and explore it and talk about it (RN).</p> <p>Well I came from a very chaotic and dysfunctional childhood so that probably helped and then working at the state hospital that really helped because if anybody's going to stay calm and be in charge it should probably be the nurse. So that was probably incredibly helpful, but I think those are things that can be learned through exposure (RN).</p> <p>The doula training involves a lot of how to not give medical advice, how to not give your opinion, how to stay within your scope, but I think that doing the dance and how to ask questions and how to utilize your skills to get the client the best outcome possible that is trial by fire, that's something that can't really be taught you have to figure it out (Doula).</p>
<p>Redefining the 'Challenging' Patient</p>	<p>Sometimes they'll have all the information and you just disagree. But that's fine. Because actually, that means that they're making an active decision about what they want to happen with their healthcare. And it would be different sometimes than what I would want to happen with my healthcare, and that's okay (NP).</p> <p>So, no matter, even if they choose the things that I personally would do differently, whatever they do decide, we [support] that you made the best choice (Doula).</p> <p>You almost have to disconnect a little from what your client's going to choose (CNM).</p> <p>They'll be like 'I'm not doing it,' and I just document it but I do tell them what they should have done and that I will never force them (NP).</p>

Table 3.2. Continued

That's something that you have to come to terms with. Because you can give all the information and education, but if someone doesn't listen to what you say, you can't push them because the decisions are theirs, the outcomes are theirs (Doula).

I'd say 'It's your body, it's your baby, it's somebody doing something to you' or 'do you want to ask questions.'" She also described ways she allowed women space to think through their options, telling them "'let's just wait on that, I want to talk to the midwife, or I want five minutes to think about that' instead of them feeling like they have to consent at the time it's presented (CNM).

Yeah. They're the expert of their life and if that's what I'm calling them then I just need to remember that and then I remember there are things that aren't for me too (RN).

Whereas somebody else might be like, 'Oh they're just complaining about such and such and then just like, blow it off.' But I see the importance of being able to, verbally walk through that and have somebody say 'I hear you' maybe 'I'm sorry that that happened, how could we make that better in the future?' That's an important piece of kind of resolving and moving forward. So hopefully that's not carried into the next pregnancy or that she's six weeks postpartum still wrestling through that in her mind (CNM).

And just switching that mindset to you are a consumer and you're consuming their medical services because sometimes we like to think that doctors are kind of in charge, and some women feel like they roll over that. So, it's just really making that distinction of you're the one who's paying them... you could clash over one issue. And you need to be able to advocate for yourself (Doula).

I think people are realizing too the the climate of birth in this country and that our country has one of the worst maternal outcomes in the developed world. Statistically, our maternal outcomes in the US are worse than any other developed nation. And people are starting to realize that and understand that there's something wrong. And when they realize that there's something wrong with the system, they feel like they need a navigator or guide, somebody who knows the system, who understands the system to sort of help them navigate through it themselves (Doula).

'Tell me a little bit more about why you think this is the best option for you.' And then I always ask their permission if I can share an opposing viewpoint. Because I don't want them to feel like I'm belittling their decision that they've made. And so, I always ask, 'Do you mind if I share a little bit of information of what I've learned about this medication or this therapy?' And I find that works really well (Clinical Pharmacist).

Table 3.2. Continued

**Creating a
Culture: The
Discursive
Function of SDM**

Just knowing that [women] have some level of control... [so] that there is more trust in the whole [healthcare] system (NP).

I think using this [SDM] would just encourage more buy-in and increase your chance of them sticking with it. Yes, I think it's absolutely important and that everybody should be doing it (NP).

A patient [who] doesn't understand and appreciate the value of the [interaction], then are going to look at that as a low-quality interaction (Clinical Pharmacist).

You know, when you're doing contraception, it's a totally different world. Like, yes, we need to prevent pregnancy. But it's not like you have to decide today or it's not like this is the end all be all. So really involving patient as much as possible in that decision is just going to help patient you know, feel more confident in their contraception decision, it's going to help build more trust, doesn't work out, they come back to you for more help and don't just, you know, have an unintended pregnancy because they didn't feel comfortable reaching out to you for another option, or whatever it may be (Clinical Pharmacist).

I've heard about it and kind of like with our public health, it's not that we don't give people options but it's not as, shared decision-making still kind of happens. But I would say, it's not the same if you're in a doctor's office setting or something, like not, we're not giving them treatments for the most part, we're not giving them but we do always like for instance, like with immunizations, we present. We recommended, you know, immunization for your child or, you know, which ones would you like to get today and those kinds of things so, we do give options in terms of things, but we it's, I think it's definitely looks a lot different here than it would like in like a doctor office where somebody's actually like prescribing treatments or testing or things like that (RN).

When people feel like they don't have choices, they feel more defensive in the future. I've just seen that...so sort of being able to have that trust from the beginning then promotes in future visits them feeling comfortable (CNM).

In the HIV clinic, you know, they can have negative experiences with healthcare providers...they don't like the way that a person talks to them, or maybe a provider doesn't allow them to ask questions or talk much...but I take that as kind of a learning point of what not to do (NP).

[Patients] had seen a doctor and they didn't like them...and they were already mad at everybody [at the next healthcare experience] because they had had a bad experience, kind of initiating another not so great experience (NP).

[Patients] had seen a doctor and they didn't like them...and they were already mad at everybody [at the next healthcare experience] because they had had a bad experience, kind of initiating another not so great experience (NP).

We know that more than half of women today are feeling not respected and their wishes are supported in maternity care (CNM).

When a woman gives birth, she's like the wrapper on the candy. As soon as the baby's out, she's just thrown away. And that's so true... But women are demanding better (Chiropractor).

A lot of recovery of like, prior bad experiences like in this pregnancy, this new pregnancy that they're having, because in their first visit, they generally tell me, all the reasons why they don't want to do what they did last time... And literally the whole appointment would be about me kind of recovering the last experience they had with the last person that didn't hear them, respect them, agree with them (CNM).

Because I can tell you women are willing to change their perception of what their birth will be like most women, if you offer them a variety of options, they're going to make the safe choice most of the time, they're going to make the right choice. Women in general are not out there taking horrible risks with their lives or the lives of their infants. But the difference between telling a woman that she's going to have this procedure and asking her and letting her make the decision... You have no idea the impact that this has on women. The difference between them feeling like a helpless victim and feeling like a part of the decision-making process has a huge impact, even on their parenting, on everything (Doula).

But there was a moment where I was vulnerable in the hospital recently, and I couldn't speak up for myself... but I can't imagine, you know, being one of these gals and going into a health system. I would like to go to every appointment with them because they come back sometime and I'm like, 'Oh my god, I cannot believe they said that to you.' Or they'll tell me things they said, and I say 'I am so sorry. They should have never said that to you. That's very disrespectful. And you don't need to tolerate that kind of disrespect' and she's like 'Medicaid won't let me change my doctor.' And I'm like, well, what can we do in the future so that you're not alone with that provider (RN)?

Table 3.2. Continued

Table 3.2. Continued

If you just discredit what the patient is concerned about, you know, because there are, there have been weird things happen with IUDs, with implants. We've had an implant that broke in somebody's arm, had to remove it in two pieces like that's not in a study anywhere. I don't have that literature like crazy things do happen. So, if you discredit what a patient is concerned about and what they're saying, and I think you lose that trust later on. So, if they were to need a new option, or if they did have questions or any issues with their current options, I think they're less likely to reach out to you if you've already discredited their thoughts and kind of broken that trust (Clinical Pharmacist).

That's one of the main reasons why I'm hired. I'm more so hired by second time, third time moms because they were mistreated in their first birth and they're looking to feel like they're in control of their birth again. This power dynamic, this control of doctor versus patient or midwife versus patient is one of the biggest issues in our society of birth... So, it's very you're doing this, otherwise your baby's gonna die. Which even though that's not even on the table, like it's something that's not even remotely connected to a fetal demise, they will always say if you don't do what I say your baby's gonna die and hang that over the mother's head (Doula).

Patients say 'I'm not quite sure about you because I've had these negative experiences before.' Our patients have told me after I have helped them, like 'You're the first person that's really listened to me,' or 'You're the first person that's really taken my menopause symptoms seriously' (Clinical Pharmacist).

Community-Based Care as Patient-Centered Care

Community Considerations

Community-based healthcare provided an important arena for patient-centered approaches to reproductive health. HCPs described the communities they served as diverse, including “the wives of surgeons who live in houses that look like castles and... also low-income women in Gary, Indiana, which is one of the poorest places in the country (Doula).” In particular, HCPs identified patients in community health settings had varied and competing needs:

We work with people that are non-English speaking, non-native people to our area... We work with people that use substances, people who have lower incomes, people, who are homeless... a lot of them have things going on in their life that may be causing or contributing to their issues. So that's kind of the majority of the population that we work within our community (RN).

Thus, understanding context was paramount to improving healthcare provision in community-based settings because “a lot of times the story is much bigger than what's written on that chart (NP),” including income, access, and lifestyle. HCPs suggested SDM and patient-centered care assisted in identifying contextual concerns like the ability to pay for contraception. One HCP shared, “I didn't really talk about contraceptive ring a whole lot because it's super expensive and only private insurance will cover it. So, Medicare and Medicaid don't cover it (NP).” Thus, increased insight into a woman’s background and access concerns helped identify systemic needs and personalize care.

Patient-centered Resources

Along with understanding women’s contexts when engaging in community-based services, HCPs also described the various ways they ensured community healthcare offerings supported patients. In particular, knowledge of other community-based resources was essential. One HCP noted, “we look at the patient as a total patient, and although we may not provide certain services, we try to plug them into other services that would meet their ongoing needs (NP).” Of particular importance to patient-centered care were the additional trainings and resources offered by the various community-based HCPs. One HCP demonstrated:

Our staff took a bus tour, the two buses that come by our office. We took the whole route one day, so that we can explain to people where to get on the bus, which bus to transition to, and where our bus stop is. We really try to think of things we can do to help our community and help people get to our office. Whenever we think of something, we try to get trained in it (RN).

Recognition of patient needs within the community facilitated trainings that incorporated a holistic approach to care, rather than focusing on a specific goal or health concern. Another HCP shared, “we created an IUD [intrauterine device] myths versus facts handout that addresses some of the most common things on Google..., all the crazy things you can find about IUDs on the internet. So, if patients are interested, I'll give them one (Clinical Pharmacist).” HCPs illustrated creative ways to incorporate patient voices and needs to ensure patient-centeredness.

Navigating the Patient-HCP Relationship

Establishing Partnerships through SDM

HCPs indicated the necessity of relationship-building in women’s reproductive healthcare. One HCP described how she enhanced collaboration during appointments, “you’re asking a patient ‘Well, what do you think? What do you want to do today? What's your goal?’ I'm not the boss. We are partners. And that's a hard concept to understand but it's really helped me (Clinical Pharmacist).” This HCP demonstrated the importance of understanding women’s priorities and preferences at the outset. Another HCP shared:

Chiropractic is cool, because... my job is to make you feel better. So, I just really try to create a space where I'm gonna present this information that may be uncomfortable - no one's talking about your pelvic floor and intercourse [after delivery] but I'm gonna bring it up. So, you know, it's okay, from that perspective, that you bring it up because I already mentioned it (Chiropractor).

She introduced sensitive topics to ensure women felt they could share. However, some suggested increased training in developing rapport with patients. One HCP described, “it would be better if there was some more [formal training] to HCPs on how to approach patients, how to approach certain patient populations... if you're rural, it's so different, just [ways of] relating to the patient (NP).” She suggested training in coursework or clinicals did not necessarily equip her with the communicative skills to meet patient contextual needs in community-based care. Other HCPs identified increased skill-building was necessary because, [‘SDM] was not part of the training I

received sadly... (Doula).” Even when they achieved SDM and patient involvement through trial and error, HCPs suggested modeling behaviors would be helpful. One HCP suggested:

Coming in and talking about some key things for HCPs to consider [asking]. I think it's really great having people in clinics who are champions of SDM patient care, someone modeling [these behaviors for you] early on (Clinical Pharmacist).

Seeing behaviors modeled, even without more formalized training allowed HCPs to attain SDM-behaviors; however, this may present gaps in expertise because of differential modeling and practice experiences.

“Meeting patients where they’re at” described by most HCPs was enhanced by system-level SDM support. For instance, “asking the patient what is most important to them, I'm embarrassed to say, to me, was novel (NP),” but occurred because of its introduction into her organization. This may enhance a “culture, if you have HCPs who are supportive of SDM and buy into these ideas (Clinical Pharmacist).” Clearly promoting the value of SDM may allow HCPs greater confidence in patient-centered communication.

Team Talk as Patient Buy-in

HCPs described demonstrating partnership, called *team talk* in SDM, was important for facilitating “patient buy-in,” which preceded any conversation about a specific women’s health concern. One HCP described, “it’s harder to get people to do [what you] want if they don’t want to, so you have to make them want to...Because there's no point in coming up with this elaborate plan if it's not feasible (NP).” Initiating *team talk* focused on exploring the most important patient concern ensured patient buy-in and follow-through. Thus, buy-in built trust and allowed patients to “feel a bit more ownership over the decision (Clinical Pharmacist).” HCPs working in community settings described decision ownership as particularly relevant, as patients may have multiple priorities and preferences. Often, understanding how to proceed in decision-making included balancing HCP priorities with patient concerns:

And we'll talk about what they want to talk about with each visit. So, I've learned, when I was first practicing, I'm like, “Nope... we got to talk about birth control.’ This does not work for anyone, because then the patient’s angry, they don't want to talk to you about whatever you're supposed to be talking about. And then I'm frustrated because I feel like my time is wasted. So, when I started letting the patient tell me what they wanted to talk about first and have a little bit more freedom to open up with me, I felt I was getting a lot better results from patients

and getting more buy-in and trust. And longer and better relationships with people (Clinical Pharmacist).

Buy-in necessitated aligning priorities to address patient and HCP goals.

Investigative Listening

HCP-suggested Strategies

HCPs described listening as one part of addressing patient concerns and identifying options such as “learning to listen and talking less than my patient (Clinical Pharmacist).” One HCP suggested listening provided opportunities to investigate women’s situations, “how to talk to people and investigate them through how to listen (RN).” Thus, investigation paired with active listening allowed HCPs to better understand patient needs. Another HCP shared, “asking open-ended questions and saying, ‘It says you’re here for birth control today. Was there a particular one that you’re interested in? And why are you interested in that one?’—to see what they tell you first... (NP).” This HCP used open-ended questions to provide space for women to share, which also offered her the ability to probe on their concerns and identify other needs. Another HCP described following up, “‘Is that helpful to you?’ and then really listening (NP).” HCPs acknowledged difficulties with the competing demands on their time and short clinic visits; however, engaging with patient priorities allowed enhanced understanding. Another HCP said she asks her patients, “‘What’s the most important thing to you while you’re here?’ ‘What do you want to happen?’ And I feel like it opens a lot more doors... The patient satisfaction scores have gone up (NP).” These open-ended questions placed patients at the center of conversations and offered opportunities for improved sharing, listening, and satisfaction.

Personality and Intuition

Many HCPs described their ability to engage in SDM as personality-based, “I would say it was more just my personality...the question-asking and open-ended questions, but then it comes back to your own personality (NP).” They perceived their intrinsic ability assisted them in engaging women in their healthcare. One HCP said, “not so much my training. I would probably say it’s more specific to me, my personality (CNM).” Closely aligned with perceiving SDM ability as innate, others described asking questions and determining women’s priorities as intuitive, rather

than teachable. One HCP said, “I kind of think I did SDM in an intuitive way: ‘What's your decisions here? What's your options? Let's go through each option, and how do you feel about each one and explore it and talk about it’ (RN).” Perceiving differences in innate ability may impede widespread SDM adoption, rather than shifts toward SDM.

Redefining the ‘Challenging’ Patient

Community-based HCPs suggested women who disagreed with or ‘challenged’ them were active in their healthcare decisions. One HCP described, “sometimes they'll have all the information and you just disagree. But that's fine. Because actually, that means that they're making an active decision about what they want to happen with their healthcare... (NP).” This HCP conceptualized disagreement as an indicator of patient involvement. Thus, HCPs suggested minimizing tension by recognizing, “that's something you have to come to terms with. Because you can give all the information, but if someone doesn't listen to what you say, you can't push them because the decisions are theirs, the outcomes are theirs (Doula).” Recognizing women’s autonomy was critical to managing differences. Another HCP described the importance of addressing challenging situations,

Whereas somebody else might be like, ‘Oh they're just complaining about such and such’ and just blow it off, I see the importance of being able to verbally walk through that and say ‘I hear you’. That's an important piece of resolving and moving forward... (CNM).

Further, one HCP discussed her strategy, “‘Tell me more about why you think this is the best option for you.’ And I always ask their permission if I can share an opposing viewpoint. Because I don't want them to feel like I'm belittling their decision... (Clinical Pharmacist).” Bringing up and asking permission to discuss other options helped HCPs overcome decision-making tensions.

Creating a Culture: The Discursive Function of SDM

SDM offered opportunities for “... [women to] have some level of control... [so] that there is more trust in the whole [healthcare] system (NP).” Thus, SDM provided important benefits. However, HCPs often described patients who had negative prior healthcare interactions, and that these negative interactions inhibited their current relationship. One HCP described, “a patient [who] doesn't understand and appreciate the value of the [interaction], then are going to look at that as a

low-quality interaction (Clinical Pharmacist).” Furthermore, HCPs described positive and negative carry-over effects, which potentially impacted perceived care quality. One HCP said, “when people feel like they don't have choices, they feel more defensive in the future. I've seen that...so being able to have that trust from the beginning then promotes, in future visits, them feeling comfortable (CNM).” Engaging in SDM, including via HCP-suggested listening and buy-in strategies, may offer benefits beyond one appointment, and across current and future appointments and healthcare settings.

Discussion

Non-physician community-based HCPs discussed their perceptions and experiences with SDM in women’s reproductive healthcare. Findings offered insight into patient involvement and opportunities to enhance and extend SDM within community-health services. HCPs described the importance of establishing partnerships and patient buy-in when working within community healthcare settings, including ways they found successful to increase trust and listening. However, they also suggested barriers to partnership related to limited SDM training and perceptions that SDM may be personality-based or intuitive as opposed to a learned skill. HCPs also redefined challenging patients as engaged patients and suggested SDM can enable long-lasting trust and positive relationships.

Most SDM work to date has focused on patient-HCP interaction in traditional clinical settings with physicians;^{40,218,221} few studies focus on SDM among non-physician HCPs, particularly in community-based healthcare services.^{52,172} Further, SDM-related research in women’s healthcare is a burgeoning field, and requires continued exploration into ways HCPs can enhance reproductive healthcare decision-making experiences across settings.^{56,102,196} Thus, this study offered novel insight toward extending the SDM model outside of traditional settings and identified key opportunities to translate SDM across healthcare contexts in reproductive health, building on current work that focuses attention on practical strategies for SDM implementation.^{56,217} Further identification of effective components and strategies for enhancing SDM across settings may improve stakeholder engagement and care quality.

Practice Implications

Strategies for Enhanced SDM

HCPs described the importance of establishing patient-HCP partnerships, allowing for relationship-building and trust development, especially when patients come to appointments with differing contextual and healthcare needs. These contextual factors impacted how best to engage patients so their experiences were central to the appointment.²³⁵ To enhance partnership formation, HCPs suggested initially asking what a woman's priorities were and verbalizing partnership opportunities to demonstrate collaborative care. One way to enhance SDM practice across healthcare settings is provision of verbiage for how to ask women about their priorities and needs, and simple ways to initiate a collaborative decision-making space. These should include communicative strategies, like questions and follow-ups, HCPs can leverage if they experience tension or uncertainty. These strategies place resources directly with HCPs that can be easily utilized in low-resource or busy community health settings.^{12,216} HCPs also suggested SDM practices should be supported throughout organizational structures, which could include promotional campaigns offering relevant SDM information, such as simple trainings and resources for HCPs, and messaging that makes asking about patient priorities integral to the organizational mission. Placing patient priorities as central may be critically important in women's reproductive healthcare as these decisions are often preference-sensitive and lifestyle-dependent.^{102,110} Larger-scale efforts may enhance HCP confidence and reaffirm effective strategies they are already utilizing.²¹⁴ In particular, building on creative trainings and resource materials (i.e., myth v. fact sheets) would ensure patient voices and HCP experiences are central to SDM resources.

Value-Driven SDM

One key aspect of SDM is *team talk*, which HCPs conceptualized as patient buy-in²⁴. Buy-in may be an important addition to SDM concepts, as this demonstrates an outcome of SDM engagement of high value to HCPs and affirms the critical nature of understanding stakeholder perceptions in encouraging practice change toward SDM.^{214,217,228} Focusing more specifically on HCP-perceived SDM benefits and outcomes may allow for enhanced adoption. It can also reduce questions about why SDM engagement is valuable and, instead, position SDM as offering real value in patient-HCP interactions. Understanding ways HCPs interpret SDM can improve how

SDM is communicated individually and systematically, enhancing model utility and allowing for co-creation of value.^{182,214,215,228}

HCPs described asking open-ended questions and listening to women's reproductive healthcare priorities as one way to investigate and best serve patients. Open-ended questioning^{52,236} and preference elicitation^{24,196} are accepted components of nursing practice, patient-centered care, and SDM; however, these have not been framed as offering an investigative benefit within SDM. Previous research shows focusing on outcomes of SDM engagement that HCPs value may assist in counteracting implementation barriers, such as increased workload, time constraints, and paternalistic decision-making models often impeding SDM.^{56,237,238} Framing active listening as investigative listening may support the value of any additional time HCPs spend inquiring into women's priorities.

SDM as a Standard of Care

HCPs described how they re-conceptualized 'challenging' or 'difficult' patients as women who were engaged and interested in participating in their healthcare decisions. A barrier to SDM often includes how to address decision tension between HCPs and patients, as it reduces HCP control during appointments.^{40,130,219} However, research shows women desire an increased role in decision-making related to contraception^{196,239} and pregnancy,⁵⁵ suggesting the importance of partnering with women in their healthcare decisions. In particular, HCPs in our sample appreciated women's healthcare involvement, even if they did not always agree with their choices. They also described methods they used to counteract tension and maintain decision respect, including ways to share alternative perspectives and information. Thus, offering these communicative strategies during training may assist in handling disagreement.

SDM offered opportunities for improved current and future healthcare appointments across settings. HCPs identified that when women felt valued in prior interactions, which improved later patient-HCP relationships. Conversely, when experiences were negative, HCPs had to do additional emotional and cognitive work to rebuild trust and develop sustainable relationships. HCPs described women feeling dismissed or disrespected in prior experiences, aligning with extant research;^{56,196} yet, these HCPs also noted their ability to improve care via listening, addressing negative experiences, and asking about patient priorities. However, the appointments frequently began negatively, which may reduce the time HCPs have to understand and attend to

patient needs via SDM, as they must refocus their efforts toward improving women's healthcare perceptions and rebuilding trust. Given the barriers that persist in SDM implementation,^{193,237,240} addressing prior negative engagement experiences is critical. Simple SDM-derived behaviors and communicative strategies may create positive decision-making spaces for all patients and prevent negative experience from impeding patient involvement. Further, with greater SDM use, patient experience may improve, suggesting SDM may enhance care beyond one communicative experience. As evidenced within this sample, SDM behaviors (or lack thereof) can impact HCPs across healthcare settings, with SDM use potentially enhancing reproductive healthcare experience in community settings.

Strengths and Limitations

The study had several strengths. Qualitative methodology and an expanded grounded theory approach allowed for robust insight into non-physician HCP experiences. Different HCP-type and community healthcare settings allowed for triangulation of ideas and generated consistent themes across HCP experiences. Varied recruitment strategies also assisted in enrolling HCPs from different women's reproductive healthcare sub-fields. The interview guide was reviewed by a clinician for accuracy and focus. Limitations included self-selection, as HCPs may have participated in this study because of an interest in patient-centered care; however, they were not informed of the SDM focus prior to the interview. HCPs also self-reported their behaviors, which may have led to social desirability and recall bias. Further, given the interview methodology, HCPs were unable to remain anonymous, potentially increasing social desirability bias. Additionally, most HCPs were white and female, which aligns with HCP demographics in Indiana, but limits generalizability of findings²⁴¹. Additionally, coding was completed by one author, limiting reliability. However, interrater reliability is not universally accepted in qualitative methodology, with numerous qualitative scholars asserting the benefit of one coder for information depth.^{208,209,242,243} Despite these limitations, findings offer practical opportunities to translate SDM across various settings and further expand SDM research to non-physician HCPs.

Future research should develop and test materials to distribute to community-based reproductive HCPs to enhance SDM behaviors. Additionally, future research should identify preferred channels to enhance SDM in community-based healthcare's organizational levels using

a top-down approach. Future research should also explore types of trainings that would work most effectively in enhancing SDM behaviors in community healthcare settings.

Conclusion

This study identified how to leverage non-physician community-based HCP voices to understand practical barriers and facilitators to SDM at the community-level. HCPs demonstrated ways they redefined patient involvement to fit within their goal of community-based patient-centered care provision. Suggested strategies may be beneficial across healthcare settings to improve women's reproductive healthcare experiences and expand SDM's practical application.

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In Review

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CHAPTER 4: AN EXPLORATORY MODEL OF SHARED DECISION- MAKING IN WOMEN'S REPRODUCTIVE HEALTH

This is an original manuscript of an article in review at Taylor & Francis in [Women & Health].

Abstract

Background: Ecological approaches to shared decision-making (SDM) are underexplored in women's reproductive health. The purpose was to identify ecological factors important to women in contraceptive and pregnancy SDM.

Methods: Women (18-45 years) living in Indiana who had sought reproductive healthcare completed an online survey (N=432). Multiple linear regression, chi-square analyses, and structural equation modeling were utilized to identify predictors of SDM, including ecological factors associated with SDM.

Results: Access, social support, and patient-healthcare professional relationship demonstrated good global and component fit. Path coefficients suggested significant relationships between these ecological factors and contraceptive and pregnancy SDM scores. Further, SDM was associated with higher reproductive healthcare quality. Additionally, utilizing community-based healthcare for reproductive health was associated with decreased contraceptive SDM scores.

Conclusion: Findings further SDM work by moving beyond option discussion and toward increased attention to women's contexts and relationships. Taking a holistic approach to SDM and the patient experience ensures that women's multi-faceted needs, influences, and preferences are met across healthcare settings.

Introduction

Women's reproductive health (e.g., contraception, pregnancy) represents an opportunity to support patient-centered care and shared decision-making (SDM), as women desire high engagement in decision-making about their reproductive health.^{56,76,244} However, research shows they may be infrequently involved.^{56,195,196} The SDM model encourages patient-healthcare professional (HCP) partnership, with a specific focus on patient needs, preferences, and lifestyles to guide decision-making.^{24,75,245} Understanding patients' need in decision-making is especially important in women's reproductive healthcare, as there are often multiple acceptable options available and a woman can select a preferred option based on what would work best for her lifestyle.^{72,102,106,196,235} Enhanced SDM adoption offers an opportunity to reduce unintended pregnancy rates while allowing women to choose contraceptive methods that align with their needs and goals.^{72,74,75} Patients indicating high-quality interpersonal relationships with HCPs were more likely to maintain their chosen contraception, experience improved satisfaction, and feel more involved in their care.⁸⁶⁻⁸⁸ SDM may also improve pregnancy experience via patient involvement that addresses gaps in current maternal care practice.^{103,104} Poor maternal outcomes in the United States have increased, even with increases in intervention technology (e.g., labor induction, epidural, Cesarean section), suggesting a need for patient-centered care.^{102,103} One study¹⁰⁵ identified that sharing high-risk pregnant women's birth stories with HCPs reiterated compassionate care and SDM goals, beginning during the prenatal period and continuing through the postpartum period. Engaging in SDM may promote positive birthing experiences, enhance the quality of obstetric care, and improve outcomes and HCP understanding of women's holistic patient experiences, including the context in which they live and make their health decisions.¹⁰⁷ Thus, women may benefit from SDM practice during contraceptive and pregnancy decision-making, including greater satisfaction with their choices.^{27,33,71,246} However, prior work^{71,141,196,235,246} has found SDM occurs infrequently in women's reproductive healthcare, particularly related to eliciting patient preferences, offering opportunities for improvement.

A key aspect of SDM includes understanding patient preferences, which tie to patients' lifestyle, interpersonal, and social contexts.^{75,110,235,245,247} and may be influential in how women make decisions.^{110,196} Limited prior SDM research has explored contextual needs and the associations with how women make reproductive health choices,^{23,24,72,196,235} suggesting further insight into ecological factors may expand SDM. Recent work has called for incorporating the

social-ecological model^{154,156,248} into SDM efforts^{158,159} to identify how lifestyle factors impact decision-making. Though extant research noted that context matters in women's reproductive health decisions,¹¹⁰ empirical studies have not specifically integrated context into SDM.^{24,159,199,235} Further, discussion of context is underdeveloped in the current SDM model;²⁴ therefore, including the social-ecological model within SDM may improve care quality and HCPs' ability to counsel women related to their lifestyle-driven healthcare needs.¹⁹⁶

Contextual factors may include social support and its role in women's reproductive health decision-making.^{112,198,199} Friends, family members, and social norms may relate to contraception and other reproductive health decisions.^{110,199,249} Additionally, access, which includes access to services and ability to pay,²³⁵ and disparities related to sexual orientation and race,^{54,152,195,250} may impact the real and perceived choices available to women making decisions.²³⁵ These barriers may be especially critical in healthcare professional shortage areas¹ and reproductive healthcare deserts,³ as they can limit access to care along a variety of dimensions. In particular, women in Indiana experience access disparities. More than half of Indiana's 92 counties are designated primary care professional shortage areas,¹ reducing primary care and women's reproductive healthcare services. Further limiting access to specialty women's healthcare, 37 of the 92 counties have no OBGYN.³ Reduced access may have detrimental effects on women's health and well-being; for instance, Indiana has a 49% unintended pregnancy rate compared with 46% nationally.^{5,6} In addition, Indiana is the 3rd worst state in the country for maternal mortality.²⁰ Thus, care quality, healthcare access, and social-ecological differences in patient involvement may have a negative impact on women in Indiana.

Therefore, the purpose of the study was to explore what ecological factors, including those related to social support, access, and HCP relationship, were associated with SDM in pregnancy and contraception:

RQ 1: What contextual factors surround women's self-reported involvement in their reproductive healthcare (i.e., contraception and pregnancy) decisional spaces?

RQ 2: What is the relationship between ecological factors and SDM in contraception and pregnancy?

Methods

The study was part of larger mixed methods project examining women's reproductive healthcare decision-making experiences. This survey examined the ecological factors associated

with SDM. Women (N=432) were eligible to participate if they were aged 18-45 years, living in Indiana, and sought reproductive healthcare (including from community health centers). Participants completed an online survey between February and June 2020. Recruitment primarily included flyers distributed at community health centers and community locations (e.g., community centers, libraries), emails through community health service listservs, paid social media advertisements, and shareable social media flyers. Online and social media recruitment were used to recruit a wider audience and ensure respondent diversity. Additionally, researchers recruited women in-person at community locations (i.e., community health centers) and asked them to complete the online survey on a personal mobile device.

Upon survey completion, all participants had the option to submit their contact information to be entered into a drawing to win one of twenty \$25 gift cards, for a one in twenty-five chance of winning. Personal information was kept separately from survey responses. The study was approved by the university's Institutional Review Board.

Procedure

The survey was developed from extant SDM and reproductive health decision-making literature. It incorporated findings from earlier qualitative phases of the project,²⁵¹ and was piloted with two women who met study inclusion criteria to ensure the survey captured the concepts important to women when making decisions.

The survey was accessed via a supplied website link, and completed at the participant's convenience on her own electronic device (e.g., personal or public computer, mobile device, tablet). Participants were first presented with a study overview and initial screening questions to determine eligibility, and then clicked continue allowing for implied informed consent. The survey took an average of 13 minutes (12.37±8.74; R:4.85-65.82 minutes) to complete.

Measures

Items included in the survey were related to reproductive healthcare type and quality, SDM-Q9 scale, social support, decisional influence items developed from prior phases, and demographics.

Reproductive healthcare type and quality

To conceptualize type of healthcare received, items related to type of healthcare and healthcare-setting were included. Additionally, a single item assessed typical reproductive health quality on a 10-point scale, with 1 being the lowest quality and 10 being the highest. This item was further categorized into tertiles: low quality (1-5), medium quality (6-8), and high quality (9, 10) to better conceptualize those women who experienced low versus high quality care.

SDM-Q9 scale^{252,253}

We used the SDM-Q9 scale to assess the extent of patient involvement in the decision-making process from the patient's perspective.^{252,253} The 9-items are measured on a 6-point Likert scale from completely disagree (0) to completely agree (5). We modified the scale questions for contraception and pregnancy consultation experiences and computed the raw composite scores.^{252,253} Example modified items include: *My HCP wanted to know exactly how I want to be involved in making the decision, My HCP precisely explained the advantages and disadvantages of the contraceptive options, My HCP precisely explained the advantages and disadvantages of various pregnancy options, including exams, birth plans.* The Cronbach's α for the modified contraceptive and pregnancy versions were 0.90 and 0.94, respectively, demonstrating very good internal reliability [Acceptable Cronbach's α range: 0.70-0.95].²⁵⁴ We computed the re-scaled scores from the raw composite score. The re-scaled scores ranged from 0-100 based on recommendations from prior work^{246,252} to allow for practical interpretation of SDM scores. Re-scaling included multiplying the raw score by 20/9. From the raw score, we also created a categorical variable for SDM level for both contraception and pregnancy (i.e., low (0-15), medium (16-30), and high (31-45)), based on prior work suggesting most scores fall in medium to high SDM ranges.^{246,253,255} We chose tertiles that retained a separate category for low SDM scores to identify if significant differences existed among the small sample of women who indicated low SDM levels.

Social support

Social support for reproductive health decisions was assessed with 5 items modified from the MOS Social Support Survey²⁵⁶ measured on a 5-point Likert scale (none of the time (1) to all

of the time(5)). These included measures of support for taking the participant to the doctor, sharing information, asking for help, and standing up for health decisions to capture how levels of support factored into decision-making experiences for contraception and pregnancy. The Cronbach's α for the modified scale was 0.84, demonstrating good internal reliability.²⁵⁴

Decision-making influences

To assess the importance of context in women's reproductive health decisions, we included 14 items developed from the prior qualitative phases of the study.^{251,257} These explored the extent to which contextual factors impact decision-making in women's reproductive health. Items were rated on Likert scales from not influential at all (1) to extremely influential (5) and included decision-making influences related to race, sexual orientation, religious beliefs, friends, family, partners, others' healthcare experiences, patient-HCP trust, HCP compassion, HCP listening, prior healthcare experiences, cost, availability of services, internet, and environment. The Cronbach's α for the decision-making influence items was 0.78, demonstrating adequate internal reliability.²⁵⁴

Data Analysis

Multiple linear regression analyses were used to examine significant predictors of participant's SDM-Q9 scores for contraception and pregnancy. Independent variables included HCP type and reproductive healthcare setting, controlling for demographic variables. Additionally, chi-square analyses were conducted to explore associations between the healthcare quality level variable and HCP type. Further, chi-square analyses were conducted on healthcare quality level and healthcare setting. Chi-square analyses were also used to examine associations between the contraceptive SDM level variable and the healthcare quality level variable. Similarly, we utilized chi-square analyses to examine the association between pregnancy SDM level variables and the healthcare quality level variable.

Exploratory factor analysis (EFA) was completed to identify decision-making influence items that related closely to each other using iterated principle factor method. Each item was operationally defined according to the item factor loadings and error terms; items that did not load onto the factors were not used. Confirmatory factor analysis (CFA) was then conducted using structural equation modeling (SEM) as a method to confirm relationships between the latent variables and the items loading onto the latent variables. CFA ensured good measurement model

fit for the decisional factors identified via EFA. Additionally, CFA was also performed on social support items to identify which measures loaded best onto the social support latent factor. SEM was then performed on the latent variables for the contraceptive SDM models and the pregnancy SDM models to identify relationships between ecological factors and SDM. Building the models stepwise via EFA and CFA allowed for identification of ecological factors associated with SDM.^{253,258} The maximum likelihood with missing variables estimator was utilized, which allowed for any items with missing values to be imputed and incorporated into the models. Global (Chi-square (X^2), Root Mean Square Error of Approximation (RMSEA) at 90% confidence; Comparative Fit Index (CFI); Non-Normative Fit Index (TLI)) and component model fit, along with factor loadings, were used to assess model fit. All models met the t-rule, where the number of unknown parameters did not exceed the number of known parameters, to prevent under-identified models.²⁵⁸ We also confirmed models were identified via the X^2 output provided by Stata/SE 16,²⁵⁹ the program in which all analyses were completed. All factor loadings and effects were standardized.

Results

Table 4.1. presents additional sample descriptives. The mean age of the sample was 30.94 ± 6.93 (R:18-45). The majority of participants self-identified as White (86.57%; $n=374$) and heterosexual (82.87%; $n=358$). More than half of participants had been pregnant (52.08%; $n=225$) and most utilized the contraceptive pill (31.02%; $n=134$) as their primary contraceptive method. Most participants had sought community-based healthcare services for reproductive health needs (66.90%; $n=289$) at some point and participants saw either a physician (62.73%; $n=271$) or non-physician HCP (37.27%; $n=161$) for their reproductive healthcare. Scores for SDM were relatively high for contraceptive services (72.47 ± 21.52 ; R:1-100) and prenatal care (70.34 ± 24.22 ; R:1-100). Overall, participants expressed high reproductive healthcare quality (8.36 ± 1.71 ; R:1-10).

Table 4.1. Sample Description

	n=432
Race	
White	86.57% (374)
Black	7.64% (33)
Other Race	5.79% (25)
Age	30.94±6.93 (R:18-45)
Sexual Orientation	
Heterosexual	82.87% (358)
LGBTQ+	17.13% (74)
Relationship Status	
Married	51.85% (224)
Single	18.98% (82)
In a relationship and not living with a partner	12.27% (53)
Living with a partner	14.12% (61)
Other	2.78% (12)
Income Categories	
\$5,000-\$49,999	25.93% (112)
\$50,000-\$99,999	35.65% (154)
\$100,000 or above	34.26% (148)
Insurance Type	
Private	81.48% (352)
Public	15.28% (66)
Do not currently have insurance	3.24% (14)
Education	
Some college or less	13.19% (57)
Currently in college	13.66% (59)
4-year college degree	37.96% (164)
Graduate degree	35.19% (152)
Employment Status	
Employed full time	57.87% (250)
Not employed outside the home	6.25% (27)
Employed part time	17.13% (74)
Not currently employed	3.01% (13)
Student	13.89% (60)
Location	
Rural	23.61% (102)
Urban	29.17% (126)
Suburban	46.30% (200)
Pregnancy Status	
Yes	52.08% (225)
No	47.45% (205)
Received Reproductive Care from Community Health Setting	
Yes	66.90% (289)
No	33.10% (143)
HCP Type	
Physician	62.73% (271)
Non-physician	37.27% (161)

Table 4.1. Continued

Typical Reproductive Healthcare Setting	
Private	86.11% (372)
Community-based	13.89% (60)
Primary Birth Control Method	
Contraceptive pill	31.02% (134)
Intrauterine device	19.91% (86)
Implant	3.94% (17)
Condoms	8.33% (36)
Withdrawal	4.63% (20)
Not currently using	14.81% (64)
Natural family planning	12.27% (53)
Other non-daily method	4.63% (20)
Raw Contraceptive SDM Score	32.61±9.68 (R:0-45)
Re-scaled Contraceptive SDM Score	72.47±21.52 (R:0-100)
Contraceptive SDM Level	
Low	6.25% (27)
Medium	25.93% (112)
High	59.49% (257)
Raw Pregnancy SDM Score	31.67±10.90 (R:0-45)
Re-scaled Pregnancy SDM Score	70.34±24.22 (R:0-100)
Pregnancy SDM Level	
Low	4.17% (18)
Medium	15.51% (67)
High	27.31% (118)
Reproductive Healthcare Quality	8.36±1.71 (R:1-10)
Healthcare Quality Level	
Low	6.94% (30)
Medium	39.12% (169)
High	53.94% (233)

Note: Listed as n (%) or Mean±Standard Deviation. Percentages that do not add up to 100% indicate missing data.

SDM Experience

Multiple linear regression analyses of contraceptive SDM and pregnancy SDM are presented in Table 4.2. Among the sample, seeing a non-physician HCP was associated with a decrease in SDM contraceptive score of 2.53 points, on average, compared to seeing a physician ($p < 0.05$). However, reproductive healthcare (i.e., private office or community-based healthcare) was not related to contraceptive SDM ($p > 0.05$), when controlling for other factors. Individuals

who had an IUD had significantly higher contraceptive SDM scores ($p \leq 0.001$). In contrast, HCP type ($p > 0.05$) and healthcare setting ($p > 0.05$) were not associated with pregnancy SDM. Additionally, no other participant demographics were related to pregnancy SDM.

Chi-square analyses revealed significant associations between participant-reported reproductive healthcare quality and HCP type and healthcare setting, respectively. Receiving care from a physician was significantly associated with high-quality care ($X^2(2, N=432)=12.17, p \leq 0.01$). Furthermore, care quality was significantly lower when receiving community-based healthcare compared to seeking care in a private office ($X^2(2, N=432)=17.48, p \leq 0.001$). Chi-square analyses examining reproductive healthcare quality and contraceptive and pregnancy SDM, respectively, also demonstrated significant associations. Low contraceptive SDM level was associated with medium healthcare quality, while high SDM level was associated with high quality care ($X^2(4, N=432)=43.61, p \leq 0.001$). Similar associations existed in pregnancy SDM levels and perceived care quality ($X^2(4, N=432)=35.08, p \leq 0.001$). Thus, for greater SDM levels, women's perceived care quality levels were higher.

Table 4. 2. Predictors of SDM

Independent Variable	Contraceptive SDM			Pregnancy SDM		
	Coef.	<i>p</i> -value	95% Conf. Interval	Coef.	<i>p</i> -value	95% Conf. Interval
HCP Type						
Non-Physician	-2.53	0.02*	-4.68, -0.38	-3.54	0.07	-7.38, 0.30
Reproductive Healthcare Setting						
Community-Based	0.62	0.70	-2.62, 3.86	-5.15	0.16	-12.33, 2.03
Primary Contraceptive Method						
Intrauterine Device	6.01	0.00***	3.28, 8.74	-0.92	0.72	-5.88, 4.05
Implant	4.33	0.09	-0.65, 9.31	5.97	0.37	-7.27, 19.23
Patch	5.23	0.35	-5.70, 16.15	-	-	-
Ring	2.69	0.42	-3.89, 9.27	6.37	0.43	-9.58, 22.33
Condoms	-1.89	0.34	-5.76, 1.98	-0.86	0.81	-8.02, 6.30
Shot	4.17	0.26	-3.19, 11.53	15.60	0.18	-38.28, 7.09
Not currently using	0.41	0.81	-2.85, 3.66	2.66	0.30	-2.43, 7.75
Withdrawal	1.36	0.61	-3.82, 6.05	7.10	0.08	-0.97, 15.18
Natural Family Planning	2.68	0.12	-0.68, 6.15	3.06	0.21	-1.68, 7.80
Age						
27-35 years	-3.60	0.01**	-6.41, -0.80	-1.65	0.65	-8.92, 5.61
36-45 years	-3.89	0.02*	-7.08, -0.69	-3.04	0.42	-10.45, 4.39
Race						
Black/African American	-3.33	0.09	-7.15, 0.50	-5.00	0.11	-11.13, 1.14
Asian	-1.56	0.70	-9.43, 6.31	17.12	0.14	-5.82, 40.05
Income Categories						
\$50,000-\$99,999	0.93	0.49	-1.71, 3.58	-2.03	0.40	-6.74, 2.68
\$100,000 or greater	3.96	0.01**	1.13, 6.80	1.37	0.59	-3.63, 6.36
Employment						
Unemployed	1.67	0.81	-5.03, 6.45	-0.22	0.96	-7.86, 7.42
Employed Part-Time	1.93	0.18	-0.87, 4.73	2.76	0.21	-1.60, 7.12
Student	-1.20	0.52	-4.87, 2.48	-7.50	0.18	-18.38, 3.38
Not Employed Outside of Home	1.67	0.46	-2.79, 6.12	-0.37	0.90	-5.86, 5.15
Self-Employed	1.60	0.65	-5.26, 8.46	-0.17	0.97	-10.23, 7.12
Education						
Currently in College	-4.61	0.04*	-9.02, -0.22	1.82	0.70	-7.57, 11.21
4-Year College	-0.51	0.76	-2.80, 3.81	-0.91	0.70	-5.57, 3.74
Graduate Degree	-0.88	0.62	-4.33, 2.56	-1.59	0.54	-6.69, 3.51
Location						
Urban	-1.00	0.48	-3.79, 1.79	-0.81	0.73	-5.42, 3.81
Suburban	-1.37	0.28	-3.86, 1.12	-0.52	0.80	-4.59, 3.54
R²			0.16			0.20
F			2.04***			1.29

Note: **p*≤0.05, ***p*≤0.01, ****p*≤0.001

Exploratory Factor Analysis

Fourteen decision influence items developed from prior qualitative work were used in EFA to identify women's considerations when making reproductive health decisions.^{251,257} We retained 3 factors, which explained 74% of the variance, to ensure all factors important to women when making reproductive healthcare choices were present. We only included items loading at or greater than 0.34. The three factors were: 1) *HCP Relationship*; 2) *Access*; and 3) *Social Network Influence*, describing others' influence on decision-making.

Confirmatory Factor Analysis

Following EFA, CFA was completed on each factor (*HCP Relationship*, *Access*, and *Social Network Influence*), as well as *Social Support*, which includes the five items from the modified social support survey (Table 4.3.). *HCP Relationship* ($X^2(2, N=432)=0.26, p>0.05$; RMSEA: 0.00; CFI: 1.00; TLI: 1.00), *Access* ($X^2(2, N=432)=0.27, p>0.05$; RMSEA: 0.00; CFI: 1.00; TLI: 1.00), and *Social Support* ($X^2(3, N=432)=3.04, p>0.05$; RMSEA: 0.01; CFI: 1.00; TLI: 1.00), demonstrated great global model fit, and significant factor loadings (Table 4.3.). However, *Social Network Influence* demonstrated a poor to moderate fit ($X^2, p\leq 0.000$; RMSEA>0.08). This latent factor was retained for the final CFA model, despite moderate fit (Table 6). The CFA had good global fit ($X^2(123, N=432)=249.01, p<0.001$; RMSEA: 0.05; CFI: 0.95; TLI: 0.94); thus, all factors were included as ecological factors in SEM for contraceptive and pregnancy SDM.

Table 4. 3. Standardized Effects

<i>Item</i>	HCP Relationship	Access	Social Network Influence	Social Support	CFA
Trust	0.77 (0.03)***				0.76 (0.03)***
Compassion	0.77 (0.03)***				0.73 (0.03)***
Listening	0.81 (0.03)***				0.79 (0.03)***
Prior Experience	0.65 (0.03)***				0.66 (0.03)***
Healthcare Environment	0.59 (0.04) ***				0.63 (0.04)***
Access		0.64 (0.08)***			0.82 (0.04)***
Ability to Pay		0.92 (0.10)***			0.73 (0.04)***
Sexual Orientation		0.27 (0.05)***			0.24 (0.05)***
Location Social Support Influence		0.01 (0.05)	0.54 (0.06)***		-0.00 (0.05) 0.55 (0.06)***
Partner Influence			0.61 (0.07)***		0.62 (0.06)***
Others Influence			0.22 (0.07)***		0.29 (0.07)***
Religious Influence			0.49 (0.06)***		0.45 (0.06)***
Someone to Discuss Problems				0.61 (0.04)***	0.61 (0.04)***
Someone to Understand				0.63 (0.04)***	0.63 (0.04)***
Someone to Care for You if Ill				0.73 (0.04)***	0.73 (0.04)***
Someone to Take You to Dr.				0.76 (0.04)***	0.75 (0.03)***
Someone to Advocate for You				0.74 (0.03)***	0.74 (0.03)***

Note: All factor loadings are presented as fully standardized. Standard errors are presented after each factor loading.

* $p \leq 0.05$, ** $p \leq 0.01$, *** $p \leq 0.001$

Structural Equation Modeling

SEM was performed to identify how ecological factors related to contraceptive and pregnancy SDM.

Contraceptive SDM

Models 1 (Fig. 4.1.) and 2 (Fig. 4.2.) tested the relationship between ecological factors and contraceptive SDM. Model 1 included *HCP Relationship, Access, Social Network Influence, and Social Support*. The raw SDM composite score served as the observed outcome for all models based on recommendations in prior work.^{253,260,261} Income, race, HCP type, education, sexual orientation, primary contraceptive method, and employment were controlled for in the models. Standardized loadings for the structural model indicated statistically significant pathways for *HCP Relationship, Access, and Social Support* and an adequate global and component model fit (Table 4.4.). *Social Network Influence* was not a significant predictor of contraceptive SDM. In the subsequent model, this pathway was removed as it was insignificant with a small effect size. The final contraceptive model demonstrated an improved model fit (Table 4.4.). *Social Support* presented as a significant ($p < 0.001$) negative predictor of contraceptive SDM.

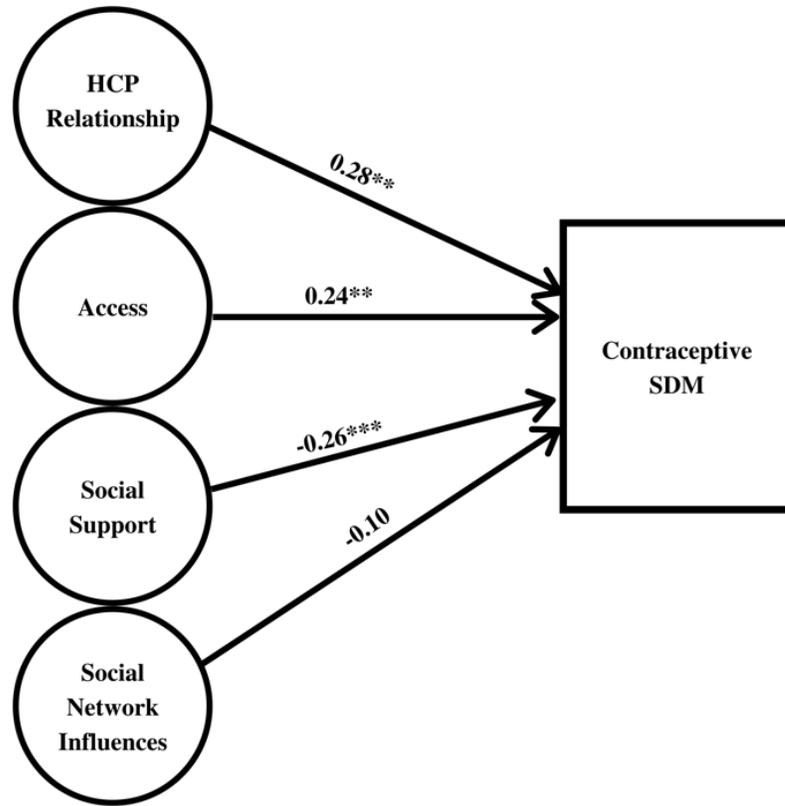


Figure 4.1. Contraceptive SDM Model 1

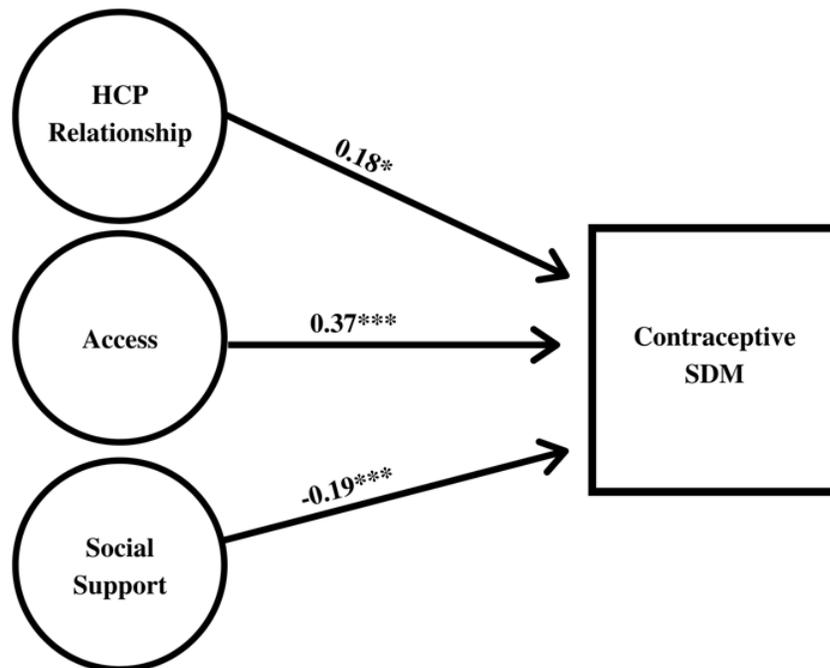


Figure 4.2. Contraceptive SDM Model 2

Pregnancy SDM

Models 3 (Fig. 4.3.) and 4 (Fig. 4.4.) tested the relationship between ecological factors and pregnancy SDM. Model 3 included *HCP Relationship*, *Access*, *Social Network Influence*, and *Social Support*, while Model 4 did not include *Social Network Influence*. Both models controlled for income, education, employment, race, sexual orientation, primary contraceptive method, and HCP type. *Social Support* was significant and negative in both models (RMSEA: 0.04; CFI: 0.96; TLI: 0.94) (Table 4.4.). Controlling for other factors, *HCP Relationship* had a significant and positive relationship with pregnancy SDM ($p < 0.05$) in Model 4.

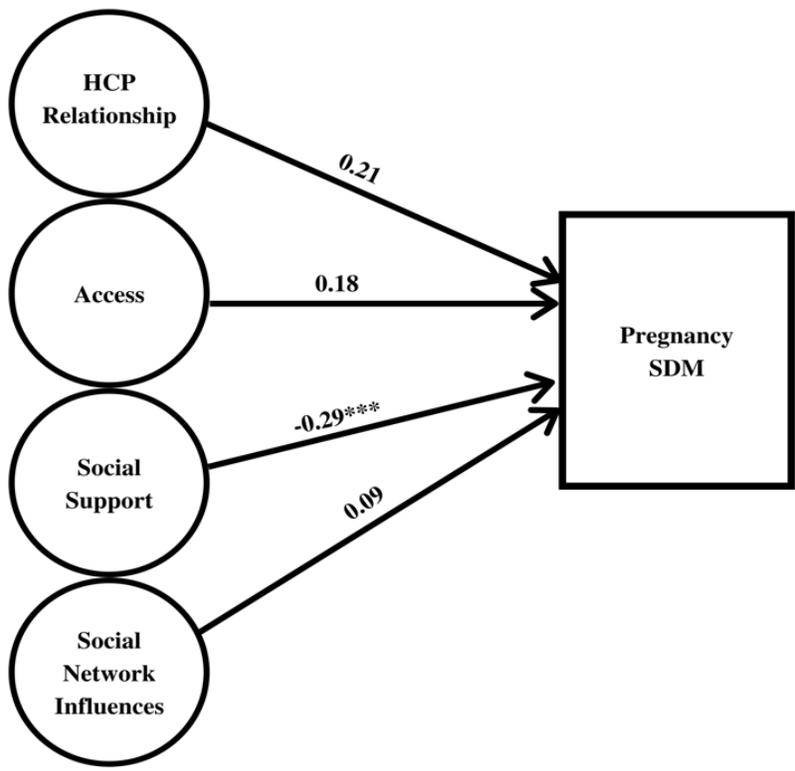


Figure 4.3. Pregnancy SDM Model 3

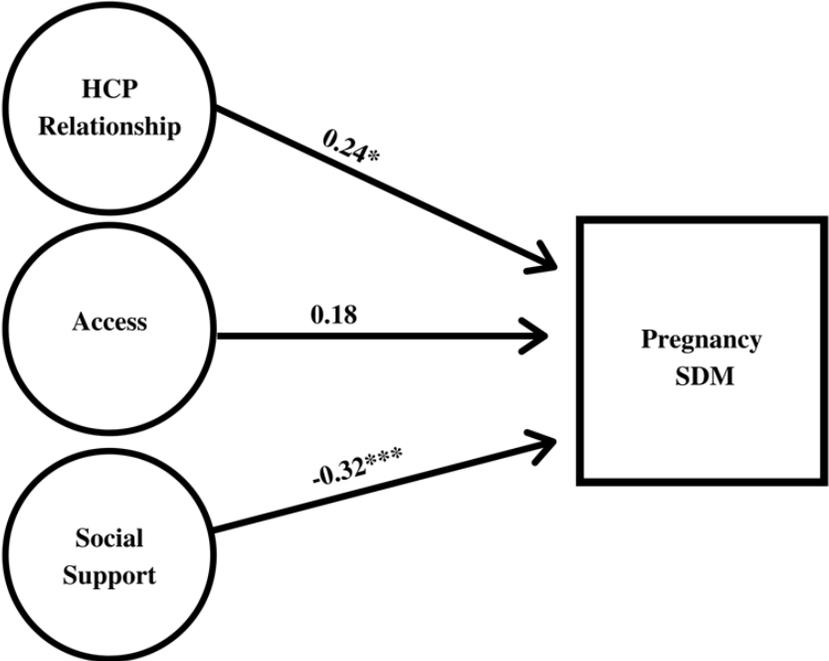


Figure 4.4. Pregnancy SDM Model 4

Table 4. 4. Global and Component Model Fit

<i>Model</i>	X²	df	p	RMSEA (90% CI)	CFI	TLI	R²
Model 1: Contraceptive SDM with all factors	269.05	162	0.00	0.05	0.95	0.94	0.05-0.75
Model 2: Contraceptive SDM without <i>Social Network Influence</i>	255.31	154	0.00	0.04	0.96	0.95	0.07-0.62
Model 3: Pregnancy SDM with all factors	293.26	155	0.00	0.05	0.95	0.94	0.07-0.66
Model 4: Pregnancy SDM without <i>Social Network Influences</i>	267.03	154	0.00	0.04	0.96	0.94	0.07-0.63

Discussion

The current study used multiple linear regression, chi-square analyses, EFA, CFA, and SEM to examine the relationship between ecological factors and SDM in women’s reproductive healthcare related to contraception and pregnancy. Regression results indicated HCP type was associated with contraceptive SDM. Chi-square analyses revealed a significant association between HCP type, healthcare setting, and reproductive healthcare quality. Additionally, perceived level of SDM in contraception and pregnancy was significantly associated with patient reported care quality, suggesting increased SDM may enhance perceived quality of care. Ecological factors (i.e., social support, access, and patient-HCP relationship) were associated with SDM in contraception and pregnancy models, and demonstrated good global and component model fit. Though the X² value remained high and significant, this was likely due to sample size effects given the good global and component model fit for other fit statistics.²⁵⁸ Further, social support and patient-HCP relationship presented as significant ecological factors when making pregnancy decisions. In contrast to contraception, access was not a significant pathway predicting pregnancy SDM. Findings provide a deeper understanding of the contextual factors that should be addressed when engaging women in SDM about their reproductive health.

Social support and its relationship to SDM extend conversations in SDM surrounding relational autonomy,^{112,245} such that patients make decisions based on their needs, and the opinions and goals of valued members of their social support systems.^{24,199} In the final contraceptive and pregnancy models, social support demonstrated a significant inverse relationship to SDM. Further characterizing social support in SDM and identifying the role it can and should play in how women make contraceptive choices is critical for continued SDM development and implementation.^{110,112,199,245} Because relatively little SDM work incorporates ways to address

others' influence and social support in decision-making,^{24,75,199} understanding opportunities for HCPs to consider these factors is important. Thus, SDM practice may be enhanced by considering how social support and others' roles are associated with women's reproductive health decisions,^{75,199,245} particularly when investigating women's preferences during preference elicitation.^{24,55,94} Open-ended questions that probe into a woman's social support system and how it may be influencing their healthcare choices in contraception and pregnancy may improve HCPs' ability to address concerns stemming from social support systems. It can also facilitate women achieving lifestyle-concordant contraceptive and pregnancy decisions.

Findings demonstrated the participant's relationship with a HCP showed a significant and positive pathway for contraceptive and pregnancy SDM. How women view their relationship with HCPs can impact their level of SDM, with better relationships likely improving perceived SDM experience in reproductive healthcare consultations. HCPs can, therefore, focus on developing trust and engaging in listening and compassionate care to encourage patient involvement and enhance SDM experiences. Prior research identified that women desire relationship-building and respect from HCPs when making contraceptive and pregnancy decisions.^{56,87,102,235,253,260} However, there is relatively limited discussion of those relationship-forming components in the current SDM model proposed by Elwyn and colleagues,²⁴ despite evidence that patients value compassion, empathy, and trust.^{86,253,260} Thus, this finding builds on prior research^{86,219} and demonstrates additional work is needed to ensure the SDM model incorporates patient-HCP relationship components to facilitate high quality reproductive healthcare across settings and visit purposes.

Access to reproductive health is a critical component of care quality,^{10,137,196,235} particularly in locations such as Indiana, where women face geographic and demographic access disparities.^{1,3,5} Findings from this study revealed that, in contraceptive consultations, HCP type was associated with SDM. Parts of Indiana are HCP shortage areas where non-physician HCPs are used more regularly.^{1,3} Thus, lower SDM scores when seeing non-physician HCPs may be confounded by barriers like reduced timely access and choice in healthcare, rather than a specific kind of HCP. Similar SDM facilitators and barriers exist among physician and non-physician HCPs, lending support for the potential impact of outside barriers on care quality.^{52,188,218,236} Further, there was no difference in SDM for both pregnancy and contraception based on healthcare setting. This finding provides support that SDM does and can take place across healthcare settings. However, quality may vary, with higher perceived care quality associated with seeking care in private office

settings and with a physician. Again, access disparities or difficulties, more so than specific HCP or setting-type, may be impacting quality.^{12,141,262} However, it may also indicate key opportunities for enhancing SDM training and experience across healthcare settings (e.g., community vs. private) and HCP type (e.g., physician vs. non-physician), as much SDM work has focused specifically on physicians.²²¹ Increased SDM training may ensure that women are involved in decision-making across healthcare settings. Furthermore, given the finding that higher SDM level was associated with higher care quality, increased SDM trainings for non-physician HCPs and in community healthcare settings may improve overall care quality.

The importance of access, including cost, demographic, and geographic components, to contraceptive SDM was further demonstrated in SEM. Because access had a strong, significant, and positive relationship to contraceptive SDM, it may be essential to investigate some of these key access issues during contraceptive consultations. Ability to pay, seek services, and achieve respectful, inclusive care, are critically important to understanding women's experiences and identifying lifestyle-concordant preferences.^{10,71,196,235} Thus, HCPs should have these conversations with women across healthcare settings to better personalize their care, including practical questions related to if they can access a pharmacy, whether or not a generic medication may be appropriate, and what programs or services would provide more convenient options for contraceptive consultations if in-person visits are difficult to attend. These practical questions may demonstrate the importance HCPs place on women's contexts and also extend SDM opportunities by providing example questions that HCPs can utilize if and when needed. Interestingly, access was not a significant predictor in pregnancy SDM among this sample. Thus, further exploration into how access fits into pregnancy decision-making is necessary, as prior research has identified the importance of access to women's health and well-being during pregnancy and birth.^{9,141} The role of access in pregnancy SDM may be especially important for women who delay prenatal care due to access difficulties.⁹ This sample may have experienced fewer access barriers to prenatal care, thus, access concerns may have been less prominent in this sample because participants were able to see a HCP about their prenatal needs.^{9,137}

The focus on the decision-making processes related to patient-HCP relationship quality and social support is novel. It provides critical insight into what women value when they make reproductive health decisions.²⁶² Findings extend the SDM model, while providing key guidance for HCPs on what to probe into during appointments to personalize care and enhance quality.

Strengths and Limitations

The study had several strengths. It was the first to identify relationships between ecological factors and SDM in two reproductive health contexts to understand better the topics HCPs should cover during appointments with women.^{56,253} Furthermore, this study was conducted outside of a clinical setting, allowing women to reflect on their typical healthcare experiences, enhancing SDM work beyond the patient-physician dyad and into a community space. Additionally, the items were developed from prior qualitative research²⁵¹ and extant validated scales and items, providing improved content and construct validity. Using a SEM approach allowed for simultaneous estimation of equations to identify relationships between latent and observed factors. SEM provided evidence for how the ecological factors under study compared in terms of effect size, significance, and factor loadings to tease out nuances in factor structure and relationship. Further, this approach allowed for identification of model fit.²⁵⁸

This study was not without limitations, however, and results should be interpreted in the context of these limitations. First, these data are self-reported and are subject to recall and social desirability bias. In particular, participants may not have remembered their women's reproductive healthcare experiences vividly, potentially biasing results. Additionally, the sensitive nature of some items may have enhanced social desirability bias and decreased women's comfort in answering questions truthfully. However, we believe the anonymous nature of the survey responses appropriately limited the social desirability bias. Further, this sample was limited to Indiana and participants reported high income and educational attainment, indicating results may not be generalizable to broader populations. Due to circumstances beyond our control with the novel Coronavirus pandemic, recruitment strategies had to be altered and were conducted virtually, likely impacting sample diversity. Thus, reaching women with diverse backgrounds and experiences was reduced, as in-person recruitment in community-based healthcare settings was not feasible or safe for study personnel or participants. Lastly, these data are cross-sectional and associations should not be interpreted as causal. Despite these limitations, findings from this study extend SDM research to better understand and characterize ecological factors of importance in women's reproductive healthcare.

Future Directions

Future research should continue to explore the characterizations and definitions of social support in SDM within women's reproductive healthcare, and beyond, including ways to incorporate these constructs into existing SDM measures, like the SDM-Q9.²⁵² Incorporating these constructs may be critically important as scholars continue to identify what SDM should look like theoretically and in practice. Additionally, effective training materials that encourage HCPs to ask questions about social support, access, and patient-HCP relationship quality should be developed and tested among physician and non-physician HCPs. Thus, HCPs would have resources available to support preference elicitation in those topics that are important to women and influential in women's decision-making. Finally, additional exploration of ways relationship-building can be incorporated into SDM in women's reproductive health is necessary so that women have positive experiences and feel empowered during their healthcare encounters.

Implications

Findings from this study demonstrated that HCPs should focus on relationship-building and contextual factors in contraceptive and pregnancy SDM when engaging with women. The SDM model presented by Elwyn et al.²⁴ sets forth critical opportunities to engage in the process of SDM. Further extending the model to identify areas that women desire to discuss during reproductive healthcare appointments may enhance HCPs' ability to effectively investigate women's needs and concerns. Using open-ended questions to ask about women's reasons for preferring specific options or making various reproductive choices, especially as they relate to social support and access, may enhance relationship-building and patient involvement. Furthermore, engaging in these SDM-behaviors with specific guidance about what is important to women when making choices can ensure that women receive high-quality healthcare and engagement across HCP types and settings.

Conclusion

This study identified ecological factors associated with women's reproductive healthcare SDM in pregnancy and contraception. Focusing on contextual factors that can improve patient-HCP communication during consultations is a critical next step in implementing and enriching

SDM across various healthcare settings and HCPs. Findings demonstrating the components important to women when making reproductive healthcare decisions, including social support, access, and patient-HCP relationship, may be beneficial as HCPs and policy continue toward involved and engaged patient-centered care. Further, identification of these and other contextual factors that can be incorporated in SDM models offer guidance for how HCPs can engage with patients during women's reproductive health appointments. Thus, women may feel empowered in their choices and experience high-quality care wherever they access health services.

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In Review

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CHAPTER 5: CONCLUSION

“Because at the end of the day, [the appointment] may be a one-time touch and [the HCP] may not see you again. I don't know if it's that one touch but I would think that in those [community-based women's healthcare] settings..., you should have that level of compassion for all people, but especially when it comes to those settings where you're helping folks who are presenting because they absolutely have nowhere else to go and they need you to help, that's when you need [to be involved] the most (FG5).”

“If you offer women a variety of options... they're going to make the right choice. Women are not out there taking horrible risks with their [health]. But the difference between telling a woman that she's going to have this procedure and asking her and letting her make the decision... You have no idea the impact that this has on women. The difference between them feeling like a helpless victim and feeling like a part of the decision-making process has a huge impact (Doula).”

Most women desire involvement in their reproductive healthcare decision-making despite infrequent SDM occurrence.^{24,72,196,263} Therefore, understanding practical application of SDM is critical to positive reproductive healthcare experience across settings.^{56,219} SDM use in community-based healthcare service is important, as these services enhance women's access to reproductive healthcare, particularly in healthcare professional shortage areas.^{12,14,17,53} Thus, community contexts are critical to facilitating SDM implementation and culture. Furthermore, prior work suggested the importance of including multiple stakeholder voices in executing SDM,^{56,193,196,214,218} such as women and non-physician healthcare professionals (HCPs) not typically considered in SDM research.^{40,218} Thus, exploring these experiences may be critical to enhancing SDM across private and community healthcare settings,²³⁸ and building a SDM culture in women's reproductive healthcare that reflects stakeholder needs and perceptions.

Findings and Interpretation in Relation to Other SDM Work

Findings among focus group discussion with women illustrated that HCPs should invite women into decision-making by prioritizing women's needs and investigating their contexts. These contexts included their social support structures, personal health needs, and prior experiences. By opening the floor for women to share their needs via open-ended questions and listening, even when distractions like technology pose barriers to communication, HCPs can better

personalize care and support women in making the best decisions for their lifestyles. This emphasized the important addition of active listening into the SDM framework,²⁴ as women valued listening as a key part of feeling involved in their care. Validating experiences and needs via active listening and other SDM-behaviors may indicate women are active in, rather than acted on, particularly if they had negative past healthcare interaction experiences. HCPs should, therefore, keep in mind that many patients may have these prior negative interactions that impact their current views and behaviors,¹⁴³ including feeling defensive, distrustful, and unengaged in the healthcare system. Women also noted the importance of touchpoints in the healthcare experience, particularly regarding community-based healthcare services, as these spurred or discouraged engagement. In addition to—and perhaps more important than—community-based healthcare serving as accessible touchpoints for women, HCPs were the touchpoints who advanced patient involvement and positive future interactions.

To extend stakeholder insights gleaned from focus groups with women, interviews with HCPs were used to further contextualize women's reproductive healthcare in community-based settings. Most SDM work has focused on patient-HCP interaction in traditional clinical settings,^{40,217,218,221} with few studies focusing on SDM among non-physician HCPs,^{52,172} particularly in community-based healthcare services. HCPs in this sample identified the critical role patient-centered care and SDM played in achieving positive healthcare experience in community health settings. A keen understanding of patients' experiences when entering the decisional space allowed HCPs to tailor care and connect women with resources to address concerns above and beyond a specific health issue. Rather than thinking of SDM as one process to achieve a specific decisional outcome, HCPs conceptualized SDM as building patient buy-in in decision-making, and in healthcare generally. In particular, verbalizing partnership opportunities, listening to investigate women's needs, and addressing tension via SDM-behaviors were critical for women to feel involved and valued. These findings expanded on prior work, suggesting multiple collaborative and inquisitive benefits from establishing SDM in community health settings.²¹⁷ Frequently, HCPs used strategies, like listening and verbalizing partnership opportunities, to counteract women's prior negative healthcare experiences. This result supported existing work suggesting SDM can enhance care quality and improve involvement beyond a single appointment.^{196,214,217} Furthermore, incorporating HCP perceptions of SDM into existing SDM constructs, like positioning team talk as patient buy-in or active listening as investigative listening,

allowed HCPs to see how SDM can support quality care provision. Outcome-oriented concepts may support increased SDM use by demonstrating that SDM offers real benefit and value to HCP interactions with women during reproductive healthcare decision-making.

The quantitative survey built on qualitative findings, providing insight into the importance of ecological factors in healthcare decision-making identified in focus groups and interviews. Survey results demonstrated the importance of taking a contextualized approach to SDM in women's reproductive health. Findings revealed HCP relationship, social support, and access were significantly associated with contraceptive and pregnancy SDM. HCP relationship and questions about access must, therefore, be explored during reproductive health appointments as these may influence how likely women are to engage in SDM. Those who reported better relationships with HCPs and improved access had a positive and significant association with SDM scores, suggesting that incorporating conversations about these ecological factors is critical to enhancing a culture of SDM and high-quality care. Additionally, social support findings extended research detailing that social support systems are associated with women's healthcare choices;^{110,199} however, a significant inverse relationship emerged between social support and SDM scores for contraception and pregnancy that warrants further consideration in the SDM model. In particular, it may be important for HCPs to address social support during appointments to better understand and counsel women about their choices. The SDM model proposed by Elwyn et al.^{24,25} offers praxis-oriented opportunities to increase patient involvement; yet, patients' contextual needs and concerns are not specifically detailed. Lack of attention to ecological approaches may limit broad application and success of SDM.^{75,245} Thus, enhancing SDM in women's reproductive health to include these key ecological factors is an important next step in achieving person-centered care across HCPs and settings. Findings supported prior research that understanding patient context allowed improved lifestyle-concordant decision-making,^{196,235,264} and reframed the patient from a singular condition or health concern to a person with relationships, experiences, and needs that affect how they make reproductive healthcare choices.^{75,245}

Implications

SDM provides the opportunity to support patient involvement, which is critical in women's reproductive health where women make decisions about multiple, acceptable options.^{56,106,196,235} Thus, understanding women and HCP needs and experiences with SDM is critical to facilitating

widespread implementation.^{56,228} Findings offer practical considerations for moving the needle forward in SDM work. In particular, results supported shifting SDM beyond the patient-physician dyad to include non-physician HCPs and community-based healthcare settings. Women frequently access non-physician HCPs and community health services when seeking reproductive healthcare,^{1,230,265} and understanding SDM across settings can improve and enhance healthcare quality and patient-centered care provision. Furthermore, SDM use across multiple touchpoints, including community-based services, is imperative for women to achieve partnership in their healthcare.

Translating Research to Practice and Policy

HCPs should utilize strategies, such as demonstrating partnership opportunities at the start of healthcare appointments, using investigative listening, inquiring into women's contexts (i.e., social support, access to care), and validating experiences to reduce tension, to create an open and supportive environment via SDM. This study further delineated that HCPs and SDM policy-makers should consider SDM as extending beyond a singular incident of patient involvement; rather, SDM can offer long-term benefits by increasing engagement and trust in the healthcare system. Thus, healthcare organization policy-makers, including in community-based healthcare settings, should establish SDM trainings and organizational resources for HCPs and staff to promote SDM as a consistent component of their health service provision. Organizational sponsorship of SDM, including within the goals and aims of the healthcare service, may promote SDM behaviors throughout the organization, and instill SDM as a standard of practice. Findings provide key evidence for perceiving SDM as a corridor of experience to help women feel heard and involved at each point in their patient journey (Fig.5.1.). SDM and patient-centered care practice, including from initiation and in all subsequent appointments, affirms women's value in decision-making and supports consistent, high-quality patient experience.

PATIENT EXPERIENCE CORRIDOR

The Patient-Provider Interaction across Reproductive Healthcare Settings

*Adapted from Liu S "Experience Corridor"

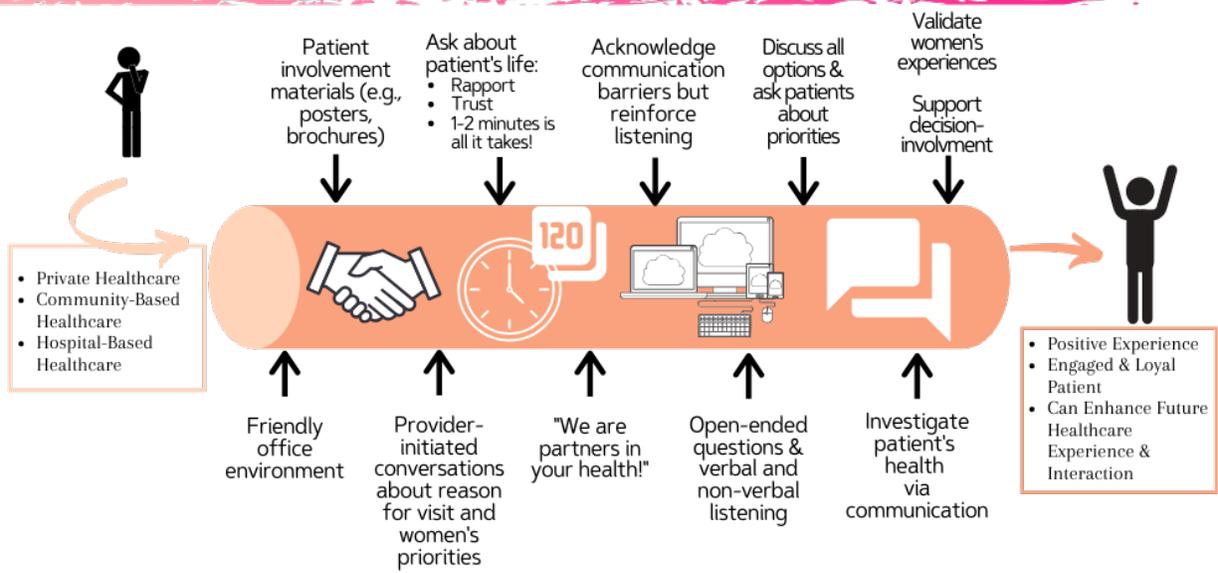


Figure 5.1. Patient Experience Corridor

An important aspect of Elwyn’s SDM model²⁴ is provision of a practical framework for involving patients in decision-making. Incorporating non-physician HCPs and women in this study offered additional opportunities for communicating SDM to patients by taking a translational approach that transforms research findings into praxis-oriented strategies. In particular, example verbiage for how to invite patients into decision-making and explore women’s contexts ensured that findings can be easily implemented within HCPs’ existing work-flow (Fig. 5.2.). Thus, improving SDM implementation, particularly among HCPs not traditionally included in SDM work,²²¹ requires moving beyond theoretical debates toward demonstrating to HCPs ways to engage in decision-making reflective of women’s needs.

Table 5.1. HCP SDM Strategies

Strategy	Example
Invitation to Engage	“I see you’re here for birth control. What would you say your priorities are for this appointment?”
Build Rapport Efficiently	Ask a few questions about how things are going in her life to enhance comfort and relationship-building.
Initiate Partnership	“You and I are partners in your healthcare, so feel free to share what is important to you or ask any questions you may have.”
Establish Listening	“I want you to know, that even if I’m on my computer or taking notes, I’m listening to you.”
Demonstrate Listening	Nod, look up occasionally, follow-up with an open-ended question for further investigate a health need.
Investigate	Use listening and question-asking about women’s experiences and lives as a way to investigate what the health concern or need is, why she has certain preferences, and what option could best fit her lifestyle. Ask about her access to healthcare, including to pharmacies, and what role her social support system plays in her decisions.
Discuss All Available and Feasible Options	Share the pros and cons, risks and benefits of women’s health options. This ensures patients are informed and can make lifestyle-concordant choices.
Validate Women’s Experiences and Support Involvement	Show understanding. Do not use words like ‘strange’ or ‘weird’, and follow-up on women’s experiences with open-ended questions. This can enhance healthcare engagement now and in the future.

Empowering Women, Creating a Culture

Beyond focusing on strategy for HCPs, SDM work should include increasing women’s SDM knowledge and showcasing ways women can be partners in their healthcare. Rather than emphasizing SDM only during healthcare appointments, SDM health promotion efforts across community settings, including community centers and services, may empower women to enter decisional spaces with the goal of partnership. Therefore, utilizing women’s voices to create

materials that support a culture of SDM is critical for enhanced implementation (Fig. 5.2; Fig. 5.3.). Researchers, health communication specialists, and healthcare policy-makers should create materials that can be easily distributed so women are empowered to engage in SDM. Placing resources in women's hands guarantees women can advocate for partnership in healthcare interactions, rather than feeling overly reliant on HCPs to introduce SDM and patient involvement. Women may, therefore, feel empowered to initiate and sustain SDM, including sharing their priorities. Thus, the approach taken in this study may be a valuable step toward increasing SDM among women and HCPs, and across healthcare settings.

Findings also demonstrated the need for HCPs to consider women's contexts when participating in SDM. By identifying contextual factors important to women, SDM can extend beyond exchanging information and options,^{24,25} toward improved understanding of how women's preferences, relationships, and experiences shape their reproductive healthcare choices. Offering evidence-based insight into the relationship between ecological factors, like social support, access, and HCP relationship, advances guidance to HCPs concerning what to ask about when eliciting women's reproductive option preferences. Furthermore, HCPs should have conversations about these contextual factors as it can improve their ability to personalize care and counsel women about the best options for their lifestyles and values. Verbiage that probes into how women's social support systems affect their choices and if they can afford or access reproductive health services, for example, may provide necessary insight for HCPs navigating reproductive healthcare decisions. Because women value open-ended questions and attention about their needs and preferences, this can also ensure high-quality and sustained patient-HCP relationships (Appendix P).



Figure 5.2. Women's SDM Reminder Magnet

Strengths and Limitations

The mixed methods approach utilized in this study extended prior SDM work^{56,217,253,266} by providing rich description into the experiences and needs of women and HCPs via qualitative methods, while enhancing generalizability of findings via quantitative methods. In particular, the multi-phase methodology enhanced our understanding of what women and providers deemed important to their decisions that was then tested in the survey. This approach is novel in the SDM literature,^{25,56,267} particularly in women's reproductive health where women's decision-making and choices are infrequently documented in their own words.⁹⁵ Thus, utilizing quantitative methodology that built on findings from the qualitative phases allowed the survey to better reflect women's lived experiences. Furthermore, the samples and the focus on community-based women's reproductive healthcare was novel compared to extant SDM literature.^{217,221} Incorporating these dimensions is a strength of the study as it allows researchers to think broadly about the application of SDM, beyond the private healthcare setting, to identify SDM barriers and facilitators and improve SDM adoption across the spectrum of healthcare services.

Qualitative methods offered several strengths, including robust insight into women and non-physician HCP experiences with SDM in community spaces. In particular, focus group findings offered suggestions for supporting HCPs in provision of high-quality care to women across the healthcare journey. Interviews with a variety of HCP-types working in various community healthcare settings allowed for triangulation of themes. The HCP interview guide was also reviewed by a clinician for accuracy and focus. Further, the inclusion of existing SDM concepts in both studies allowed for increased trustworthiness as analysis incorporated existing SDM model components. Multiple recruitment strategies also assisted in enrolling participants from various locations and HCPs from different women's reproductive healthcare sub-fields.

However, qualitative results should be interpreted in the context of some limitations. Results may not be generalizable across different populations, including other geographic locations or sociodemographic groups. Because of the social nature of focus groups and interviews, some participants may not have shared their experiences due to social desirability bias. Focus group and HCP interview limitations included self-selection, as HCPs and patients may have participated in this study because of an interest in patient-centered care or women's healthcare; however, they were not informed of the SDM component of the study upfront. Additionally, most

HCPs were white and female, which aligns with HCP demographics in Indiana, but limits generalizability of findings.²⁴¹

The online survey methodology had several strengths. This was the first study to identify relationships between ecological factors and SDM in two reproductive health contexts to better understand topics HCPs should address.^{56,253} Furthermore, the study was conducted outside of a clinical setting, extending SDM work beyond the patient-physician dyad and into the community space. Additionally, the items were developed from prior qualitative research²⁵¹ and extant validated scales and items, providing improved content and construct validity. Using an SEM approach allowed for simultaneous estimation of equations to identify relationships between latent and observed factors. SEM also provided evidence for how the ecological factors under study compared in terms of effect size, significance, and factor loadings to identify nuances in the relationships.

The survey methodology was not without limitations, however. First, these data are self-reported; thus, they are subject to recall and social desirability bias. Participants may not have remembered their women's reproductive healthcare experiences vividly, potentially biasing results. Additionally, the sensitive nature of some items may have enhanced social desirability bias and decreased women's comfort answering questions honestly. Further, the sample is not generalizable to geographically and demographically diverse women and contexts. Participants in this sample had higher income and educational achievement, limiting generalizability to women of lower socioeconomic status. Recruitment strategies likely impacted sample diversity, as all recruitment was moved online due to novel Coronavirus pandemic guidelines.²⁶⁸ Thus, reaching women with diverse backgrounds and experiences was limited, as in-person recruitment in community-based healthcare settings was impossible. Though 95% of United States citizens own a cellphone, the percentage of smartphone users decreases substantially with lower socioeconomic status indicators (i.e., education, income, location),²⁶⁹ limiting survey access. Additionally, concerns about health and well-being during the pandemic may have resulted in reduced interest in completing the online survey. Women in the sample also reported relatively high perceived reproductive healthcare quality, relatively high SDM scores, and high social support. These findings may reduce generalizability to women who consistently rate lower along these dimensions. Lastly, these data are cross-sectional and associations should not be interpreted as causal.

Despite these limitations, findings from this study extend SDM to include multiple stakeholder voices, enhancing women's and HCPs' ability to engage in SDM and patient-centered care. The strengths of the novel sample and focus, and of the mixed methods approach, outweighed the limitations because the study offered keen insight into women's and HCP's SDM perceptions that reflected their lived experiences. By contextualizing SDM approaches, findings provide novel guidance and strategies to facilitate SDM that ensures women's multi-faceted needs and preferences are addressed during reproductive healthcare appointments, while moving SDM work outside the patient-physician dyad and into community contexts.

Future Research

Future research should further identify what ecological factors affect women's decisions, beyond those identified in this study, and examine their role in the SDM process. Additionally, future research should explore the feasibility of the suggested communication strategies for enhancing patient involvement in reproductive healthcare. Further work should develop and test simple materials—like the prototypes developed here—to distribute to community-based reproductive HCPs to enhance SDM-behaviors, including training materials that incorporate question-asking about social support, access, and patient-HCP relationship quality. Additionally, other studies should investigate preferred channels for disseminating SDM resources in community-based healthcare using a top-down approach. Research should also continue to characterize and define social support in women's reproductive healthcare SDM, including how to incorporate these constructs into existing SDM measures, like the SDM-Q9.²⁵² This may be critical as scholars continue to pinpoint what SDM should look like theoretically and in practice. Finally, additional exploration of ways relationship-building can be incorporated into SDM in women's reproductive health is necessary so that women have positive experiences and feel empowered during their healthcare appointments.

Conclusion

This study offered novel insight into how women and HCPs in community-based settings engage in reproductive health SDM. By extending beyond the patient-physician dyad and into the community space, this work demonstrated SDM does not simply facilitate a one-time positive

experience. Instead, it represents a broader opportunity to enhance patient involvement across the spectrum of women's reproductive healthcare. Findings emphasize the need to incorporate and support SDM into community-based settings, as these facilities improve access to services for women in Indiana and beyond. Engaging in SDM that incorporates contextual needs and preferences also allows HCPs to better understand women's experiences, and moves the current model forward, with the goal of increasingly personalized and high-quality care. HCP trainings that highlight context when engaging with patients may provide necessary guidance as HCPs navigate decision-making. Integrating women and HCP experiences using a mixed methods and translational approach offers practical strategies to engage in SDM and strengthen patient involvement reflective of women's lifestyle needs and HCPs' existing workflow. Prioritizing how women and HCPs perceive and practice SDM ensures all stakeholder voices are represented to increase adoption and success, improving healthcare satisfaction and outcomes. Thus, findings advance SDM in women's reproductive health to support a culture of SDM that empowers women to collaborate in their healthcare.

Reflection

I often reflect on my journey from an undergraduate degree in biology at a small liberal arts college to my current position, a PhD candidate at a large Midwestern research institution, so far removed from my original plans. My entire life, I knew I wanted to be a doctor; of course, doctor, then, meant medical doctor. Even as a child in daycare, I read books about germs and microbes I found in the donated bookshelf – strange books to have available for children in hindsight. However, during my senior year of college, I found myself in an existential crisis. After completing coursework and research in public health, health communication, and women's health, I realized medical school was not my path. I was thrilled by research with women that identified problems and supported feasible, practical solutions. Armed with a new perspective, I made my first leap in this direction and entered the Masters in Communication program at the University of Charleston, South Carolina to study health communication.

My master's degree program was fun – there's no other way to describe it. I worked on an interdisciplinary research team, honing my research skills, receiving more challenging and exciting opportunities as a leader, and making changes in women's lives using their voices and experiences as the guide. I also learned from amazing scholars and classmates. I think it felt fun because I was

on the right path after drifting for a while in my senior year. During the last year of my master's degree program, I began identifying other opportunities to continue my educational advancement – I still knew I wanted to be a doctor. Unfortunately (at the time), my long-time mentor, Dr. Andrea DeMaria, had recently accepted a new position at Purdue University, which took her away from Charleston. However, we remained close, as she was on my thesis committee, and when I shared with her my plans for seeking out a doctoral program, and that I was interested in Purdue University's health communication program, she suggested I come for a visit.

My visit to Purdue was exciting; I was sure the health communication program would be where I ended up, and I was happy I would know people there. My informational meetings with the department went well and were followed up with a campus tour and lunch with Andrea. After the campus tour, we stopped by her research lab. I learned more about the work that she was doing as part of the lab—including blending healthcare, public health, women's health, and international research—, more about the program in Consumer Science, and about opportunities available for students like mentor-the-mentor approaches and study abroad leadership. After listening for 15 minutes, I was hooked. I decided, instead of communication, I wanted to apply to work with Andrea as a doctoral student and improve the interdisciplinary work I had been doing in this new environment. When I told Andrea about my interests working with her, she was not expecting it. I was thrilled when she expressed excitement about continuing our advisor-advisee relationship in her lab. I applied for the Department of Consumer Science and, in January, was accepted into the program. I could not contain my excitement for my next leap, this time from the South, where I had spent my whole life, to the Midwest, where, among other things, I knew I would have to get used to snow. However, I still had to complete my thesis work and defend it.

My thesis work laid the groundwork for my current interests in patient-centered care and SDM. I initially began with the goal of understanding Latina women's experiences with contraception; however, when that became an impossibility, I began to read and think more about how healthcare providers played a role in contraceptive choice – beyond prescribing. This is where I began to blend my initial desire to go to medical school with listening to women's voices regarding their perceptions and experiences with their health. I quickly became passionate about what was and was not happening during patient-provider communication about contraception, and through reading, learning, and speaking with my thesis advisors, I came upon SDM. It became the basis for my thesis, and, now, continues to be the basis of my work and passion. On the day of my

defense, I was excited and prepared. I felt good about the feedback I had received and was ready for a strong finish, so I could think about my next steps forward to Purdue. Besides a few hiccups, like the presentation software in the conference room refusing to work, forcing me to give my presentation from memory, without my slides, the presentation went well. I felt calm and at peace knowing I had successfully researched and defended something so important to me, that aligned with my interest in bridging public health and healthcare in women's health. I knew my next steps, including continuing this line of research.

My first two years of the PhD program could best be described as a whirlwind. I completed coursework that challenged me and created opportunities to enhance the depth of the work I was doing with Andrea and of my own ideas. Dr. Shield's intervention design course facilitated my first foray into and designing my SDM study. His feedback throughout the course not only enhanced my grant writing ability, but also bolstered my confidence to continue SDM work in women's health. The courses I took with Dr. Liu were equally influential, as they honed my ability to think strategically and creatively about health needs, specifically when engaging in community-based work. Whether moving beyond demographic data to understand a priority audience's perceived barriers and needs, or going above and beyond stakeholder requests, the lessons I learned were invaluable to my approach to research and practice. Probably the most influential course for my trajectory was translational research; this course pieced all of the lessons I had learned and my interest in making impacts with research into one. I was inspired to think broadly about the impact research can make when you think translationally at the conception of a project, especially when considering health disparities and community-informed research. This was truly the starting point and directive for where I wanted to take my work. Through all of my coursework and practical experience working on Andrea's projects, I was able to deeply explore what and how I wanted to approach research for my upcoming dissertation. Without Andrea's expertise, training, and open-mindedness, I would never have had the ability or background to take a translational approach to research.

Beyond the research skills I amassed working in Andrea's interdisciplinary research lab, I also gained extensive mentoring and leadership experience. As part of the mentor-the-mentor approach in our team, I was able to serve as a first-line leader for undergraduates and master's students. This opportunity honed my ability to explain our research and writing in different ways to ensure the research assistants understood what their roles and responsibilities were, and

enhanced my empathy and patience when things did not always go to plan. I was lucky enough to work with an accomplished student during my dissertation phase in a one-on-one capacity, which allowed me to combine everything I learned from my experiences to serve as a mentor to Natalie. I learned the best ways to structure project goals and deadlines, that reflected her needs and mine, and we built a strong personal and professional bond because of my prior experience with mentorship. However, no experience embodied the mentorship opportunities I received more than the two study abroad programs in Florence, Italy that I TA'd. Serving as a TA on these programs was my first experience studying abroad, and I honestly cannot imagine a better study abroad experience. Not only did I work with a large research team of undergraduates, training them in methods and writing, under Andrea's stewardship, but I also became immersed in the culture, sights, sounds, and tastes. Andrea was the perfect mentor to provide this experience; her passion for all things research and culture, and her laughing acceptance of my aqueduct water obsession, made these experiences that much more joyful. I will always remember when Andrea introduced me to the very best pizza in Florence, Torricoda (I still dream about it), and the time we spent talking over delicious meals about my interests in patient-centered care, women's health, and consulting. In these conversations, I was able to merge my training from Andrea, with my ideas and her feedback. In addition, working closely with students taught me the wins and difficulties that exist when managing a project, and I became adept at handling conflict compassionately, while celebrating achievements in research. This extends to now, as I still hear from students I have mentored about their successes, career paths, and needs.

Presentations also provided me opportunities for growth. Andrea has served as a stellar mentor through the presentation process and was always supportive of building my knowledge and insights via conference attendance. The time we spent wandering the streets of Portugal and attending presentations about improving patient-provider communication allowed me to stay up-to-date on the latest research and practice, and identify potential gaps as I further considered dissertation topics. During my time in Italy, I was also afforded the opportunity to attend and present at a social marketing conference in Edinburgh. Though Andrea did not attend, the prep work we did made me feel confident and ready for the 25-minute oral presentation I was slated to give on the translational project improving access to emergency contraception in Italy. It was at this conference that I felt truly excited about my dissertation topic being translational. The

presentations focused on how we can make our research count in real-time and I knew that I wanted to do that in my dissertation, though exactly how, I had not determined yet.

My preliminary exams were a blur; however, the grueling process stimulated ideas for translating my research to practice. I was able to combine my interest in community health, with patient-centered care, for a community approach to SDM. My preliminary exam questions forced me to further identify my ideas, and translate these to practical implications. I used my preliminary exam questions as a jumping-off point for ensuring the work I did with SDM could translate across contexts, and create a broader change in patient-centered care via understanding stakeholder perspectives and turning these into useful materials for women and community-based healthcare providers. My proposal encompassed this approach, and following approval from my committee, they provided feedback for funding opportunities that enhanced the translation of my findings via the Service Learning Grant. After successfully passing my proposal, achieving the Service Learning Grant was probably the next best feeling because I knew my project merited funding and I could actually realize my goal of turning my findings into materials stakeholders could utilize to enhance patient-centered care. This drive to incorporate the translational course Andrea taught and the many experiences I had working on the lab's research agenda guided my dissertation process.

The dissertation seemed to whirl by as well, though with much hard work to realize my goals. I knew my work extending SDM into the community space was novel and provided insight to those practitioners and policymakers who desired to broaden SDM across contexts. I was excited, but realized the community focus required strategy and ingenuity, including hours walking around community centers, local stores, and libraries, among others, to talk to women and share my study information. This came with a lot of strange looks and brushing off, but when I was able to connect, I felt so happy and grateful! Cold calls and email paired with in-person recruitment were stressful, sometimes draining, but ultimately rewarding when I filled my last focus group in mid-December. I learned so much from the women during our conversations and became keenly aware of various communities in Indiana, which I had not been introduced to in prior years. Interviews with HCPs were equally rewarding and challenging; I was inspired by the providers' passion for women's health, which made making connections exciting, but recruiting from community locations added another layer to achieving the interview total. In my pursuit of sharing my study, I made amazing connections with community HCPs and community-centered champions who facilitated an increased provider network. I realized, in these moments, the critical nature of sustained

partnerships in community-based work, which until that point, I had only read in books or learned in courses. It was an exhilarating process and I will take the lessons and successes with me in my next endeavors.

Recruitment difficulties did not end for me in the final phase of my study, the online survey. Almost as soon as my survey was approved by the IRB, COVID-19 racked the world. In this time of uncertainty and fear, everything had to pivot. We began a long road of self-isolation, and along with growing concern, I had to reframe my recruitment strategy – everything became online and I worked tirelessly to cold call and email community organizations, asked friends to share my survey on social media, and utilized various online platforms to reach women so they could share their voices. Despite the many hours spent online hoping I could reach my recruitment goal, I learned new skills in design and social media to enhance interest in my study, which I will carry forward into future positions. Beyond data collection and analysis, I was also excited to create materials that could be easily adopted by women and providers in community settings to enhance patient-centered care. I created magnets, strategies for providers, and a booklet with tips and tricks to enhance healthcare experiences with the invaluable support of Natalie. Though I have had to wait to see final products, when I got my first request for resources from a cold email, I could not help but dance around my apartment. My goal of changing women’s lives via their healthcare experiences was even closer and I was thrilled to have made these community connections so this could materialize! Despite the anxiety, occasional doubt, rejection, and current events, my committee’s support and my passion for my project have made the dissertation experience impactful, important, and worthwhile. I am excited about my next steps following this degree and hope to continue improving women’s healthcare experience using these translational and audience-centered approaches.

My entire academic career feels like it was fated; from merging my initial interest in healthcare provision with enhancing healthcare via formative research, and continuing my mentorship with Andrea through my doctoral journey, I feel as though where I am now is kismet. As I apply for various positions that play to the many skills I have gleaned in my doctoral program—conducting various research methods, building stakeholder relationships, thinking critically, merging art and science, and so much more—I know I will end up where I am supposed to be. I have received the best and most supportive training, which will only set me up for success as I make my next giant leap. As I am writing this, I do not know where I will end up, nor exactly

what I will be doing, but I am reaching out for opportunities and seizing them as they come. I am open to what the future holds, and know I will make my dreams, which I talked about for hours with Andrea over Torricoda pizza, of consulting come true, one step at a time.

APPENDIX A. FOCUS GROUP RECRUITMENT EMAILS

Recruitment Email

Subject Line: Reproductive Health Decision-Making Focus Group Study

Dear [First and Last Name],

Thank you for your interest in participating in a focus group regarding reproductive health decision-making.

[Or]

Your name and email were given by someone you know who thought you may be interested in participating in my research study regarding reproductive health decision-making.

As a participant in this research, you will be asked to participate in a 1.5 – 2-hour focus group that will be audio-recorded. You will be asked questions related to sexual and reproductive health decisions, factors influencing those decisions, and community healthcare access. Upon completion of your focus group participation, you will receive \$20.

Learn more about the study here: <https://www.purdue.edu/hhs/csr/womenshealth/>

Please email me back if you are [still] interested in participating. I am happy to schedule a time that would work best for you.

[This study was approved by Purdue University's IRB. Protocol: IRB-2019-160].

Sincerely,
Stephanie Meier, MA
Doctoral Candidate
Purdue University
West Lafayette, Indiana
United States of America
meier11@purdue.edu

APPENDIX B. FOCUS GROUP FLYER

For in-person and social media distribution

IWRHC
Purdue University
College of Health and Human Sciences

Reproductive Health Decision-Making Study

Women aged 18 - 45

Living in Indiana

Seek reproductive & Women's Healthcare in Community Health Settings

IRB Protocol: IRB-2019-160.

Researchers at Purdue University invite you to participate in a research study exploring reproductive health decision-making in community health settings, such as Community Health Centers and Community Health Programs. The study will explore experiences with and perceptions about decision-making surrounding contraception, pregnancy, and birth.

Participants will be asked to take part in focus group discussions and will receive a \$25 gift card and food/beverage during the discussions.

Email Stephanie Meier, meier11@purdue.edu, or Natalie Murdock, nmurdoc@purdue.edu, for more details and if interested in attending!

PI: Andrea L. DeMaria, PhD, MS
ademaria@purdue.edu
(765) 494-8300

APPENDIX C. FOCUS GROUP CONSENT FORM

RESEARCH PARTICIPANT CONSENT FORM

Reproductive Health Decision-Making: Extending the Shared Decision-Making Model into the Community Space

PI: Andrea DeMaria, PhD, MS

Co-I: Stephanie Meier, MA

College of Health and Human Sciences
Purdue University

Key Information

Please take time to review this information carefully. This is a research study. Your participation in this study is voluntary which means that you may choose not to participate at any time without penalty or loss of benefits to which you are otherwise entitled. You may ask questions to the researchers about the study whenever you would like. If you decide to take part in the study, you will be asked to sign this form, be sure you understand what you will do and any possible risks or benefits.

You are invited to participate in a research study conducted by Dr. Andrea DeMaria from Purdue University and her doctoral student, Stephanie Meier University.

This study is designed to understand experiences with and perceptions of reproductive healthcare decision-making in community health settings, including what your impacts decision-making. You are being asked to participate because you are a woman between the ages of 18-45, who lives in Indiana, and has received reproductive healthcare in community health settings. We will be completing 4-6 focus groups with a maximum of 60 participants over three months. Each focus group is expected to last between an hour and a half and two hours.

What is the purpose of this study?

The purpose of this study is to get your insights and experiences about your reproductive health and decision-making about reproductive health during community healthcare appointments. You are being asked to participate because you are a woman between the ages of 18-45, who lives in Indiana, and has received reproductive healthcare in community health settings. We will be completing 4-6 focus groups, with 6-10 participants each, with a maximum of 60 participants.

What will I do if I choose to be in this study?

As a participant in this research, you will be asked to participate in a focus group discussion. This focus group will be audio recorded. You will be asked to share your insights and perspectives related to reproductive decision-making, your level of involvement in your healthcare, and what you feel impacts the decisions you make about your reproductive health, including contraception, pregnancy, and birth.

How long will I be in the study?

Participation in this study will require approximately 1.5 to 2 hours.

What are the possible risks or discomforts?

Risks from participating in this study are no greater than you would encounter in daily life. Breach of confidentiality is always a risk with data, but we will take precautions to minimize this risk as described in the confidentiality section.

Are there any potential benefits?

Although it is not anticipated that you will benefit directly through your involvement in this study, this research is expected to benefit women when they are counseled in their reproductive health decisions in community health settings.

Will I receive payment or other incentive?

You will receive a \$25 gift card for your participation in the focus group discussion. You will receive this payment following your focus group participation and you will be asked to sign a payment log with your name and email address for Purdue University records. These will be kept separate from any information shared during the focus group session. According to the rules of the Internal Revenue Service (IRS), payments that are made to you as a result of your participation in a study may be considered taxable income.

Will information about me and my participation be kept confidential?

Confidentiality cannot be guaranteed when collecting data via focus groups, due to multiple participants being involved. Additionally, the project's research records may be reviewed by departments at Purdue University responsible for regulatory and research oversight. Despite these potential circumstances, the researchers will still take certain precautions to protect confidentiality such as asking participants to use pseudonyms instead of actual names, password-protecting the focus group audio-recordings, storing them in a locked location at Purdue University, and destroying the files when the research is complete. For research purposes, we may quote information offered during focus group conversations in professional presentations and publications. However, at no time will you be identified by name or job title in any reports or publications resulting from this research.

What are my rights if I take part in this study?

Your participation in this study is voluntary. You may choose not to participate or, if you agree to participate, you can withdraw your participation at any time without penalty or loss of benefits to which you are otherwise entitled. Please be sure to let your research representative know if you wish to discontinue your participation at any time throughout the focus group process.

Who can I contact if I have questions about the study?

If you have questions, comments or concerns about this research project, you can talk to one of the researchers. Please contact Stephanie Meier at meier11@purdue.edu.

If you have questions about your rights while taking part in the study or have concerns about the treatment of research participants, please call the Human Research Protection Program at +1 (765) 494-5942, email (irb@purdue.edu) or write to:

Human Research Protection Program - Purdue University
Ernest C. Young Hall, Room 1032
155 S. Grant St.
West Lafayette, IN 47907-2114

To report anonymously via Purdue's Hotline, see www.purdue.edu/hotline.

Documentation of Informed Consent

I have had the opportunity to read this consent form and have the research study explained. I have had the opportunity to ask questions about the research study, and my questions have been answered. I am prepared to participate in the research study described above, and I agree to having my responses audio recorded. I will be offered a copy of this consent form after I sign it.

Participant's Signature

Date

Participant's Name

Researcher's Name

Date

APPENDIX D. FOCUS GROUP GUIDE

Focus Group Guide

Welcome. I want to start by saying how thankful I am that you are here today to help me with this research project I am conducting about reproductive health decision-making experiences.

My name is Stephanie Meier and I will be moderating the focus group. This is my co-moderator, _____ . We are both students at Purdue University.

Let me say just a few words about the process for the focus group. First, the goal today is for me to hear your thoughts and opinions about reproductive health decision-making, factors that are important to you when making decisions, and your involvement in your health consultations—there are no right or wrong answers, everyone can have an opinion and I hope you are willing to share and talk about with each other. Everyone’s confidentiality is very important. Nothing you discuss here should or will be discussed outside of the focus group. You are welcome to share stories about people in your life, without giving their names. You are also welcome to skip any questions, and not everyone has to answer each question. If you feel uncomfortable at any time during the discussion, you are welcome to leave the conversation, and may return as you feel comfortable.

We’re audio recording the session because we do not want to miss any of your comments. But, your names will always remain confidential, so anything we discuss in this room will not be tied to your name in any final reports that we write.

Our role today is to ask questions and listen. We will be moving the discussion from one question to the next. During our talk, I may sometimes have to interrupt you if I feel we are running out of time and there are several more questions to get to; please do not feel this has to do with what you are saying, it is just a matter of me keeping my word about getting you all out of here in no more than two hours.

So, let’s go around and introduce ourselves. You may share your first name or a nickname or other name if you prefer not to share your name during the group.

Okay! I would like to begin by exploring your perceptions on some important issues. The first few questions deal with what you know and how you feel about your healthcare experiences.

1. Please use the paper and pen provided, and take a moment to write down what comes to mind when you think about how you make decisions about your health. I am going to give you 30 seconds. Try to write down as many things that come to your mind.

(pause at least 30 seconds)

What were some things you wrote down?

Probe: Explain why these were your first thoughts.

Probe: What are some of your experiences making healthcare decisions?

Probe: Walk me through how you make health decisions?

2. Please write down the top three things that come to mind when you think about making reproductive and sexual health decisions? Try to write down the top three things that come to mind.

(pause at least 30 seconds)

What were some things you wrote down?

Probe: Why did you write these down?

[Reproductive health decision-making includes the process of making a decision about your reproductive health, including about birth control, pregnancy and childbirth planning, and/or annual check-ups, with a healthcare provider and family/friends/partners. This includes all the things you care about and that are important to you, such as your health, your preferences, your lifestyles, your goals, and your needs.]

3. Please share your experiences making decisions about reproductive and sexual health?

Probe: How did you make decisions about birth control? Pregnancy? Birth?

Probe: Describe how you talked to your healthcare provider.

Probe: Did you share your opinions and the things important to you? Why or why not?

4. How did your healthcare provider talk to you? Did you feel they listened to you? Why or why not?

Probe: Did they ask about your ideas, plans, goals, or preferences?

Probe: How did they let you know you could share or stop you from sharing your thoughts or concerns?

5. What would you change about your experience? Why?

Probe: Are there any things you wish you had done differently? Why or why not?

Probe: Is there anything you wish your provider had done differently? Why or why not?

Now, we are going to move into a discussion about your experiences with reproductive decision-making in community health settings, such as community health centers, community health programs (e.g., Nurse-Family Partnership), Planned Parenthood, or CVS Minute Clinic or urgent care.

6. How have your experiences been receiving reproductive healthcare in these settings?

Probe: What types of reproductive healthcare did you seek?

Probe: How did you feel about your interaction with the healthcare provider? Why?

Probe: What was it like to talk to the provider?

7. Please describe how you made decisions during that appointment?
Probe: Did the provider talk about your options? Why do you think this was the case?
Probe: Did the provider invite you to share your thoughts and concerns? How or why do you think they did not?
Probe: How involved did you feel in the decision-making process? Why?
Probe: Have you ever felt like you had to go along with a health decision even though you didn't want to? Why?
8. Have you ever had trouble 'speaking up' or sharing your situation or preferences in community health situations? Please tell me more about that.
Probe: What do you think stops women from talking to their healthcare provider?
Probe: What are some suggestions you have for a woman who is having trouble 'speaking up' to their providers?
9. How do you think community-based healthcare is different from other healthcare? Either in general or in your personal experience.
Probe: Why or why not?
Probe: What makes you think this?
10. How do you think community-based healthcare decision-making is different from other healthcare decision-making experiences?
Probe: Better or worse?
Probe: Why or why not?
Probe: How do you think community healthcare providers compare to other healthcare providers in involving patients? Please share.
Probe: Do you think people close to you would have similar thoughts? Why or why not?

Now, I'd like to hear your thoughts on things that affect or influence your reproductive health decisions.

11. Please use the paper and pen you were provided, and take a moment to write down the top five things that influence your reproductive health decision-making. These could be anything that is important to you, including outside of the healthcare situation (e.g., friends/family, personal beliefs, previous experiences, etc.) I'll give you 60 seconds.

(pause at least 60 sec)

Please share some of the things you wrote down.

Probe: Why were these important to you?

Probe: Listening to the other responses, is there anything you would like to add? Why or why not?

Probe: If so, what are they?

Probe: [If do not mention]

- Social support (friends, family, partners)
- Race/ethnicity
 - Do you think that race affects people's relationships with their doctors?
 - Can you tell me a situation where race played a role [either good or bad] in communicating with the provider?
 - Do you think that providers treat *African American/Latina* patients, in reproductive healthcare, the same, better, or worse than white patients? Why or why not?
- Access
- Patient/provider relationship
- Negative prior healthcare experiences
- Religious/spiritual beliefs
- Romantic/sexual partners' preferences
- History of unwanted sexual experiences, such as rape or being convinced to do something they didn't want to do
- Other people telling you what you should or should not do?

12. How have or might some of the things we just talked about affect your reproductive health decisions?

Probe: Do you think any of these factors would change your decision? Why or why not?

Probe: How might these change your decisions?

13. Tell me about a time you have discussed your reproductive health with family or friends either before an appointment or before making a final decision.

Probe: Have you ever taken a family member or friend to a healthcare consultation with you?

Probe: Do they play a role in your decision-making during, before, or after the consultation?

Probe: How did the provider treat him/her?

Probe: Would you have preferred him/her to play a greater or lesser role in the reproductive health decision? Why or why not?

Probe: [for those who have not] Why have you not discussed with family or friends?

14. Describe a time you have had a negative reproductive healthcare experience?

Probe: How has this affected your later reproductive healthcare interactions or decisions?

Probe: How have these affected your attitudes or thoughts about your taking part in reproductive health decisions?

Probe: Tell me about any other effects from these experiences? (e.g., stress,

dissatisfaction, anger, greater or less involvement, etc.)

15. How might sexual violence affect how women make decisions about their body?

Probe: For example, about birth control or pregnancy?

Probe: Do you think this would affect women? Why or why not?

Probe: What about coercive behaviors by a partner, such as deliberately breaking a condom or being convinced to do something they didn't want to do?

Probe: Who do you think has control over women's choices about their health, specifically their reproductive and sexual health? Why?

Probe: Have you or someone you know ever had an experience with sexual abuse or violence that affected decisions you made about your reproductive or sexual health choices (e.g., birth control, pregnancy, etc.) How?

16. Has a healthcare provider ever asked you or someone you know about sexual violence or sexual abuse experiences when talking about sexual or reproductive health?

Probe: Do you think healthcare providers should ask about this? Why or why not?

Probe: Do you think this would be a good thing, a bad thing? Why or why not?

Probe: If yes, how did this make you feel?

Probe: If not, do you wish they would have? Why or why not?

17. Are there any other things that you can think of that may affect how women make decisions about their reproductive and sexual health? If so, what are these?

18. What are some things you would suggest to increase reproductive healthcare involvement during community healthcare consultations?

Probe: What types of information or tools would be helpful to you?

Probe: Would you like this information to be on something you could use or hold or take to an appointment with you? If so, what? (e.g., magnet, mini-book, button, etc.)

Probe: Where would you like to receive this? (e.g., online, in provider offices, social media, other?) Why?

That is all the questions I have prepared for today.

19. Is there anything you wish to add?

20. Are there any questions you wish I would have asked?

Thank you very much for your time! To help ensure we are gathering insight from a diverse group of participants, we are asking if you would be willing to fill out an anonymous **brief demographic questionnaire**.

Upon completion, please give your form to my co-moderator, _____. Again, thank you for your participation. We greatly appreciate the information you have provided.

APPENDIX E. FOCUS GROUP DEMOGRAPHIC FORM

Demographics

1. What is your age?

_____ Years

2. What is your race/ethnicity? Mark all that apply.

- a. White
- b. Hispanic or Latino
- c. Black or African American
- d. Native American or American Indian
- e. Asian / Pacific Islander
- f. Not Listed (Specify) _____

3. What is the highest degree or level of school you have completed?

- a. Middle school
- b. High school
- c. College
- d. Graduate school
- e. Other. (Specify) _____
- f. I prefer not to answer

4. What is your employment status?

- a. Employed
- b. Not employed outside of the home
- c. Unemployed
- d. Student
- e. Other
- f. I prefer not to answer

5. What is the combined household income of all working persons permanently living in your home?

- a. Less than \$20,000
- b. \$20,000 - \$49,999
- c. \$50,000 - \$99,999
- d. \$100,000 or more
- e. I prefer not to answer

6. What type of insurance do you currently have?

- a. Private
- b. Medicaid
- c. Military
- d. Other
- e. I do not currently have health insurance
- f. I prefer not to answer

7. What is your relationship status?

- a. Single
- b. Married
- c. Other
- d. I prefer not to answer

8. How many people permanently live in your household?

- a. Number of children under the age of 18 _____
- b. Number of adults aged 18 years or older _____
- c. Nobody, I live alone

9. What is your current contraceptive method?

- a. Birth control pill
- b. IUD (intrauterine device) (i.e. Mirena, Kyleena, Liletta, Skyla, Paragard)
- c. Implant (Implanon, Nexplanon)
- d. Patch
- e. Ring (NuvaRing)
- f. Condoms
- g. Other _____
- h. I am not currently using a contraceptive method

10. Have you ever been pregnant?

- a. Yes
- b. No

11. [if yes] How many of your pregnancies resulted in (enter the number for each line)

- a. Live birth: _____
- b. Still birth: _____
- c. Abortion: _____
- d. Miscarriage: _____

APPENDIX F. KEY INFORMANT INTERVIEW RECRUITMENT

Introduction Email

Subject Line: Reproductive Health Decision-Making Interview Study

Dear [First and Last Name],

My name is Stephanie Meier. I am a third-year doctoral candidate at Purdue University. My dissertation work centers on reproductive health decision-making within community health settings.

I found your organization and bio online, and I was hoping to connect. I would love to speak to you about your experiences and insight from your work in the community and stay connected as I continue my work in community health decision-making

[Or]

My name is Stephanie Meier. I am a third-year doctoral candidate at Purdue University. My dissertation work centers on reproductive health decision-making within community health settings. We met at the Purdue University Breaking Barriers: Improving Access to Health Services for Women and Children in Indiana. I so enjoyed speaking with you there and learning about your impactful and important work

[Or]

My name is Stephanie Meier. I am a third-year doctoral candidate at Purdue University. My dissertation work centers on reproductive health decision-making within community health settings. You know [Insert Contact's Name They Already Know].

I would appreciate the opportunity to speak to you about your experiences and insight from your work in the community and stay connected as I continue my work in community health decision-making.

I look forward to connecting with you,

Sincerely,

Stephanie Meier, MA
Doctoral Candidate
Purdue University
West Lafayette, Indiana
United States of America
meier11@purdue.edu

Follow-Up Interview Interest

Subject Line: Reproductive Health Decision-Making Interview Study

Dear [First and Last Name],

Thank you for your interest in participating in a focus group regarding reproductive health decision-making

[Or]

Your name and email were given by someone you know who thought you may be interested in participating in my research study regarding reproductive health decision-making.

As a participant in this research, you will be asked to participate in a 60-minute interview that will be audio-recorded. You will be asked questions related to your experience providing reproductive and sexual healthcare in community health settings. These questions will focus on your experiences with decision-making and barriers and facilitators to patient involvement.

Learn more about the study here: <https://www.purdue.edu/hhs/csr/womenshealth/>

Please email me back if you are [still] interested in participating. I am happy to schedule a time that would work best for you.

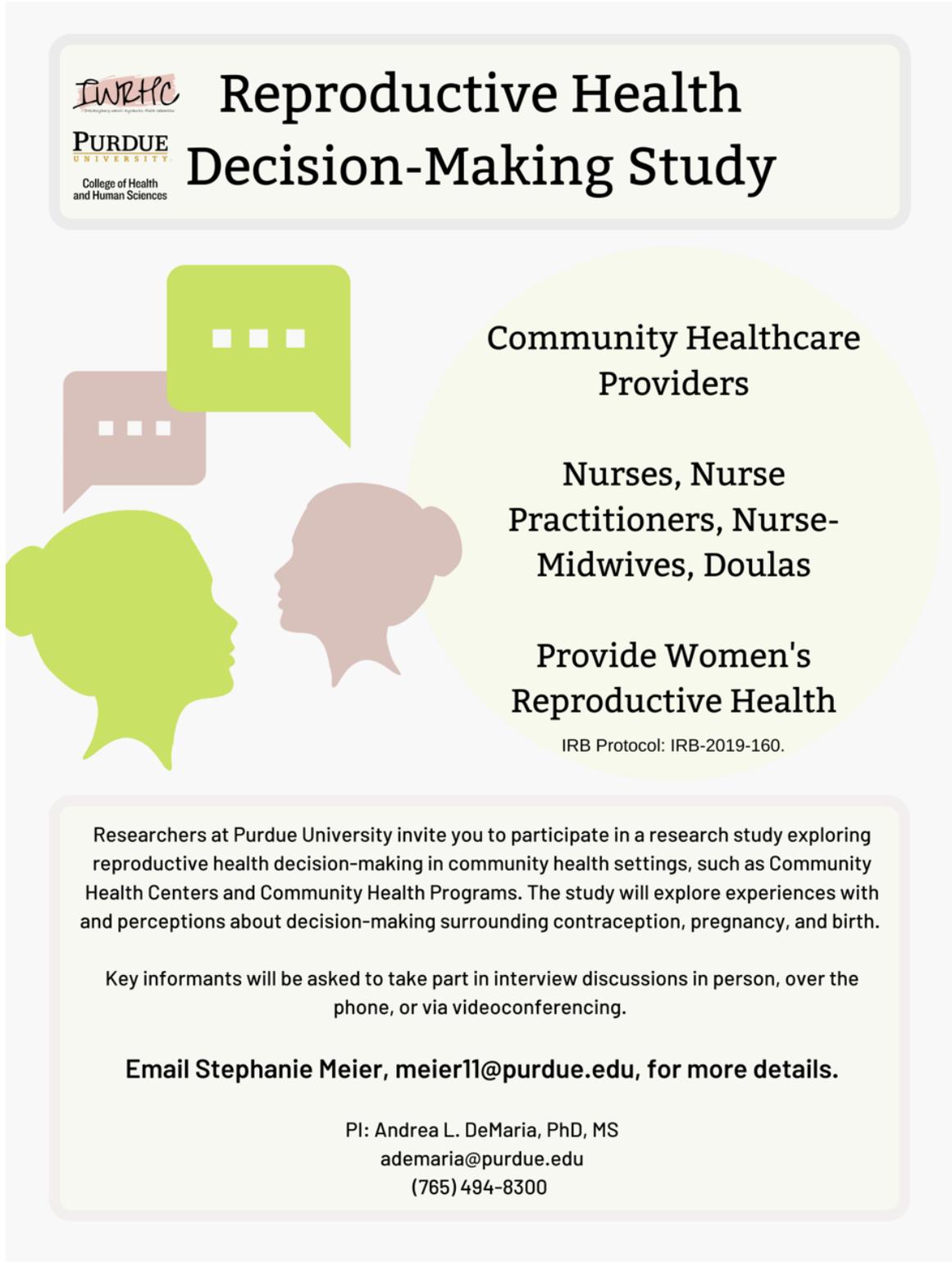
[This study was approved by Purdue University's IRB. Protocol: IRB-2019-160].

Sincerely,

Stephanie Meier, MA
Doctoral Candidate
Purdue University
West Lafayette, Indiana
United States of America
meier11@purdue.edu

APPENDIX G. KEY INFORMANT INTERVIEW FLYER

For in-person and social media distribution



IWRHPC
Improving Women's Reproductive Health

PURDUE UNIVERSITY
College of Health and Human Sciences

Reproductive Health Decision-Making Study

Community Healthcare
Providers

Nurses, Nurse
Practitioners, Nurse-
Midwives, Doulas

Provide Women's
Reproductive Health

IRB Protocol: IRB-2019-160.

Researchers at Purdue University invite you to participate in a research study exploring reproductive health decision-making in community health settings, such as Community Health Centers and Community Health Programs. The study will explore experiences with and perceptions about decision-making surrounding contraception, pregnancy, and birth.

Key informants will be asked to take part in interview discussions in person, over the phone, or via videoconferencing.

Email Stephanie Meier, meier11@purdue.edu, for more details.

PI: Andrea L. DeMaria, PhD, MS
ademaria@purdue.edu
(765) 494-8300

APPENDIX H. KEY INFORMANT CONSENT FORM

Reproductive Health Decision-Making: Extending the Shared Decision-Making Model into the
Community Space

PI: Andrea DeMaria, PhD, MS

Co-I: Stephanie Meier, MA

College of Health and Human Sciences

Purdue University

Key Information

Please take time to review this information carefully. This is a research study. Your participation in this study is voluntary which means that you may choose not to participate at any time without penalty or loss of benefits to which you are otherwise entitled. You may ask questions to the researchers about the study whenever you would like. If you decide to take part in the study, you will be asked to sign this form, be sure you understand what you will do and any possible risks or benefits.

You are invited to participate in a research study conducted by Dr. Andrea DeMaria from Purdue University and her doctoral student, Stephanie Meier.

This study is designed to understand experiences with reproductive healthcare decision-making in community health settings, including what impacts decision-making during your practice. We anticipate 20 participants for this study over three months.

What is the purpose of this study?

The purpose of this study is to get your insights and experiences about reproductive health decision-making and shared decision-making in community healthcare settings. You are being asked to participate because you are a non-physician healthcare provider (e.g., nurse, nurse-practitioner, nurse-midwife) who lives in Indiana, and provides reproductive healthcare in community health settings. We will be completing approximately 20 interviews to understand barriers and facilitators to patient involvement in practice.

What will I do if I choose to be in this study?

As a participant in this research, you will be asked to participate in an in-depth individual interview. This interview will be audio recorded. You will be asked to share your insights and perspectives related to existing reproductive decision-making, patient involvement, and barriers or facilitators to patient involvement. Additionally, you will be asked recommendations about opportunities to engage in patient centered care.

How long will I be in the study?

Participation in this study will require approximately 45-60 minutes.

What are the possible risks or discomforts?

Risks from participating in this study are no greater than you would encounter in daily life. Breach of confidentiality is always a risk with data, but we will take precautions to minimize this risk as described in the confidentiality section

Are there any potential benefits?

Although it is not anticipated that you will benefit directly through your involvement in this study, this research is expected to benefit healthcare providers to better counsel women in their reproductive health decisions in community health settings.

Will information about me and my participation be kept confidential?

Confidentiality cannot be guaranteed when collecting data via individual interview. Additionally, the project's research records may be reviewed by departments at Purdue University responsible for regulatory and research oversight. Despite these potential circumstances, the researchers will still take certain precautions to protect confidentiality such as password-protecting the interview audio-recordings, storing them in a locked location at Purdue University, and destroying the files when the research is complete. For research purposes, we may quote information offered during interview conversations in professional presentations and publications. However, at no time will you be identified by name or job title in any reports or publications resulting from this research.

What are my rights if I take part in this study?

Your participation in this study is voluntary. You may choose not to participate or, if you agree to participate, you can withdraw your participation at any time without penalty or loss of benefits to which you are otherwise entitled. Please be sure to let your research representative know if you wish to discontinue your participation at any time throughout the focus group process.

Who can I contact if I have questions about the study?

If you have questions, comments or concerns about this research project, you can talk to one of the researchers. Please contact Stephanie Meier at meier11@purdue.edu.

If you have questions about your rights while taking part in the study or have concerns about the treatment of research participants, please call the Human Research Protection Program at +1 (765) 494-5942, email (irb@purdue.edu) or write to:

Human Research Protection Program - Purdue University
Ernest C. Young Hall, Room 1032
155 S. Grant St.
West Lafayette, IN 47907-2114

To report anonymously via Purdue's Hotline, see www.purdue.edu/hotline.

Documentation of Informed Consent

I have had the opportunity to read this consent form and have the research study explained. I have had the opportunity to ask questions about the research study, and my questions have been answered. I am prepared to participate in the research study described above, and I agree to having my responses audio recorded. I will be offered a copy of this consent form after I sign it.

Participant's Signature

Date

Participant's Name

Researcher Signature

Date

APPENDIX I. KEY INFORMANT INTERVIEW GUIDE

Key Informant Interview Guide

[INFORMED CONSENT FORMS – one for me, one for participant]

Thank you for coming today to help me with my research project about reproductive healthcare decision-making and patient involvement. I have a consent form for you to review before we get going, which describes the study's purpose and details for your participation. **[Hand participant two consent forms, or email the consent forms if occurring via telephone or Skype].** Let me say just a few words about the process for today. Before we begin our conversation, I want to thank you for talking with me today. I want you to know that your opinions are very important and there are no right or wrong answers. You don't have to answer any questions, you can ask me to skip a question, and you can end the interview at any time. And if you need clarification on any questions, please do not hesitate to ask me to further explain.

I am going to give you an additional minute to review the consent form, and please know that I am willing to answer any questions you may have. **[Allow participant additional minute or two to read].** Do you understand what the study is exploring, and what your role will be? **[Allow participant to respond].** Do you have any questions for me about the study before you sign the consent form? **[Allow participant to respond.] [Participant signs both or provides consent verbally. I sign both or consent verbally. I keep one copy, and participant keeps the other copy.]** Please keep this copy of the consent form for your records. It contains information about the study, including the contact information for our primary investigator. Do you need anything before we get started?

Ok, I am now turning the audio recorder on, so from here forward both of our voices will be captured. Thank you, again, for agreeing to speak to me today. Just to be sure, are you okay with me audio recording today's conversation? Please say 'yes' or 'no.'

[If they say yes, say this]: Great, let's begin. **[If they say no, say this]:** Okay, thank you for your time today. Unfortunately, to be included in the study, you will need to have your interview recorded. Thank you for joining me today.

I am audio recording the session because we I not want to miss any of your comments.

[Begin audio-recording].

[If the interview is occurring via phone or Skype – I will have at least verbal consent] Do you agree to participating in this interview today? [Yes or No], Do you agree to audio-recording? [Yes or No]

Let's start with some general questions about your work in the area of women's health and women's reproductive health.

1. How would you describe your area of expertise?
[Following questions will be adjusted to their specific field/expertise]
2. How would you describe the community you work in?
Probe: What are some positive attributes of the community you work in? Why?
Probe: What are some negative aspects of the community you work in? Why?
Probe: Do you think your patients would identify similar things? Why or why not?
3. Can you walk me through what a typical women's health consultation looks like for you?
Probe: In general, what types of questions do you ask?
Probe: How do you determine the comfort level of your patient? What do you do to increase their comfort during the consultation?
4. What do you think are two or three of the main differences between providing community-based reproductive healthcare services and private or other reproductive healthcare services? Why?
Probe: Can you describe some of the benefits?
Probe: Can you share some of the barriers?

Okay, now I would like to talk more about your experience with decision-making during women's health and women's reproductive health consultations.

5. Please describe your reproductive health decision-making process during a healthcare consultation.
Probe: How do you develop trust with your patients?
Probe: What are some things you are sure to include in these discussions? Why or why not?
Probe: What does a positive decision-making process look like for you?
 Negative?
Probe: How involved do you perceive patients to be or want to be in decision-making? Why or why not?
6. How do you conceptualize sharing decisions with patients or engaging in patient-centered care in your experience?
Probe: How do you demonstrate this in your practice?
Probe: Are there certain skills you feel are most important? What are these? Why?
7. What have you heard about the concept of shared decision-making, if anything?
[if yes] Probe: Where have you heard about this concept?
[if yes] Probe: What do you understand this concept to mean? Why?
[if yes] Probe: What do you think about this concept?
[if yes] Probe: Have you been trained in shared decision-making or something similar? If so, what?

[if no] Probe: Shared decision-making is the process of involving or sharing decisional responsibility between a provider and a patient. The provider invites the patient to participate and collaborate in decision-making and describes the types of treatment available, risks/benefits, side effects, and effectiveness for each of the options. The provider also asks for the patient to share their experiences, needs, goals, and preferences and the preferences are used to guide the final, shared decision.

[if no] Probe: Knowing this, how do you feel about this concept?

8. What are some examples of your experience with shared decision-making?
Probe: What is your role in shared decision-making in community reproductive health settings?
Probe: What do you see or think is the role of the patient in shared decision-making? Why?
Probe: What is a positive experience you have had with shared decision-making? A negative?
9. What do you think impacts shared decision-making during consultations?
Probe: In your experience, what are some facilitators to shared reproductive health decisions in community health settings? Why?
Probe: What are some practical barriers? Why?
Probe: Have patients ever described prior experiences with sharing or not sharing decisions during healthcare consultations to you? What did they share? How did you feel?
10. Do you think healthcare providers are responsible for engaging patients in shared decision-making? Why or why not?
Probe: What do you feel is your responsibility for engaging patients in shared decision-making?
Probe: Do you think other healthcare providers should be responsible for this? Why or why not?
Probe: Do you feel you are more responsible for shared decision-making or another type of healthcare provider or health professional? Please share why or why not.

Okay, now I would like to talk about things that you think impact reproductive health decision-making.

11. What are some things you have found to affect your decision-making process in community health settings? Why?
Probe: If not mentioned:
 - Patient family or friend involvement
 - Patient race/ethnicity
 - Patient age
 - Negative experiences with patient involvement
 - Time

Expertise/training/skills
Patient disagreement/difficulty
Religious/spiritual beliefs

12. Who do you think shared decision-making or patient involvement is appropriate for?
Probe: Everyone? Only some? Why do you think this?
Probe: What are these differences?
13. What do you perceive is the provider's role in discussing sexual violence experience with women in community reproductive healthcare?
Probe: Why do you think this?
Probe: Do you think these experiences play a role in women's reproductive health decision-making? Why or why not?
Probe: Do you think these experiences are important in community health settings, specifically? Why or why not?
14. Have you ever discussed a patient's sexual violence experience during a reproductive health consultation? Why or why not?
Probe: [*if yes*] Please describe what leads to these conversations?
Probe: [*if yes*] How do you broach the subject of sexual violence with women?
Probe: [*if yes*] How do these conversations go? Why do you think so?
Probe: [*if no*] Can you share why you haven't had these conversations?
15. What do you think are the benefits of shared decision-making?
Probe: How do these benefits differ across groups of people?
If not mentioned: By gender, Race, Geographic location, Religion, Health status
16. What are the biggest challenges providers face implementing shared decision-making?
Probe: How can these barriers be addressed?
Probe: What would be your ideal way to implement shared decision-making in community health settings that fit within your daily work-flow and practice?
Probe: What might you need to do that? (e.g., training, conversation kits, patient aids, posters, etc.)
Probe: What would be the most useful or helpful way to receive this information or skill-building?
17. Those are all the questions I have. Can you think of other questions I should have asked, that I did not?
16. Are there any final comments you would like to share?

Thank you very much for your time! I have a short demographic survey for you to complete to make sure we are capturing responses from a diverse range of providers.

APPENDIX J. KEY INFORMANT DEMOGRAPHIC FORM

Demographics

[Separate sheet if in-person, Collected out loud if over the phone]

To help ensure we are gathering insights from a diverse group of participants, I would like to conclude the interview by asking you some demographic questions. These will be kept separate from your interview responses.

1. What is your age? _____ years
2. What is your gender?
3. How many years have you worked in women's health/women's reproductive health? ____ years
4. How many years have you worked in the current community in which you serve? _____ years
5. What organization do you work for? _____
6. What is your professional title? _____
7. What is your specialty? _____
8. What is your religious affiliation? _____
9. What is your race/ethnicity?
 - a. White/Caucasian
 - b. Black/African American
 - c. Latino/a
 - d. Asian
 - e. Native American/Pacific Islander
 - f. Please Specify? _____
10. What is the highest level of education you have attained?
 - a. Undergraduate degree
 - b. Some graduate education
 - c. Graduate degree
11. In what city and county do you work? _____
City County

Thank you for taking the time to talk with me today. Do you know anyone that we should invite to participate in our study?

If Yes, Name: _____

Email/Phone Number: _____

APPENDIX K. QUALITATIVE CODEBOOKS

HCP Interview Codebook

- Women's Reproductive Healthcare Service Provided
 - o Women's wellness care
 - o Birth control services
 - o Pregnancy/prenatal care
 - o Labor/Delivery
 - o Pharmacy services
 - o Other (i.e., STI screenings, preconception, fertility, etc.)
- Healthcare Setting Description
 - o Community work in: How HCPs describe the community or patient population they serve
 - o Community-based services (i.e., community health centers, home health programs, etc.)
 - o Private services, includes private agencies like doula agencies
 - o Provider type: Type of provider HCP is
- Negative Experiences
 - o Interaction: Description of negative interactions that patients have shared, have seen play out
 - o Emotions: Description of emotions associated with negative interaction from patient and HCP perspective
 - o Consequences: Consequences of negative interactions on women's healthcare engagement, HCPs practice
- Traditional SDM Model Constructs
 - o Team Talk
 - o Option Talk
 - o Decision Talk
 - o Active Listening
 - o Preferences: Preference elicitation, including how HCPs describe doing this, if they do it
- SDM in Practice
 - o Asking patients what they want: How do HCPs ask about patient priorities
 - o Asking questions: Specifically related to patient's life and lifestyle to better understand healthcare decisions
 - o Attitude: HCPs emotional descriptions when engaging in SDM
 - o Burn out: Experiences that led to burn out, difficulties related to decision-making
 - o Challenging providers: When patients question or challenge providers and how HCPs react
 - o Change readiness: Determining where patients are in terms of changing or adopting or making a health decision
 - o Checking a box: Doing patient-centered care minimally
 - o EHR: Impact of technology on communication and SDM
 - o Family involvement: Friend and family involvement in decision-making experiences for HCPs

- Follow-up: How do providers follow-up with patients tied to code: Is there anything else?
- Initiating conversations: How and do HCPs initiate decision-making to increase comfort
- Intuitive: How did HCPs come to SDM
- Investigate: How HCPs described understanding patient contexts via open-ended questions
- Judgment: Experiences of judgment of patients, by other HCPs, how they avoid it etc.
- Materials for patients: What sorts of materials did HCPs offer patients
- Training: What types of past or current SDM training, needs
- SDM Knowledge: What, if anything, did HCPs know about SDM
- Navigate: Descriptions of how navigated decision-making
- System level: Organizational perspective on SDM
- Time: Time for SDM

Women Focus Group Codebook

- Healthcare Type
 - Community-based
 - Private: Includes private agencies, like doula agencies
- Visit Reasons
 - Birth control
 - Women's wellness Visit
 - Pregnancy/Birth
- Traditional SDM
 - Team Talk
 - Option Talk
 - Decision Talk
 - Active Listening
 - Preferences: Include how and if HCPs asked about their preferences related to various options
- The Interaction
 - Alone: Feelings of being ignored, dismissed, felt alone
 - Ask doctor: Comfort asking HCP questions
 - Ask questions: Did HCP ask questions about you, your need
 - Asking about you: Related specifically to asking about life that may relate to how women make decisions
 - Customer service: Women described this as critical and sometimes lacking when they engage with HCPs
 - Delay decision-making: Ways women used to delay making a decision, get more time to make a decision
 - Doctor talk: Not understanding what they are being told by HCP
 - Don't have to know everything: Okay if HCPs don't know everything but have real conversation about what is going on with them

- Don't know what you don't know: Made it difficult to think of questions
- Downplay: Downplayed what was going on because of judgment concerns or past experience
- Explaining my experiences: How they accomplished this or if they weren't able to
- Generalizing: Didn't feel listened to about their specific questions and lifestyle, that HCP was just going off what other patients had said
- Initiating conversations: How to do this, preferences for who initiates
- Navigate: How women navigated decision-making
- Not a number: Don't want to feel like another number or patient
- Organic: Want normal conversation, not list of questions
- Person, not dollar sign: Want holistic care
- Rapport: How to increase comfort at beginning
- Stupid questions: Worried about sounding dumb if ask questions
- Time perceptions: How much time spending versus preference
- Value: Want to feel like part of process
- Tools: Ways women suggested would help them feel involved in their care
- Ecological Factors
 - Beyond pregnancy: Birth control for reasons outside of pregnancy
 - Cost: Ability to afford services, part of discussion during appointments
 - Culture: Cultural needs during appointments
 - Doctor gender: Gender concordance and why/why not
 - Family: Family and friend involvement in decision-making
 - Judgment: Perceptions of judgment from HCP for health choices
 - Race: Race impact on decision, healthcare experience
 - Sexual orientation: If sexual orientation was part of decisions, healthcare
- Negative Healthcare Experience
 - Interaction: Description of negative interactions with HCPs
 - Emotions: Emotions resulting from a negative HCP interaction
 - Consequence: What they did as result of negative experience

APPENDIX L. WEB-BASED SURVEY RECRUITMENT EMAIL

Recruitment Email

Subject Line: Reproductive Health Decision-Making Online Survey

Dear [First and Last Name],

Thank you for your interest in participating in an online survey regarding reproductive health decision-making

[Or]

Your name and email were given by someone you know who thought you may be interested in participating in my research study regarding reproductive health decision-making.

As a participant in this research, you will be asked to participate in a 15-minute survey on your own device. You will be asked questions related to sexual and reproductive health decisions, factors influencing those decisions, and community healthcare access. Upon completion of the survey, you will be entered into a drawing to receive 1 of 12 \$20 gift cards.

Learn more about the study here: <https://www.purdue.edu/hhs/csr/womenshealth/>

Please email me back if you are [still] interested in participating. I am happy to schedule a time that would work best for you.

[This study was approved by Purdue University's IRB. Protocol: IRB-2019-160].

Sincerely,

Stephanie Meier, MA
Doctoral Candidate
Purdue University
West Lafayette, Indiana
United States of America
meier11@purdue.edu

APPENDIX M. WEB-BASED SURVEY FLYER

For in-person and social media distribution



The flyer features a dark blue header with the title 'Reproductive Health Decision-Making Study' in white. Below the header, there is a light blue background with a large dark blue circle containing survey details. To the left of the circle are silhouettes of two women's heads in profile, one dark blue and one orange, with speech bubbles above them. The top left corner includes the IWRHC logo and the Purdue University logo. The bottom section of the flyer has a dark blue background with white text providing a description of the study, participation details, and contact information. The bottom-most section has a light blue background with the slogan 'We Want to Hear Your Voice!' in large orange letters.

Reproductive Health Decision-Making Study

IWRHC
INTEGRATING WOMEN'S REPRODUCTIVE HEALTH DECISION-MAKING

PURDUE UNIVERSITY

Women aged 18 - 45
Living in Indiana

Seek women's healthcare in
community health & clinical
settings

Link to Survey:
<http://bit.ly/SDMPurdue>

IRB Protocol: IRB-2019-160.

Researchers at Purdue University invite you to participate in a research study exploring reproductive health decision-making in community health settings, such as Community Health Centers and Community Health Programs. The study will explore experiences with and perceptions about decision-making surrounding contraception, pregnancy, and birth.

Participants will be asked to complete an online survey and will be entered for a chance to win a \$25 gift card.

Email Stephanie Meier, meier11@purdue.edu, for more details!

PI: Andrea L. DeMaria, PhD, MS | ademaria@purdue.edu | (765) 494-8300

We Want to Hear Your Voice!

APPENDIX N. WEB-BASED SURVEY INSTRUMENT

Reproductive Health Decision-Making Survey Reproductive Health Decision-Making: Extending the Shared Decision-Making Model into the Community Space

PI: Andrea DeMaria, PhD, MS

Co-I: Stephanie Meier, MA

College of Health and Human Sciences
Purdue University

What is the purpose of this study?

You are invited to participate in a research study conducted by Dr. Andrea DeMaria from Purdue University and her doctoral student, Stephanie Meier. This research is designed to understand your reproductive health decision-making experiences in community health settings. You are being asked to participate in this study because you are a cis-woman (biological sex and gender identity are female) between the ages of 18 and 45 years who has sought reproductive healthcare, including birth control services, pregnancy/prenatal care, labor and delivery, including in community health settings (community health centers, minute clinics/urgent care, Planned Parenthood, and/or community programs, such as Nurse-Family Partnership, OB Navigator programs, among others) in Indiana.

What will I do if I choose to be in this study?

As a participant in this research, you will be asked to complete a web-based survey. You will be asked questions related to reproductive health decision-making, healthcare experiences, and other factors that impact your reproductive health choices.

How long will I be in the study?

Participation in this study will require about 15 minutes of your time. Please complete the survey only once.

What are the possible risks or discomforts?

Risks from participating in this study are no greater than what you would encounter in daily life. However, if you feel like you are experiencing any psychological or social distress from this survey, please contact your personal healthcare provider.

Are there any potential benefits?

Although it is not anticipated that you will benefit directly through your involvement in this study, this research is expected to benefit women making reproductive healthcare decisions through a better understanding of women's healthcare experiences and needs.

Will I receive payment or other incentives?

Upon completion of your questionnaire, you can choose if you want to be entered into a drawing to win a gift card valued at \$25. Twenty prizes will be awarded, for a 1 in 25 chance to win.

Will information about me and my participation be kept confidential?

The project's research records may be reviewed by departments at Purdue University responsible for regulatory and research oversight. All survey data will be kept on a password-protected, secure computer server. At no time will your name be associated with the answers you provide.

What are my rights if I take part in this study?

Your participation in this study is voluntary. You may choose not to participate or, if you agree to participate, you can withdraw your participation at any time. If you choose to withdraw prior to questionnaire completion, you will not be eligible for a chance to win a gift card.

Who can I contact if I have questions about the study?

If you have questions, comments, or concerns about this research project, you can talk to one of the researchers. Please contact Stephanie Meier at meier11@purdue.edu or (864) 593-6327.

If you have questions about your rights while taking part in the study or have concerns about the treatment of research participants, please call the Human Research Protection Program at 1 (765) 494-5942, email (irb@purdue.edu), or write to:

Human Research Protection Program - Purdue University
Ernest C. Young Hall, Room 1032
155 S. Grant St. West Lafayette, IN 47907-2114

Documentation of Informed Consent:

I have read the consent form. I agree to participate in this research study and certify that I am at least 18 years old.

- Yes
- No

How old are you?

What sex were you assigned at birth, on your original birth certificate?

- Male
- Female

What is your gender identity?

- Cis woman [your gender identity (woman) matches your biological sex (female)]
- Trans woman [you identify as a woman but you were assigned male at birth]
- Trans man [you identify as a man but you were assigned female at birth]

Do you live in the state of Indiana?

- Yes
- No

Have you ever sought OBGYN healthcare?

[OBGYN healthcare includes visiting a healthcare provider (e.g., doctor, nurse-practitioner, nurse-midwife, nurse, physician assistant) for women's health related services, including gynecological services (i.e., birth control and family planning, STI screening, pap tests, women's wellness visits) and obstetric services (i.e., pregnancy/prenatal care, labor/delivery).]

- Yes
- No

Has any of your OBGYN healthcare been in a community health setting (e.g., community health center, Planned Parenthood, public health clinic/department of health clinic, minute clinic/urgent care, college clinic)?

- Yes
- No

Have you ever been pregnant?

- Yes
- No
- Prefer not to answer

How many of your pregnancies resulted in? [Enter the number (e.g., 1, 2, etc.) for each line]

- Live birth: _____
- Still birth: _____
- Abortion: _____
- Miscarriage: _____
- Prefer not to answer

HEALTHCARE ACCESS & GYNECOLOGY

In this section, you will be asked general questions about where you go to receive OBGYN-related healthcare.

1. Where do you typically go to receive OBGYN healthcare?

- Provider's office (e.g., Doctor, Nurse Practitioner, Nurse-Midwife, etc.)
- Urgent care/Minute clinic
- Emergency Room
- Hospital
- Public health clinic/Department of health clinic
- Mobile health clinic
- Community health center
- I do not receive routine healthcare
- Other (Specify) _____
- Prefer not to answer

2. **How would you describe the typical OBGYN healthcare quality you receive?**

	1	2	3	4	5	6	7	8	9	10	
Poor											Exceptional

3. **What is the main type of healthcare provider you see for OBGYN healthcare?**

- Medical Doctor
- Nurse Practitioner
- Physician-Assistant
- Nurse-Midwife
- Nurse (RN)
- Public Health Nurse
- Community Health Worker
- Paramedic
- Other (Specify) _____
- Prefer not to answer

4. **How many OBGYN appointments have you had in the past 12 months?**

- Number of appointments (e.g., 1,2, etc.)

- I have not had an OBGYN appointment in the last 12 months
- Prefer not to answer

5. **When was your last OBGYN appointment if it was not in the past 12 months?**
(Number of years since last appointment)

6. **Have you ever had an OBGYN experience you considered to be bad or negative?**

[A negative OBGYN experience is your perception that the interaction and communication with OBGYN healthcare providers was negative. This IS NOT related to receiving bad news or an upsetting diagnosis from a healthcare provider.]

- Yes
- No
- Prefer not to answer

7. **What was the purpose of the visit where you had the bad or negative OBGYN experience?** [Mark all that apply]

[A negative OBGYN experience is your perception that the interaction and communication with OBGYN healthcare providers was negative. This IS NOT related to receiving bad news or an upsetting diagnosis from a healthcare provider.]

- Recommendation/referral from another healthcare provider
- Annual exam
- Birth control services

- Pregnancy/fertility consultation
- Prenatal care
- Pap test
- STD/HIV appointment
- Women's health concern
- Labor/delivery
- Other (Specify) _____
- Prefer not to answer

8. For each of the following statements, please indicate how accurate you feel the statements describe why your OBGYN experience was negative.

[A negative OBGYN experience is your perception that the interaction and communication with OBGYN healthcare providers was negative. This IS NOT related to receiving bad news or an upsetting diagnosis from a healthcare provider.]

I didn't feel like there was enough time	Not accurate at all	Slightly accurate	Moderately accurate	Very accurate	Extremely accurate
I felt pressured to make a certain decision	Not accurate at all	Slightly accurate	Moderately accurate	Very accurate	Extremely accurate
I didn't feel listened to	Not accurate at all	Slightly accurate	Moderately accurate	Very accurate	Extremely accurate
I didn't feel like I shared the information about my health that I needed to	Not accurate at all	Slightly accurate	Moderately accurate	Very accurate	Extremely accurate
I didn't get enough information from my healthcare provider about my concern	Not accurate at all	Slightly accurate	Moderately accurate	Very accurate	Extremely accurate
I didn't understand the information the healthcare provider was giving me	Not accurate at all	Slightly accurate	Moderately accurate	Very accurate	Extremely accurate

I didn't feel like I could ask questions	Not accurate at all	Slightly accurate	Moderately accurate	Very accurate	Extremely accurate
I didn't like how the healthcare provider acted toward me	Not accurate at all	Slightly accurate	Moderately accurate	Very accurate	Extremely accurate
I wasn't asked about what was important to me	Not accurate at all	Slightly accurate	Moderately accurate	Very accurate	Extremely accurate
I didn't feel like my concern was taken seriously	Not accurate at all	Slightly accurate	Moderately accurate	Very accurate	Extremely accurate
I wanted to talk about other options but we didn't	Not accurate at all	Slightly accurate	Moderately accurate	Very accurate	Extremely accurate
I felt judged	Not accurate at all	Slightly accurate	Moderately accurate	Very accurate	Extremely accurate
I experienced discrimination	Not accurate at all	Slightly accurate	Moderately accurate	Very accurate	Extremely accurate
I wanted to talk to someone close to me about my choices but didn't get the chance	Not accurate at all	Slightly accurate	Moderately accurate	Very accurate	Extremely accurate

9. How well do the following statements describe your emotions related to your negative OBGYN experience?

[A negative OBGYN experience is your perception that the interaction and communication with OBGYN healthcare providers was negative. This IS NOT related to receiving bad news or an upsetting diagnosis from a healthcare provider.]

I felt uncomfortable	Not well at all	Slightly well	Moderately well	Very well	Extremely well
I felt confused	Not well at all	Slightly well	Moderately well	Very well	Extremely well

I felt dismissed	Not well at all	Slightly well	Moderately well	Very well	Extremely well
I felt sad	Not well at all	Slightly well	Moderately well	Very well	Extremely well
I felt angry	Not well at all	Slightly well	Moderately well	Very well	Extremely well
I felt defensive	Not well at all	Slightly well	Moderately well	Very well	Extremely well

10. How accurately do each of the following statements describe what you did following the negative OBGYN experience?

I stopped sharing information about myself	Not accurate at all	Slightly accurate	Moderately accurate	Very accurate	Extremely accurate
I stood up more strongly for myself and my choices	Not accurate at all	Slightly accurate	Moderately accurate	Very accurate	Extremely accurate
I did not follow my doctor's advice	Not accurate at all	Slightly accurate	Moderately accurate	Very accurate	Extremely accurate
I changed providers	Not accurate at all	Slightly accurate	Moderately accurate	Very accurate	Extremely accurate
I looked into changing providers	Not accurate at all	Slightly accurate	Moderately accurate	Very accurate	Extremely accurate
I stayed with my same provider but trusted them less	Not accurate at all	Slightly accurate	Moderately accurate	Very accurate	Extremely accurate
I talked about the negative experience with someone close to me	Not accurate at all	Slightly accurate	Moderately accurate	Very accurate	Extremely accurate
I stopped getting healthcare as often as I needed to	Not accurate at all	Slightly accurate	Moderately accurate	Very accurate	Extremely accurate

I stopped getting healthcare entirely	Not accurate at all	Slightly accurate	Moderately accurate	Very accurate	Extremely accurate
The negative experience did not affect me	Not accurate at all	Slightly accurate	Moderately accurate	Very accurate	Extremely accurate

MODIFIED SHARED DECISION-MAKING SCALE: SDM-Q9

11. Have you sought birth control services from a healthcare provider?

- Yes
- No

12. In this section you will read nine statements related to the decision-making in your appointment listed below. For each statement please indicate how much you agree or disagree. When thinking about your most recent birth control appointment:

My healthcare provider made clear that a decision needed to be made.	Completely Disagree	Strongly Disagree	Somewhat Disagree	Somewhat Agree	Strongly Agree	Completely Agree
My healthcare provider wanted to know exactly how I want to be involved in making the decision.	Completely Disagree	Strongly Disagree	Somewhat Disagree	Somewhat Agree	Strongly Agree	Completely Agree
My healthcare provider told me that there are different options for birth control.	Completely Disagree	Strongly Disagree	Somewhat Disagree	Somewhat Agree	Strongly Agree	Completely Agree
My healthcare provider precisely explained the advantages and disadvantages of the birth control options.	Completely Disagree	Strongly Disagree	Somewhat Disagree	Somewhat Agree	Strongly Agree	Completely Agree
My healthcare provider helped me understand all the information.	Completely Disagree	Strongly Disagree	Somewhat Disagree	Somewhat Agree	Strongly Agree	Completely Agree
My healthcare provider asked me	Completely Disagree	Strongly Disagree	Somewhat Disagree	Somewhat Agree	Strongly Agree	Completely Agree

which birth control option I prefer.						
My healthcare provider and I thoroughly weighed the different birth control options.	Completely Disagree	Strongly Disagree	Somewhat Disagree	Somewhat Agree	Strongly Agree	Completely Agree
My healthcare provider and I selected a birth control option together.	Completely Disagree	Strongly Disagree	Somewhat Disagree	Somewhat Agree	Strongly Agree	Completely Agree
My healthcare provider and I reached an agreement on how to proceed.	Completely Disagree	Strongly Disagree	Somewhat Disagree	Somewhat Agree	Strongly Agree	Completely Agree

13. Have you sought pregnancy/prenatal healthcare?

- Yes
- No

14. In this section you will read nine statements related to the decision-making in your appointment listed below. For each statement please indicate how much you agree or disagree. When thinking about your most recent pregnancy/prenatal healthcare appointment:

My healthcare provider made clear that a decision needed to be made.	Completely Disagree	Strongly Disagree	Somewhat Disagree	Somewhat Agree	Strongly Agree	Completely Agree
My healthcare provider wanted to know exactly how I want to be involved in making the decision.	Completely Disagree	Strongly Disagree	Somewhat Disagree	Somewhat Agree	Strongly Agree	Completely Agree
My healthcare provider told me that there are different pregnancy options available to me.	Completely Disagree	Strongly Disagree	Somewhat Disagree	Somewhat Agree	Strongly Agree	Completely Agree

My healthcare provider precisely explained the advantages and disadvantages of various pregnancy options, including exams, birth plans, etc.	Completely Disagree	Strongly Disagree	Somewhat Disagree	Somewhat Agree	Strongly Agree	Completely Agree
My healthcare provider helped me understand all the information.	Completely Disagree	Strongly Disagree	Somewhat Disagree	Somewhat Agree	Strongly Agree	Completely Agree
My healthcare provider asked me which options I preferred.	Completely Disagree	Strongly Disagree	Somewhat Disagree	Somewhat Agree	Strongly Agree	Completely Agree
My healthcare provider and I thoroughly weighed the different pregnancy options available to me.	Completely Disagree	Strongly Disagree	Somewhat Disagree	Somewhat Agree	Strongly Agree	Completely Agree
My healthcare provider and I selected pregnancy options (including exams I needed, tests, birth plans, etc.) together.	Completely Disagree	Strongly Disagree	Somewhat Disagree	Somewhat Agree	Strongly Agree	Completely Agree
My healthcare provider and I reached an agreement on how to proceed.	Completely Disagree	Strongly Disagree	Somewhat Disagree	Somewhat Agree	Strongly Agree	Completely Agree

SOCIAL SUPPORT: Modified from the MOS Short Form

15. Who do you usually bring to OBGYN appointments with you?

- Partner/Spouse
- Mother/Grandmother/Aunt
- Sister/Cousin
- Friend
- I do not bring anyone to OBGYN appointments with me
- Other (Specify) _____
- Prefer not to answer

People sometimes look to others for companionship, assistance, or other types of support. How often is each of the following kinds of support available to you if you need it?

[Choose the response that best fits each statement]

16. Someone to turn to for suggestions about how to deal with a personal problem

- None of the time
- A little of the time
- Some of the time
- Most of the time
- All of the time

17. Someone who understands your problems

- None of the time
- A little of the time
- Some of the time
- Most of the time
- All of the time

18. Someone to help you if you were confined to bed

- None of the time
- A little of the time
- Some of the time
- Most of the time
- All of the time

19. Someone to take you to the doctor if you needed it

- None of the time
- A little of the time
- Some of the time
- Most of the time
- All of the time

20. Someone to stand up for your OBGYN healthcare decisions during an appointment if you needed it

- None of the time
- A little of the time
- Some of the time
- Most of the time
- All of the time

DECISION-MAKING INFLUENCES

In this section, you will be asked about factors that influence your OBGYN health decision-making.

21. Please indicate how influential the following are on your OBGYN decisions.

My family and friends' opinions	Not influential at all	Slightly influential	Moderately influential	Very influential	Extremely influential
My partner's opinions	Not influential at all	Slightly influential	Moderately influential	Very influential	Extremely influential
Other people's experiences	Not influential at all	Slightly influential	Moderately influential	Very influential	Extremely influential
My race/ethnicity	Not influential at all	Slightly influential	Moderately influential	Very influential	Extremely influential
My sexual orientation	Not influential at all	Slightly influential	Moderately influential	Very influential	Extremely influential
My religion/spirituality	Not influential at all	Slightly influential	Moderately influential	Very influential	Extremely influential
My level of trust in my healthcare provider)	Not influential at all	Slightly influential	Moderately influential	Very influential	Extremely influential
The compassion of my healthcare provider	Not influential at all	Slightly influential	Moderately influential	Very influential	Extremely influential
Feeling listened to by my healthcare provider during appointments	Not influential at all	Slightly influential	Moderately influential	Very influential	Extremely influential
My previous healthcare experiences	Not influential at all	Slightly influential	Moderately influential	Very influential	Extremely influential
Information I find on the Internet	Not influential at all	Slightly influential	Moderately influential	Very influential	Extremely influential

My ability to access services	Not influential at all	Slightly influential	Moderately influential	Very influential	Extremely influential
My ability to pay for services	Not influential at all	Slightly influential	Moderately influential	Very influential	Extremely influential
The healthcare provider's office/overall environment	Not influential at all	Slightly influential	Moderately influential	Very influential	Extremely influential

SEXUAL VIOLENCE & TRAUMA

This section includes questions about healthcare screening for sexual violence and past experiences with sexual violence and trauma. These items help us to understand your women's health experiences as a whole.

Sexual violence can include being touched sexually without your consent, forced or pressured to have sex when you didn't want to, or feeling like you couldn't say no to sexual activities. This can occur in childhood, adolescence, or adulthood; is common; and can impact your health.

22. Has your OBGYN provider ever asked you a question about sexual violence during a health history screening?

- Yes
- No
- No applicable, I have not been screened for sexual violence experience
- Unsure
- Prefer not to answer

23. Have you and a healthcare provider ever talked in-depth about sexual violence experience during an OBGYN appointment?

- Yes
- No
- Not applicable, I have not had a sexual violence experience
- Prefer not to answer
- Unsure

24. How comfortable did you feel being asked about sexual violence by the healthcare provider?

	1	2	3	4	5	6	7	8	9	10	
Not comfortable at all											Very comfortable

25. **Would you have changed the way you were asked about sexual violence?**
- Yes
 - No
 - Unsure
 - Prefer not to answer
26. **Even if you have not had a sexual violence experience, would being asked about sexual violence during OBGYN visits be helpful?**
- Yes
 - No
 - Unsure
 - Prefer not to answer
27. **Have you experienced any of the following?** [Mark all that apply]
- Someone exposing their sex organs to you when you did not want it
 - Someone threatening to have sex with you when you did not want it
 - Someone touching your sex organs when you did not want it
 - Someone making you touch their sex organs when you did not want it
 - Someone forcing you to have sex when you did not want it
 - Other unwanted sexual experiences
(Specify) _____
 - Prefer not to answer
28. **Has sexual violence experience(s) impacted your OBGYN decisions?**
- Yes
 - No
 - Unsure
 - Prefer not to answer
29. **What areas of your OBGYN healthcare did sexual violence experience(s) affect?**
[Mark all that apply]
- Whether or not to go to a healthcare provider
 - Type of healthcare provider you see
 - Type of birth control selected
 - Whether or not to receive a pap test/pelvic exam
 - Your pregnancy/prenatal care
 - Decisions about labor and delivery
 - Whether or not to breastfeed
 - Other (Specify) _____
 - Prefer not to answer
30. **What area do you feel sexual violence experience(s) affected most strongly?**

- Whether or not to go to a healthcare provider
- Type of healthcare provider you see
- Type of birth control selected
- Whether or not to receive a pap test/pelvic exam
- Your pregnancy/prenatal care
- Decisions about labor and delivery
- Whether or not to breastfeed
- Other (Specify) _____
- Prefer not to answer

31. How strongly would you say your sexual violence experience affected this area of women's health?

	1	2	3	4	5	6	7	8	9	10	
Not very strong at all											Very strong

DEMOGRAPHICS

In this section you will be asked for information about you, including your age, race/ethnicity, pregnancy history, and beyond. These items help to understand who is taking the survey.

32. What is your ethnicity?

- Hispanic or Latina/x
- Not Hispanic or Latina/x
- Prefer not to answer

33. What is your race? [Mark all that apply]

- American Indian or Alaska Native
- Asian
- Black or African American
- Native Hawaiian or Other Pacific Islander
- White or Caucasian
- Other (Specify) _____
- Prefer not to answer

34. What is your sexual orientation?

- Heterosexual/Straight
- Gay/Lesbian
- Bisexual
- Pansexual
- Asexual

- Queer
- Questioning
- Other (Specify) _____
- Prefer not to answer

35. What is the highest degree or level of school you have completed?

- Less than high school
- Some high school, no diploma
- High school diploma or GED
- Some college
- Currently in college
- 2-year degree (associates degree or trade certification)
- 4-year college degree
- Master's degree (e.g., MS, MA, MFA, MBA)
- Doctoral degree (e.g., MD, JD, PhD)
- Other (Specify) _____
- Prefer not to answer

36. What is your employment status?

- Employed full time (40+ hours a week)
- Employed part-time (less than 40 hours a week)
- Not employed outside of the home
- Unemployed
- Student
- Other (Specify) _____
- Prefer not to answer

37. What is the combined household income of all working persons living in your home?

- Below \$5,000
- \$5,000 - \$9,999
- \$10,000-\$14,999
- \$15,000-\$19,999
- \$20,000 - \$49,999
- \$50,000 - \$99,999
- \$100,000 or more
- Prefer not to answer

38. How many people permanently live in your household?

[Mark all that apply and enter in the corresponding number]

- Number of children under the age of 18

Number of adults aged 18 or older

Nobody, I live alone

Prefer not to answer

39. What type of insurance do you currently have?

Private

Medicaid

Medicare

Military

Other (Specify) _____

I do not currently have health insurance

Prefer not to answer

40. What is your relationship status?

Single

I have sexual partner(s) but I am not in a relationship

In a relationship and not living with partner

Living with partner

Married/civil union

Divorced

Other (Specify) _____

Prefer not to answer

41. How often do you attend church or other religious meetings?

Never

Once a year or less

A few times a year

A few times a month

Once a week

More than once a week

Prefer not to answer

42. My religious beliefs are what really lie behind my whole approach to life

Definitely not true

Tends to not be true

Unsure

Tends to be true

Definitely true of me

Prefer not to answer

43. How would you describe the location where you live in Indiana?

Rural

- Urban
- Suburban
- Prefer not to answer

44. What form(s) of birth control did you use the last time you had sex (penis in vagina)?

- Birth control pill
- IUD (intrauterine device) (i.e. Mirena, Kyleena, Liletta, Skyla, Paragard)
- Implant (Implanon, Nexplanon)
- Patch
- Ring (NuvaRing)
- Shot (Depo Provera)
- Condoms
- Withdrawal (pull out method)
- Other (Specify)_____
- I did not use a birth control method the last time I had sex
- I am not currently having sex
- I have never had sex
- Prefer not to answer

45. What is your primary birth control method?

Birth control pill

- IUD (intrauterine device) (i.e. Mirena, Kyleena, Liletta, Skyla, Paragard)
- Implant (Implanon, Nexplanon)
- Patch
- Ring (NuvaRing)
- Shot (Depo Provera)
- Condoms
- Withdrawal (pull out method)
- Other (Specify)_____
- I am not currently using a birth control method
- Prefer not to answer

THANK YOU FOR COMPLETING OUR SURVEY!

THANK YOU FOR COMPLETING THIS SURVEY!

Should you have further questions about the research study, please email Stephanie Meier at meier11@purdue.edu.

If you feel like you are experiencing any psychological or social distress from this survey, please contact your personal healthcare provider.

Would you like to provide your contact information to be entered into a drawing to win a \$25 gift card?

(All information you provide will be kept separate from your survey responses)

Yes

No

APPENDIX O. WEB-BASED INCENTIVE SURVEY INSTRUMENT

Women's Health Decision Study Incentive Survey

Start of Block: Default Question Block

Please click the arrow below so that your response can be recorded.

If you clicked 'yes' to the question above, you will be directed to a separate survey to enter your personal contact information. If you clicked 'no', your survey participation will be concluded.

Please enter your information below to be entered into the drawing. This information will not be associated with your survey responses.

First and Last Name: _____

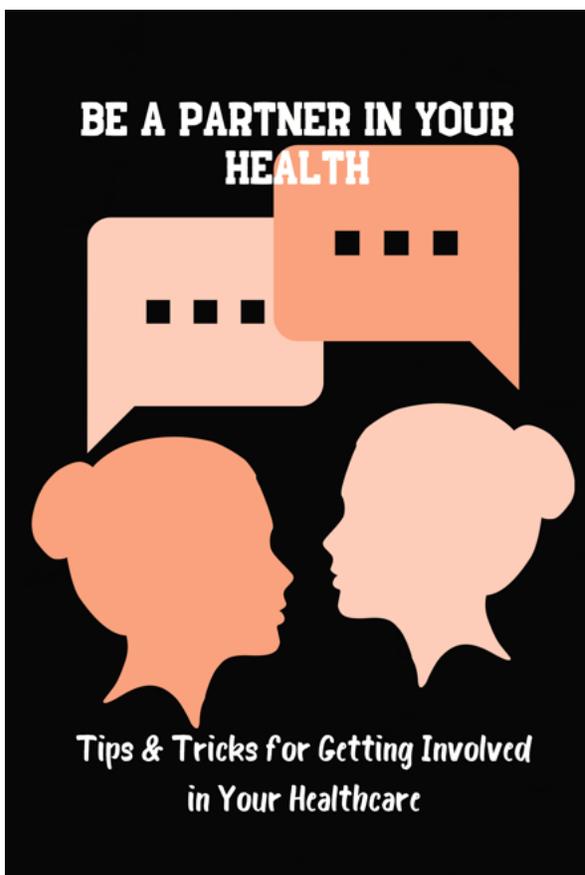
Email Address: _____

Home Address: _____

Phone number (xxx-xxx-xxxx): _____

Please click the arrow below so that your response can be recorded

APPENDIX P. WOMEN'S SDM BOOKLET



WHAT DOES IT MEAN TO BE A PARTNER IN MY HEALTH?

Where you and your healthcare provider work together to ask questions, share information, listen, and decide on what options works best for you. It is a joint process that values your priorities and concerns, while making sure you receive the information you need to make a decision.

What is shared decision-making?

Why is being a part of your healthcare important?

Feeling overlooked or lost during a healthcare appointment can make it hard to share your opinions, priorities, or concerns.

BUT... sharing these are important because they can help your healthcare provider personalize your care to you!

To give you some helpful tools to begin, or continue being, a partner in your healthcare experiences and decisions. This book is the product of hours of research with women and healthcare providers living in Indiana so women can feel **EMPOWERED** in their health decisions.

What is the purpose of this booklet?





I realized you have to take control of your health and part of taking control of your health is engaging with doctors and systems



HOW HAVE WOMEN BECOME PARTNERS IN THEIR HEALTHCARE?

"I'm pregnant and I just take the form and write down all the things that I asked or that they mentioned."

"I always make sure to have notes in my phone, because I forget everything and, at the end, I'll be like everything's fine with this medication even when it's not. And I have to wait to get my questions answered."



LESSON LEARNED

Remembering questions you have, especially when making decisions about pregnancy or women's health, can be hard.

Writing down notes before or during an appointment can help you remember questions, information, and what's important to you.



**LESSON
LEARNED**

Sometimes when you make a health decision you need more time to think about if the options match your daily life.

If you feel like you need more time or are worried that the provider won't like your decision, it's okay to take more time. You can say you'll call back with your decision, get another opinion, or look up information on your own.

"I feel like I'm slower to act now if I can, let me read a little bit about this so I can feel like I'm making an informed decision as a healthcare consumer."

"Just to be able to say like, every step along this road, you can choose to proceed or you can choose to not proceed."

"I need to go home and decompress and think about it. Not that I find my experience at my OBGYN to be tense, but I just need some space to think about it, just make a decision for myself."

WOMEN'S
WORDS



"I think it's important, especially when you're dealing with more serious issues, to have someone there to help advocate for you, and to have someone who knows you well enough to advocate for you. And to ask questions you didn't think of."

"I'm going to have a Black doula because I was really affected by the recent conversations around how women are treated when they have a baby by doctors."

WOMEN'S
WORDS



**LESSON
LEARNED**

If you feel stressed or worried about a health problem or decision, it can be hard to follow everything a provider is saying.

Taking someone to an appointment with you can help make sure you are listened to and your questions are answered. It can be a family member, friend, or health professional, like a doula.

WONDERING WHAT HEALTHCARE PROVIDERS HAVE SAID?

LESSON LEARNED

Your experiences and priorities matter. Most women aren't sure if it's okay or don't know that they can share these with their providers.

If a provider doesn't ask what your priority or goal is, intentionally let them know. This way, you have shared what was most important to you.

"I don't necessarily even think that's my priority, I just want them to be able to get that from what I'm saying. If doctors are unclear then maybe say, "It sounds like this is important to you. Can you clarify what you mean?"

"Asking about your experience in the first place would be a great place to start. I feel like I'm never asked what does it feel like to you, or how does it impact your daily life? Which seems like a good question a doctor can ask."

WOMEN'S WORDS



"So I'd say my approach is to actively engage patients in the conversation and try to get their viewpoint. I don't ever approach patients very authoritative. I provide them with as much information as possible and then have them be an active participant in that healthcare decision."

-Clinical Pharmacist

PROVIDER'S POINT OF VIEW

Along with women believing partnership in healthcare was important, healthcare providers also valued women participating in healthcare.

TRY THIS STRATEGY

When you feel nervous about speaking up, remember that lots of providers want women to be involved in health choices.



Sometimes being a partner in your healthcare means not always agreeing about healthcare choices, which can be hard.

TRY THIS STRATEGY

Expressing your reasons for wanting a different choice is important, and reminds providers that your health priorities matter. If it feels tense, you can always take more time to think through your decision.

"Sometimes they'll have all the information and you just disagree. But that's fine. Because that means that patients are making an active decision about what they want to happen with their healthcare. It would be different sometimes than what I would want to happen with my healthcare, and that's okay."

-Nurse Practitioner

PROVIDER'S POINT OF VIEW



"What's your decision here? What are your options? Let's go through each option, and how you feel about each one then explore it and talk out it."

-Nurse

"You're asking a patient 'What do you think? What do you want to do today? What's your goal?' I'm not the boss. We are partners."

-Clinical Pharmacist

PROVIDER'S POINT OF VIEW

Many providers want to ask questions to partner with patients.

TRY THIS STRATEGY

If a provider asks, share what's important to you. If you aren't asked but want to share, use these questions as a guide to ask about options and share priorities.



- **Ask about other options that are available to you.** Sometimes appointments move quickly, but it is important to talk to your provider about all the choices you have.
- **Know that you are allowed to say no.** If at any point during your appointment you are uncomfortable or do not like the way the provider is handling your appointment, you are absolutely allowed to say something, and saying no is okay.
- **Bring someone with you** who can ask questions, listen to information, and stand up for you. This can be a friend, family member, or health professional.
- **If your experience is negative, notify the patient care coordinator or a provider you trust.** You can also look for new providers. Online provider bios can be a great tool to find out more about them.



Even providers understand healthcare experiences may not always be great.

TRY THIS STRATEGY

If you feel like you are not listened to, take a minute, reach out to another provider you trust, look for a new provider if possible, or find ways to get your priorities met by minimizing contact if safe and healthy to do so.

"I tell women to say 'Let's just wait on that, I want to talk to the midwife, or I want five minutes to think about that' instead of them feeling like they have to consent at the time it's presented."

-Certified Nurse Midwife

"Stay home as long as possible if you're in labor if they're gonna do all these things you don't want. So that way you can minimize your exposure to the facility that is not going to do things the way you want to do them. Or if you only like one doctor, schedule an induction when that doctor is on call."

-Doula

PROVIDER'S POINT OF VIEW



HERE'S WHAT YOU CAN DO IN YOUR NEXT APPOINTMENT...

- **Write down questions you have before your appointment.** This way you won't worry about forgetting things.
- **Take notes in your appointment.** We provided note pages for you at the end of this booklet.
- **Even if a healthcare provider doesn't bring it up, don't be nervous about bringing up other health-related concerns.**
- **Share your priorities and goals related to your health concerns with your provider** even if they don't always ask.
- **Ask questions.** It can be nerve-racking to walk into an appointment and then ask for more information. But know that you can, and it only makes you more informed.



appt. notes



appt. notes

WANT TO KNOW THE WOMEN BEHIND THE PROJECT?

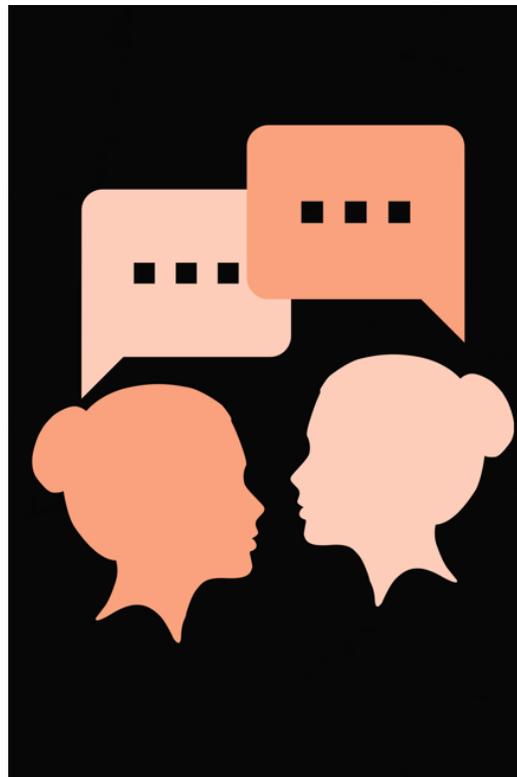
Natalie Murdock received her Bachelor of Science degree in Public Health. She is currently pursuing her Master's in Public Health in a Family and Community Health track. Her desire to continue to advocate, support, and empower women was stimulated through this project.

Natalie Murdock

Stephanie Meier

Stephanie Meier received her PhD from Purdue University and holds a Masters in Communication. The goal of all of her work is to provide action-oriented ways for women and healthcare providers to work together when making healthcare decisions, where women's voices are listened to and respected. For more details about the project, email Stephanie at meier11@purdue.edu.

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