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Shared Decision Making for Primary Care Patients with Medical Complexities

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Shared Decision Making for Primary Care Patients with Medical Complexities

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Introduction

Fragmented healthcare among adult primary care patients with medical complexities, including those with multiple comorbidities or a singular complex health condition can result in poor health outcomes and low patient satisfaction. Singular health condition has been defined as, conditions that are life-threatening (i.e., cancer, stroke, HIV/AIDs); conditions that lead to significant disability with or without being considered life threatening; (i.e., stroke, spinal cord injury, global developmental delay, and congenital malformations); conditions that cause significant disruption in daily activities due to pain or other complications (i.e., sickle cell disease, migraine, and arthritis); conditions that lead to significant time or effort from support systems over a substantial period of time (i.e., mobility disorders, blindness, para or quadriplegia, and Down's syndrome); and conditions that require frequent, long term monitoring or are associated with severe complications or poor outcomes, (i.e., poorly controlled hypertension, poorly controlled diabetes, poorly controlled mental health disorders, and kidney disease or failure) (Nicolaus et al., 2022). In addition, socio-economic status, demographics, environment, and medical decision-making ability also contribute to a patient's medical complexity (Nicolaus et al., 2022).

Fragmented healthcare occurs when lack of coordinated, and/or interrelated efforts are provided to an individual due to the systemic, asymmetrical, and opposing points of view or objectives. Healthcare fragmentation negatively affects patient outcomes as well as the quality and cost of healthcare delivery (Enthoven, 2009). A lack of patient understanding of treatment options, a lack of essential communication regarding patient values and preferences, and perceived provider time constraints increase medical complexity, thus yielding poor health outcomes and low patient satisfaction. Therefore, the purpose of this clinical project was to

implement and assess the effect of a shared decision-making model in a primary care setting to engage patients who have medical complexities in their care and treatment decisions.

Background

Patients with medical complexities often receive care from multiple providers, across several settings, and there are many risks for fractioning of care, miscommunication, and misunderstanding. Shared decision-making in healthcare is a patient-centered model in which patients and those providing care collaborate on decisions such as diagnostics tests, treatments, medication selection, and care planning. Shared decision-making, at the primary care level, places the patient at the center of care through education, involvement in decision making, collaboration with specialists, and care planning that spans all care areas. The benefits of shared decision making include increased patient participation, increased understanding of risks and benefits, increased patient autonomy, better understanding of shared goals on the part of both the patient and provider, and facilitation of next steps in the care process (Office of the National Coordinator for Health Information Technology [ONC], 2021).

Review of Literature

This literature review was conducted using the search terms “shared decision-making”, “primary care”, “nurse practitioner”, “medical complexities”, “oncology”, and “shared care”. The search parameters included English language, peer reviewed, evidence based, full text, and research articles. The databases PubMed and CINAHL were used through the University of Massachusetts Amherst library. Articles were chosen based on 1) the date of publication (articles prior to 2011 were excluded), 2) relevance to the purpose of the study, 3) included a primary care setting, and 4) included a shared decision making model or shared care model for patients with medical complexities. The search yielded a total of 258 articles of which 15 were chosen based

on the criteria in areas of date of publication, purpose, setting and use of the shared decision making (care) model. A matrix was developed to organize the sources considering purpose, methods, results, and discussion and commentary on the content of the articles in relation to the proposed literature review.

Findings from the Literature Review

All 15 articles chosen related to patients with medical complexities, six with specific medical conditions (such as cancer and chronic kidney disease), while nine used the generic term to include patients with one or more chronic medical conditions that necessitated complex decision making. The term “shared decision-making” was specifically found within the text of each article. Approaches to planning, implementation, data collection, and evaluation varied across the articles chosen, as did the depth to which the overall topic of shared decision-making was addressed. Seven of the articles targeted one key component of shared decision-making such as the role of implementing electronic health records (Harry et al., 2020; Sada et al., 2011), the role of shared decision-making in chronic disease prevention (Manca et al., 2015), and the use of self-management tools, which included a shared decision-making tool, (Kennedy et al., 2014). Eight articles took a broader approach to address the overall role of primary care in shared decision-making for those with cancer (Jain et al., 2019; Lawn et al., 2017), chronic kidney disease (Walker et al., 2013) and those with multiple comorbidities (Ng et al., 2019).

Research methods varied across the studies including cluster-randomized control trials (Harry et al., 2020; Jain et al., 2019), literature reviews (Morgan et al., 2015), qualitative study (Kennedy et al., 2014), mixed method approaches (McDonnell et al., 2018), case summaries (Ng et al., 2018), and non-comparative intervention design (Noteboom et al., 2019). Six studies focused on individual participants such as patients, caregivers, and healthcare professionals with

sample sizes ranging from 21 to 40 (Jain et al., 2019; Kennedy et al., 2014; Lawn et al., 2017; McDonnell et al., 2018; Ng et al., 2019; Poitras et al., 2020). Nine studies focused on healthcare settings ranging from sole practices to individual clinics (Harry et al., 2020; Lee & Ng, 2021; Manca et al., 2015; Misra et al., 2019; Morgan et al., 2015; Noteboom et al., 2019; Pullon et al., 2016; Sada et al., 2011; Walker et al., 2013). The studies were inclusive of urban and rural areas.

Optimizing care was a common theme seen throughout all the articles and was addressed in varying ways. Specifically, screening and prevention can be enhanced using shared decision-making by implementing Electronic Health Record (EHR) tools that track patient preferences and values in order to provide individualized education and collaboration for cancer screenings in primary care provided for rural locations (Harry et al., 2020). Improving existing tools to better target the intended demographic and to improve outcomes in areas of prevention and risk was also shown to optimize outcomes for patients (Manca et al., 2015).

For those patients that have a medical history of childhood cancer, the role of the primary care provider is integral in long term management of anxiety and depression (Jain et al., 2019). Systems such as the Whole System Informing Self-Management (WISE) (Kennedy et al., 2014) and the Building on Existing Tools to Improve Chronic Disease Prevention and Screening in Family Practice (BETTER) (Manca et al., 2015) were evaluated for their usefulness in shared decision-making in primary care. Following meetings by individual topic teams the improvements from the BETTER to the BETTER 2 tools were determined to address previous gaps in areas of family history assessment, recruitment of local resources, understanding risk factor, and disease prevalence at the local level (Manca et al., 2015).

Interprofessional collaboration affects patient outcomes and addressing discrepancies in understanding between professionals caring for those with medical complexities can enhance

patient outcomes (Morgan et al., 2015; Pullon et al., 2016). Two studies reported interpersonal collaboration as a barrier to implementing shared decision-making, both suggested strategies to overcome this barrier (Jain et al., 2019; Pullon et al., 2016). Researchers discussed the use of self-management support practices for patients to enhance the shared decision-making process through better communication of needs as well.

Researchers reported knowledge barriers on the part of both providers and patients as to what shared decision-making entails and how to integrate it into care as a gap in implementation (Lawn et al., 2017). In three studies, researchers evaluated the use of electronic health record tools to ensure that patient preferences and values are documented and acknowledged (Harry et al., 2020; Misra et al., 2019; Sada et al., 2011). In two studies researchers indicated that time constraints during patient encounters had a significant negative impact on the shared decision-making process (Ng et al., 2019). In others, researchers evaluated the use of decision aids to enhance shared decision-making (McDonnell et al., 2018; Kennedy et al., 2014; Lee & Ng, 2021; Manca et al., 2015). All 15 articles acknowledge that, when properly implemented, the shared decision-making model of care positively impacts patient outcomes and enhances the experience for both the patient and the provider. Overall, the findings are consistent that shared decision-making improves communication, patient centered education and choices, and understanding of patient preferences and values. Perceived barriers to shared decision-making in areas of time required by the provider were eased when shared decision-making tools in the form of standardized surveys and questionnaires were implemented, particularly when they were integrated into the already existing EHR (Sada et al., 2011). Patients also reported that these tools assisted them in communicating their preferences and values in a way that enhanced their experience and ability to participate more collaboratively in their care (Sada et al., 2011).

Literature Review Summary

Shared decision-making is a care model developed out of a need to improve patient understanding and participation in care. This model replaces the old paternalistic model of care in which the healthcare provider knows best and in the patient is expected to blindly follow the advice and recommendations of the healthcare provider. Patients with medical complexities often face complicated decisions to make around medications, procedures, diagnostic testing, and treatment. Within these decisions there are many opportunities for patients to make informed decisions about their preferences. This literature review evaluated barriers and enhancements to implement a shared decision-making model of care within the primary care setting. In the primary care setting, patients with medical complexities can work collaboratively with a provider that knows them over time, thus understands them holistically and their specialists which can ensure the patient remains at the center of care planning and treatment (Lawn et al., 2017).

Implementing shared decision-making into the primary care setting has some barriers which include difficulties in interprofessional communication, knowledge gaps between what shared decision-making is, and how to implement shared decision-making within the time constraints of the primary care setting (Lawn et al., 2017). The decision-making aids and EHR tools can aid implementation by evaluating patient preferences and values, assessing patients' level of interest in shared decision-making, and using of self-management tools (Harry et al., 2020; Misra et al., 2019; Sada et al., 2011). While some studies indicated barriers to implementation and others were focused on solutions, all the studies concluded that there were better outcomes when shared decision making was properly implemented in the primary care environment.

The limitations of this review included the somewhat abstract nature of the topic. There is no one set definition of what shared decision-making entails despite a common understanding of the purpose. Also, the term “medical complexities” can be considered too broad and vague. Clear definition of the term would benefit the implementation of a project to evaluate the usefulness of shared decision-making. For example, cancer as a single diagnosis is generally considered medically complex (Jain et al., 2019; Lawn et al., 2017). However, it would be helpful to define what criteria is being used to decide which single diagnoses (such as chronic kidney disease) can be considered a complex health condition (Walker et al., 2013). The term medically complex has been defined for our purposes in the introduction of this paper and when the term is referred to within this proposal it is in reference to that definition.

Shared decision-making should replace the paternalistic care delivery. Shared decision-making is based on the premise that patients deserve autonomy, respect, and knowledge around their health care needs. Patients with medical complexities face complicated and difficult decisions that make this integral to them. Many tools exist that can enhance the implementation of a shared care model in the primary care setting. Addressing barriers in time and knowledge through the inclusion of decision aids and EHR tools will assist in the success of implementation and optimizing patient outcomes. Implementing such tools may have an impact on patients perceived participation in care decisions and lead to enhanced communication and collaboration between primary care providers and patients with medical complexities.

Project Framework

The theoretical framework that guided this clinical project is the Ottawa Decision Support Framework (Conceptual Framework - Patient Decision Aids - Ottawa Hospital Research Institute). This framework conceptualizes the support needed by patients, families, and their

practitioners for complex decisions with multiple options while maintaining the patient values and preferences to the best degree possible. It guides healthcare providers to assess patients' decisional needs and provides decision support interventions in the form of clinical counselling, patient decision tools, decision coaching, and others to evaluate their effects on decisional outcomes.

This framework has been recognized and used by practitioners and patients for more than 20 years to improve decision making quality. This framework is used to create interventions with the support of decision aide tools that facilitate decisional support through communication, collaboration and enhanced understanding of available decisions, support, and improved outcomes. This framework allows patients and providers to conceptualize the support needed for complex or difficult medical decisions by providing decisional aides (Conceptual Framework - Patient Decision Aids - Ottawa Hospital Research Institute).

Methods

Following a brief interview to determine if a patient meets the criteria to be considered medically complex, patients were invited to engage in a shared decision-making intervention. To assess intervention effectiveness, questionnaires were used to evaluate knowledge, values, support, and certainty with health care decisions before and after the intervention. These items included clarity of what decision needed to be made, desired level of involvement, options available, advantages and disadvantages of each decision, understanding of the information related to the decision, recognition of patient preferences, and collaboration on a final decision (See Appendix A). This project was implemented in a primary care setting in North Carolina with patients who have medical complexities.

Goals and Objectives

Considering the research evidence of the benefits of the shared decision-making model among patients with complex medical conditions, the purpose of this clinical project was to implement and assess a shared decision-making model in a primary care setting to engage patients with medical complexities in care and treatment decisions.

The following objectives were developed for this project:

1. Assess the number of patients who are eligible to participate in the project:
 - a. Criteria of “medically complex” as defined in the introduction section of this proposal was the inclusion criteria.
2. Evaluate patients’ level of perceived participation in care decisions prior to the intervention using the Shared Decision-Making Questionnaire (SDM-Q).
3. Implement the Ottawa Decision Making Tool at the primary care site during the patients’ routine care.
4. Reevaluate patients’ level of perceived participation in care decisions at the end point of the intervention using the SDM-Q.

The following were the expected outcomes following the implementation of the project:

1. 50 patients with medical complexities will participate in this clinical project.
2. Participants in this project will report low levels of perceived participation in health care decisions prior to the intervention.
3. Intervention using the Ottawa Decision Making Tool will be conducted Tool at the primary care site during the patients’ routine care.

4. Participants will report a higher perceived level of participation in care decisions after the implementation of the shared decision-making tool that is statistically significant.

Project Site and Population

The setting for this project was one primary care practice in a large city in North Carolina. The population of the city as of 2022 is 925,290. The city is ethnically diverse with the following racial demographic profile: White: 48.83%, Black or African American: 35.22%, Asian: 6.52%, Other race: 6.12%, Two or more races: 2.81%, Native American: 0.43%, and Native Hawaiian or Pacific Islander: 0.06%. This practice serves individuals within this diverse population, of all ages and provides both primary and urgent care services. Services offered include onsite x-ray, blood draw, and point of care testing for urinalysis, blood glucose, and initial viral swabbing. The practice is staffed with one medical director, one manager, one clinical supervisor, six providers who rotate with one to two providers on site during business hours, medical assistants, and clinical staff.

Potential participants were screened by chart review because of the large size of the population and the high percentage of individuals that have medical complexities. The stakeholders at this site included patients, providers, and support staff, along with specialty collaborators that contribute to patient care management. The population for this clinical project was adults with medical complexities. Patient inclusion consisted of patients with medical complexities, that were willing to participate in the entire process of the project from inception to completion. Exclusion criteria were patients with high percentages of no-show appointments (more than 10%) in the past year or noted difficulty with contact (unreturned phone calls, more than 10% of appointments cancelled or rescheduled same day) as determined by chart review, because participation in this clinical project required prolonged engagement.

The Intervention: Shared Decision-making Model

The Ottawa Personal Decision Guide was completed by the participant to assess decisions around medications, treatments, and/or procedures. This guide has been used for more than 20 years and offers a way for patients and providers to conceptualize a problem and possible decisions. The guide is used to walk patients and providers through the patient thought process, allowing for consideration of key categories of decision-making including knowledge, values, support, and certainty (*Ottawa Personal Decision Guides - Patient Decision Aids - Ottawa Hospital Research Institute*), See Appendix B). The tool involves a four-step process.

1. The decision is clarified. (What decision do you face?)
2. The decision is explored. (What are the options, reasons to choose each and reasons to avoid each option. What supports are available and how can these supports be utilized)
3. The decision-making needs are identified in areas of knowledge, values, support, and certainty.
4. A plan is set for next steps.

Measurement Instruments

In order to measure the outcomes, the Shared Decision-Making Questionnaire (SDM-Q) was used (Rencz et al., 2019). The SDM-Q was completed pre intervention and post intervention, to evaluate each patient's perceived personal knowledge, support, and certainty with medical decisions (see Appendix A). This 6-point Likert scale consists of 9 items designed to determine a patient's perceived participation in care decisions. Responses range from strongly disagree (1) to strongly agree (6). This questionnaire is one of the most widely used and has been found to be very reliable with a Cronbach's alpha of 0.925 (Moran, 2021) and numerous studies

demonstrated a good internal consistency and construct validity with excellent known-groups validity (Rencz et al., 2019).

Data Collection and Procedure

During the pre-intervention phase participants were screened through chart review and recruited in person interviews conducted during scheduled appointments based on inclusion criteria. After the interview participants were enrolled based on their willingness to participate. Participants completed the SDM-Q questionnaire in paper form at the time of enrollment. During the intervention phase the Ottawa Decision Aid for care decisions was explained and reviewed with participants and then used throughout the implementation period of 12 weeks. Providers reviewed the form and made a shared decision with the participants based on the responses on the form. During the post-intervention phase participants completed the SDM-Q. At the completion of the data analysis the results were presented to the site for review and recommendations. See Appendix D for additional timeline information.

Data Analysis

Data analysis focused on the differences between responses to the SDM-Q to evaluate the effectiveness of the intervention in the sample of participants. Responses to the items were assigned numerical values from 1-6 and entered an Excel file. In order to prevent missing data, the form was reviewed for completeness and any omitted items were reviewed with the patient to obtain a value. Scores were summed to yield a total score. A paired sample t-test was used to compare pre and post SDM-Q scores to determine if the difference was statistically significant. The significance level, alpha, was set at 0.05.

Ethical Considerations/Protection of Human Subjects

The University of Massachusetts, Amherst (UMASS) Internal Review Board (IRB) approval was obtained prior to initiating the DNP Project (See Appendix E). Additionally, the DNP student followed the Standards of Care for practice in the primary care office. All information collected as part of the evaluating the impact of this project was aggregated data from the project participant and does not include any potential identifiers.

The risk to patients participating in the project was no different from the risks of patients receiving standard care. Participant confidentiality was assured by coding the participants using individual identification numbers. The list of participants and their identifying numbers was kept in a locked filing cabinet in the provider office, only accessible to the DNP student, used only for the purposes of this project. All electronic files containing identifiable information were password protected to prevent access by unauthorized users and only the DNP student had access to the passwords.

Results

The following outcomes were achieved following the implementation of the project:

1. 42 patients with medical complexities participated in this clinical project.
2. There was significant improvement in the perceived participation in health care decisions after implementation of the shared decision-making tool. The

This DNP project was completed in one primary care setting in a major city in North Carolina over a period of 12 weeks. The participant population was adult patients with medical complexities. The target number of participants was 50 the final number was 42, allowing for analysis using a paired t-test. The results of the paired t-test with a mean score of 34.29

indicating a low to moderate level of perceived participation before the intervention and a mean score of 50.57 indicating a high level of perceived participation after the intervention (Table 1). The paired t-test results indicate that there was a statistically significant increase in mean SDM-Q scores before and after the intervention ($p < .001$).

Table 1.

A Paired Sample T-test Results (n=42)

	Pre- Intervention	Post- Intervention	Paired Differences						
			Mean (SD)	Mean (SD)	95% Confidence Interval of the Difference		<i>t</i>	<i>df</i>	<i>p</i> -value (one tailed)
					<i>Lower</i>	<i>Upper</i>			
SDM-Q Total score	34.29 (7.1)	50.57 (4.11)	-18.09	-14.48	-18.2	41	<.001		

Discussion

Patients with medical complexities face many difficult care decisions with multiple options often with providers that do not fully understand their preferences, values, and available supports. This fragmentation of healthcare among adults with medical complexities has been shown to result in low levels of patient perceived participation in care and poor health outcomes (Enthoven, 2009). The purpose of this project was to determine if the use of a shared decision-making tool, would significantly improve the participants reported perception of involvement in care decisions. The results of this project indicate that patients with medical complexities do benefit from the use of a shared decision-making tool in areas of perceived participation in care decisions with a mean SDM-Q score of 34.29 prior to implementation of the tool and a mean

SDM-Q score of 50.57 after the implementation, indicating a significantly improved outcome after the intervention.

Participants actively engaged in the process and expressed interest in continuing to use the tool in the future. Several participants stated that the tool made things much easier to understand in terms of options and that using the tool helped them feel empowered to follow through with care decisions as it gave a structure for how to do so. One area that showed particular promise was for those with the comorbidity of hypertension. These participants had all previously been instructed to make lifestyle changes along with medications. The decision aid gave an opportunity to discuss what this means to the individual participants. For example, many felt that they could not make drastic dietary changes and join a gym due to time and financial constraints. However, using the tool allowed the opportunity for clarity around these topics and collaboration on small but important dietary changes such as reduced salt that could be made simply and activity changes such as parking further away and taking extra steps daily to increase activity. Bringing in participant supports was helpful in overcoming perceived barriers to making these improvements as well. Discussion around who was available in the participants life to help make necessary improvements as well as who in the participants life was not supportive of these changes helped facilitate real life solutions to problems. The 4-step process involved in the decision-making tool kept the conversation on task and helped ensure that the participant preferences and values were at the center of the encounter.

The literature review identified one perceived barrier to improving the understanding of these vital patient needs, which is time. Both providers and patients perceive that time constraints are a deterrent to fully collaborating on care decisions (Lee & Ng, 2021; Misra et al., 2019). The use of the shared decision-making tool did not result in a longer visit time compared to the usual

visit time allotted for these patients. Additionally, the literature review findings supported that shared decision-making tools have been shown to improve patient perception of involvement in care and subsequently lead to better patient outcomes (McDonnell et al., 2018; Kennedy et al., 2014; Lee & Ng, 2021; Manca et al., 2015). The results of this project support that the use of the decision-making tool does improve patients' perception of involvement in care and the participants did indicate a better understanding of how to make lifestyle choices that will improve their health in areas of diet, weight loss, increased activity, and medication compliance. Areas where this can be applied to further optimize care would be in screening and prevention which is vitally important for those with medical complexities as these are areas of care that are neglected in deference to the existing medical conditions. The use of the tool also adds to the provider understanding of patient preferences, values and support system which assists in collaboration in future care decisions.

Theoretical Framework Connection

The theoretical framework used to guide this project; the Ottawa Decision Support Framework, is specifically designed to assist patients in making these complex decisions while simultaneously providing an avenue for providers to navigate these decisions collaboratively (Ottawa Personal Decision Guides - Patient Decision Aids - Ottawa Hospital Research Institute). The framework is straightforward in its contention that the use of decisional aides helps to identify decisional needs, improves the quality of decisions made and improves outcomes through understanding of available supports and barriers for the individual. The site staff were introduced to this framework and the associated decision tool prior to the recruitment of participants. Staff were given the opportunity to ask questions in small groups as well as at any point individually to clarify the framework, the use of the tool and the application in the project.

The staff as a whole invested in the purpose of the project and understanding the framework assisted in conceptualizing the use of the tool. The framework contends that the use of decision supports that address patients' specific decisional needs will improve the quality and efficacy of collaborative decision-making.

Barriers and Facilitators

The project was implemented in a large urban city in the state of North Carolina. The population size assisted in the ease of recruitment of participants. Although the site is in a large urban area, as with many large cities there are small communities within the larger population. The patients that come to the site are familiar with staff and many were open to the project based on trust and rapport that was already established.

Not all patients that were approached chose to participate but of those that did, a total of 42 (100%) completed the process. One barrier to recruitment was that it was done through chart review of future appointments. There were many times that patients were scheduled for an appointment that was either subsequently rescheduled or the patient was a no show completely. Efforts were made to see the patients that rescheduled but the patients that were complete no-show appointments were excluded due to difficulty in following up with when the appointment may be scheduled in the future.

Another barrier was the fact that the process was paper based. The pre and post surveys and the decision tool were on paper which could be cumbersome at times, especially since most other processes at the site are electronic. This was aided by the fact that all paperwork was completed while the student was on site and all paperwork was managed by the student. The surveys were completed and given to the student and number coded for anonymity which was

explained to the participant. This helped the participant to feel secure that they could be honest about their responses and that the staff would not connect their responses to them personally.

Recommendations for Future Studies and Clinical Practice

Future recommendations would be to continue to implement the shared decision-making model into practice as the results indicate a significant improvement in patients' perception of participation in care. This could be accomplished by implementing either the Ottawa Personal Decision Guide, or a similar tool into each encounter with patients that are medically complex. This project was completed with adults with medical complexities. In the future it could be considered to use this process with pediatric patients with medical complexities as well.

As shown above, one barrier is the lack of an established tool within the electronic health record and the cumbersome nature of continuing this process in paper form. The staff at the site indicated that they saw immense value in the use of the decisional tool and that they would use such a tool regularly if it were integrated into the electronic health record. While the decisional tool does offer a framework for decision making it would be prudent to develop a structured way to track progress and outcomes on these decisions. Attaching the plan to an outcome tracker could benefit not only the patient but also the provider with a visual representation of the process. Monitoring decisional needs, facilitating progress and continued support must happen after the decision is made in order to optimize the collaboration in care. Some suggestions for support after the decision is made would be follow up with clinical counseling and coaching around progress towards the plan between follow up appointments. Many of the follow up appointments for the participants were made for three months, which is standard for the type of encounters these patients have for medication refills, blood pressure and diabetes checks. During

this time phone or telehealth check in could be scheduled to monitor progress and actively adjust the plan as needed.

Project Limitations

This project was limited by the 12-week timeframe. The types of outcomes that are possible from implementing shared decision-making tools can take time to develop. It would be beneficial to track these patients over a longer time and to use the tool in multiple encounters over this time to develop a more complete plan that is evaluated and adjusted to meet the individual needs. This project was additionally limited by the number of participants in relation to the population size. It would be beneficial to implement the tool with a much larger group to see if the results are consistent.

This project demonstrates that patients with medical complexities do benefit from the use of a decisional tool in areas of perceived participation in care decisions. There was no barrier to the use of the tool in terms of time, but the cumbersome nature of a paper format was a challenge. In the future implementing a shared decision-making tool into the electronic health record and pairing it with scheduled check ins and tracking of progress would optimize the outcomes for patients and providers.

Conclusion

Patients with medical complexities face many difficult health related decisions and often do not participate in care and treatment decisions. Shared decision-making has been shown to improve patient participation in their healthcare. This clinical project intended to translate research evidence in support of a shared decision-making model at one primary care practice and to evaluate the impact of the shared decision-making tool on patients perceived participation in care decisions. Thus, synthesizing healthcare delivery to patients with complex health conditions

and improving health outcomes and patient satisfaction. Through the implementation of this project participants and providers had an opportunity to utilize a shared decision-making tool and utilize the shared decision-making process to improve patients' perception of participation in care decisions. The results indicate that utilizing the shared decision-making tool significantly improved the perception of participation in care decisions.

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Appendix A

SDM-Q

Survey Item	Completely Disagree 1	Strongly Disagree 2	Somewhat Disagree 3	Somewhat Agree 4	Strongly Agree 5	Completely Agree 6
My provider makes it clear when a decision needs to be made.						
My provider wants to know exactly how I want to be involved in decisions.						
My provider tells me when there are different options for treating my medical conditions.						
My provider explains the advantages and disadvantages of my treatment options.						
My provider helps me understand all information.						
My provider asks me which treatment options I prefer.						
My provider and I weigh each treatment option together.						
My provider and I choose treatment options together.						
My provider and I reach decisions on how to proceed together.						

Appendix B

Ottawa Decision Making Guide

Adapted Ottawa Personal Decision Guide: For People Making Health or Social Decisions

There are four steps: ① ② ③ ④

① Clarify your decision

What decision do you face?

Why are you making this decision?

When do you need to make a choice?

Where are you with making a choice? Not yet thought about the options Close to making a choice
 Thinking about the options Already made a choice

② Explore your decision

	Reasons to Choose this Option (Benefits / Pros)	How much it matters Use 0 to 5★s	Reasons to Avoid this Option (Risks / Cons)	How much it matters Use 0 to 5★s
Option #1				
Option #2				
Option #3				

Which option do you prefer? #1 #2 #3 Unsure

How motivated are you to take action *Not Motivated* 0 1 2 3 4 5 *Very Motivated*

How confident are you that you can take action? *Not Confident* 0 1 2 3 4 5 *Very Confident*

List things that may get in the way of doing this:

List things that may help you to do this:

Support

Who is involved?	
Who else can support you?	
Which option do they prefer?	
Is this person pressuring you?	
How can they support you?	
What role do you prefer in making the choice?	<input type="checkbox"/> Share the decision with _____ <input type="checkbox"/> Decide myself after hearing views of _____ <input type="checkbox"/> Someone else decides _____

③ Identify your decision making needs

Certainty Do you feel sure about the best choice for you? Yes No

Knowledge Do you know the benefits and risk of each option? Yes No

Values Are you clear about which benefits and risks matter most to you? Yes No

Support Do you have enough support and advice to make a choice? Yes No

④ Plan the next steps based on your needs

✓ Things you would like to try

A. Certainty If you feel unsure about the best choice for you:	<input type="checkbox"/> Working through the steps below may help.
B. Knowledge If you need to know more:	<input type="checkbox"/> Find out more about the options and the chances of the benefits and risks. <input type="checkbox"/> List your questions. <input type="checkbox"/> List where to find the answers (e.g. library, care provider, counsellor).
C. Values If you need to think about what matters most to you:	<input type="checkbox"/> Review the stars in the balance scale to see what matters most to you. <input type="checkbox"/> Talk to others who have made the decision. <input type="checkbox"/> Read stories of what mattered most to others. <input type="checkbox"/> Discuss with others what mattered most to you.
D. Support If you need support:	<input type="checkbox"/> Discuss your options with a trusted person (e.g. care provider, counsellor, family, friends). <input type="checkbox"/> Find help to support your choice (e.g. funds, transport, child care).
If you feel pressure to make a certain choice:	<input type="checkbox"/> Focus on the views of others who matter most. <input type="checkbox"/> You can share your guide with others. <input type="checkbox"/> You can ask others to try this guide. See where you agree. If you disagree on facts, agree to get more facts. If you disagree on what matters most, consider each other's view. <input type="checkbox"/> Find a trusted person to help you and others involved.
Other ideas and plans:	

Appendix C

Cost to Implement

The site incurred no expenses related to this clinical project. The costs associated with implementation of the project were the cost of materials to create the questionnaire and decision-making tool. All necessary materials were provided by the student.

Supply	Cost x Amount	Total Cost
SDM-Q 9 form	0.23 x 50 forms	\$11.50
Ottawa SDM form	0.23 x 50 forms	\$11.50
Patient Consent form	0.23 x 50 forms	\$11.50
Patient Confidentiality form	0.23 x 50 forms	\$11.50
Total cost to implement	0.23 x 200 forms	\$46.00

Appendix D

Timeline

Task	October	November	December	January	February	March	April
Recruitment of eligible participants	X	X					
Intervention		X	X	X			
Data Analysis					X	X	
Data Verification						X	X
Post analysis of outcomes							X
Results presented to site							X
Recommendations							X

Appendix E**IRB Determination Form****UMassAmherst**

Human Research Protection Office

Mass Venture Center
100 Venture Way, Suite 116
Hadley, MA 01035

Memorandum – Not Human Subjects Research Determination

Date: June 13, 2022**To:** Cori Fappiano, Nursing**Project Title:** *Shared Decision Making for Primary Care Patients with Medical Complexities***HRPO Determination Number:** 3633

The Human Research Protection Office (HRPO) has evaluated the above named project and has made the following determination based on the information provided to our office:

The proposed project does not involve research that obtains information about living individuals

[45 CFR 46.102(f)].

The proposed project does not involve intervention or interaction with individuals OR does not use identifiable private information [45 CFR 46.102(f)(1), (2)].

The proposed project does not meet the definition of human subject research under federal regulations [45 CFR 46.102(d)].

Submission of an Application to UMass Amherst IRB is not required.

Note: This determination applies only to the activities described in the submission. If there are changes to the activities described in this submission, please submit a new determination form to the HRPO prior to initiating any changes. ***Researchers should NOT include contact information for the UMass Amherst IRB on any project materials.***

A project determined as “Not Human Subjects Research,” must still be conducted ethically. The UMass Amherst HRPO strongly expects project personnel to:

- treat participants with respect at all times
- ensure project participation is voluntary and confidentiality is maintained (when applicable)
- minimize any risks associated with participation in the project
- conduct the project in compliance with all applicable federal, state, and local regulations as well as UMass Amherst Policies and procedures which may include obtaining approval of your activities from other institutions or entities.

Please do not hesitate to call us at 413-545-3428 or email humansubjects@ora.umass.edu if you have any questions.



Jorge A. Guzman, Assistant Director
Human Research Protection Office