HEALTH BEHAVIOR CHANGE IN ADVANCE CARE PLANNING: AN AGENT-BASED MODEL

by

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ABSTRACT

Significance: A practical and ethical challenge in advance care planning research is controlling and intervening on human behavior. Additionally, observing dynamic changes in advance care planning (ACP) behavior proves difficult, though tracking changes over time is important for intervention development. Agent-based modeling (ABM) allows researchers to integrate complex behavioral data about advance care planning behaviors and thought processes into a controlled environment that is more easily alterable and observable. Literature to date has not addressed how best to motivate individuals, increase facilitators and reduce barriers associated with ACP. We aimed to build an ABM that accurately reflects: 1) the rates at which individuals complete the ACP process, 2) how individuals respond to barriers, facilitators, and behavioral variables 3) the interactions between these variables, 4) suggests -future -public health interventions and validation studies.

Methods: We developed an ABM of the ACP -decision making process. We integrated into this dynamic model the barriers, facilitators, and other behavioral variables - that -agents encounter as they move- through the Transtheoretical Model's stages of change.

Findings: We successfully incorporated ACP barriers, facilitators, and other behavioral variables into our ABM, forming a plausible representation of ACP behavior and decision-making. In addition, the resulting distributions across the stages of change replicated those found in the literature, with approximately half of participants in the action-maintenance stage in both the model and the literature.

Public Health Implications: Our ABM is the first of its kind to outline potential intervention points for behavior change in the context of ACP. The ABM approach to ACP is a useful method for representing dynamic social and experiential influences on the decision making process. This model could be used in the future to test structural interventions (e.g. increasing access to ACP materials in primary care clinics) theoretically before implementation. Future studies can expand on this by gathering longitudinal, individual-level data and integrating it into the ABM for a more comprehensive representation of decision-making patterns with respect to ACP.

TABLE OF CONTENTS

1.0		ACKGROUND1
	1.1	ADVANCE CARE PLANNING1
	1.2	THE USES OF AGENT-BASED MODELING IN ADVANCE CARE
	PLA	NING
2.0		IETHODS
	2.1	CONCEPTUALIZATION
		1.1 Pre-Contemplation9
		1.2 Contemplation 10
		1.3 Preparation10
		1.4 Action-Maintenance 10
	2.2	DYNAMIC MODELING OF EXPERIENCES11
		2.1 Exposure to Personal Critical Illness12
		2.2 Exposure to Personal Critical Illness12
		2.3 Exposure to a Primary Care Provider
	2.3	DYNAMIC MODELING OF SOCIAL INTERACTIONS 14
	2.4	SUSCEPTIBILITY15
	2.5	LOGIC

	2.6	EXPERIMENTS 16
3.0		RESULTS
	3.1	SIMULATION 1 18
	3.2	SIMULATION 2 20
	3.3	SIMULATION 3 22
	3.4	SIMULATION 4 24
4.0		DISCUSSION
		4.1.1 Explanation of Observed Outcomes by Stage
		4.1.2 Progression of the Model
	4.2	STRENGTHS OF THE MODEL 30
	4.3	LIMITATIONS OF THE MODEL 30
	4.4	SUGGESTIONS FOR FUTURE STUDIES
	4.5	CONCLUSION
API	PENI	DIX: NETLOGO CODE FOR HEALTH BEHAVIOR CHANGE IN ADVANCE
CA	RE P	LANNING
BIB	LIO	GRAPHY

LIST OF TABLES

Table 1. Development of the model	5
Table 2. Variables in the model.	. 8

LIST OF FIGURES

Figure 1. Model flow diagram.	
Figure 2. Results from Simulation 1.	
Figure 3. Results from Simulation 2.	
Figure 4. Results from Simulation 3.	
Figure 5. Results from Simulation 4.	

1.0 BACKGROUND

1.1 ADVANCE CARE PLANNING

Many Americans experience severe illness during which they cannot make health care decisions for themselves (1). Instead, they rely on previously expressed preferences and values with respect to utilizing life sustaining therapies. Preemptive planning for this decision making process is referred to as advance care planning (ACP), and it can consist of a patient (2) considering decisions in advance with loved ones and healthcare providers, (3) designating a proxy decision maker, or (4) documenting preferences (or any combination thereof). Preferences and values for medical intervention vary greatly between patients, and surrogates decision makers are not particularly skilled at making these difficult decisions, though some studies indicate speaking with surrogates in advance may aid in making more patient-centered decisions upon incapacitation (2).

Current best practices recommend incorporating surrogates and physicians in the ACP process by discussing patients' end-of-life values and preferences with them prior to incapacitation (4, 5). Additionally, patients cite multiple reasons to develop an advance care plan, including the opportunity to exercise autonomy and control, considering personal relationships, and relieving the burden on loved ones (6).

Given a multi-dimensional focus, surrogates cite a variety of barriers to advance care planning, including the belief that an advance care plan is irrelevant due to perceived health, emotional barriers, relationship concerns, lack of information, and time constraints (7, 8). Overcoming the emotional and relational barriers may aid in integrating end-of-life values and preferences into future clinical care (2).

Previous literature has demonstrated a gap between patients' values and preferences for end-of-life care and the care they actually receive, with many patients receiving more intensive treatment than they would want were they able to make their own treatment decisions (9). Researchers have shown advance directives are associated with more patient-centered end-of-life outcomes (10, 11). Determining ways to reduce barriers to ACP and increasing end-of-life planning behaviors may ultimately improve patient-centered end-of-life outcomes (12).

Literature indicates the primary motivational factors for developing an advance care plan include the diagnosis of oneself or a friend and familiarity with advance care plans and the processes for adopting them (13). The literature to date has not addressed how best to increase the salience of these motivational factors while reducing barriers associated with ACP.

1.2 THE USES OF AGENT-BASED MODELING IN ADVANCE CARE PLANNING

A practical and ethical challenge in public health research in general is controlling, intervening on, and observing dynamic changes human behavior. In ACP, this is due partly to the difficulty in reaching and intervening on an outpatient population with varying diagnoses and severities of illness. Agent-based modeling (ABM) allows researchers to integrate complex behavioral data into an environment that is more easily alterable and observable.

Given the challenges in implementing a population-level intervention to increase the awareness and salience of ACP, ABM provides a useful means for mimicking population ACP behaviors and testing interventions on a simulation population prior to implementing larger-scale public health interventions. Agent-based modeling methods allow for the integration of causal dynamics into a simulated population, rather than relying on correlations. Preliminary conceptual evidence supporting an intervention may aid in justifying time and money allocation to public health programs with the aim of increasing a population's propensity to develop advance care plans.

If an ABM can be designed to mimic population dynamics of ACP, interventions can be designed to act on barriers in the model, and those interventions can therefore be assessed for potential effectiveness in the population.

Investigators use ABM in the public health setting, particularly in the context of tangible changes such as infectious diseases, obesity and tobacco cessation (14, 15). These models are based in models of dynamic change (16).

Though modeling health behavior change is relatively novel, it has been demonstrated in models of alcohol abuse and child maltreatment (17, 18). ABM has yet to be applied in the context of behavior change in the ACP process, which is multifaceted.

The Transtheoretical Model (TTM) has been used widely as a theoretical framework for conceptualizing behavior change, including ACP (8, 19-23). Based on TTM's conceptual framework, agents move through five qualitatively different stages—encountering different barriers at each stage—and potentially alter a behavior.

We developed an ABM depicting ACP as a behavior change process using a Transtheoretical Model framework. We aimed to build an ABM the accurately reflects the rates

3

at which individuals and the population complete the ACP process, barriers (emotional and psychological readiness, having necessary materials), facilitators (increasing salience of the need to develop an ACP, social support), and behavioral variables (susceptibility, baseline distributions) for future application testing public health interventions that address barriers at different stages of change prior to implementation.

2.0 METHODS

The ABM for ACP contained variables at three levels: the individual, the environment, and globally across the model. Variable and their associated parameters and logic are outlined below and in Table 1. We used NetLogo for all simulations (Wilensky, U. (1999). NetLogo v.5.0.4. http://ccl.northwestern.edu/netlogo/. Center for Connected Learning and Computer-Based Modeling, Northwestern University, Evanston, IL.).

 Table 1. Development of the model.

Conceptualization	Logic
 Based on statistics for a population ages 65+ Baseline ACP behavior distribution (from literature) % pre-contemplation % contemplation % preparation % action-maintenance Cut-points (on 0-100 scale) determine each of TTM stages Each stage consists of a different (not equally-distributed) point range Based on different difficulties to move up in TTM stage Agents move each day 	 Distributed to fit percentages (0-100) based on TTM Sliders for each of 5 stages to determine starting distribution ACP propensity based on a changing number of points (0-100 scale) per individual; varying cut points to designate Threshold rules for moving up stages Turtle changes color at action stage Each tick equals 1 day Move for at least 5 years

Table 1 continued

Dynamic Modeling of Experiences	Logic
 Dynamic Modeling of Experiences Personal critical illness Smaller patch (less likely) Higher impact factor (one's own severe illness likely has a greater impact on Death Planning Anxiety) Loved one's critical illness/death Larger patch (more likely to know someone who has had severe illness) Smaller impact factor (the experiences of others likely have a lesser impact on Death Planning Anxiety) Advance care planning discussion with primary care provider Relative small influence, based on non-urgency of the primary care setting 	Logic1 patch for each event (personal illness, loved one's illness, and primary care interaction)Sliders to indicate degree of impact for eachProbability of affecting ACP change when land on patches can vary (sliders 0- 100 indicate likelihood)• If gain points, then count points• If count > next TTM threshold, then move to higher stage• If count < next TTM threshold, then stay in current stage• If in Action- Maintenance stage, then turn designated color• If not in Action- Maintenance stage, then terevaluate current
Dynamic Modeling of Social Interactions	then retain color
Interactions with other individuals	If interact with neighbor,
Recognize level of ACP	increase ACP propensity for lesser neighbor
• Susceptibility (not all agents are impacted by other agents)	Different degrees of disparity will have a different levels of influence

Table 1 continued

 At each tick, evaluate any agents on same patch At each tick, if patch-mate in higher stage, then gain interaction points If neighbors, then evaluate for higher stage than self If neighbor at high stage, then probability of assign associated number of points Susceptibility: slider-based probability at agent level Each stage associated with a number of points gained by lower stages upon interaction Local Networks Observable connections between agents that 	If gain points, then count points If count > next TTM threshold, then move to higher stage If count < next TTM threshold, then stay in current stage If on same patch, then make connection with agent At each tick, move at random 360° and move forward at designated moving-rate
• Agents move at a constant rate, from patch to patch in random directions (in contrast to randomly across entire matrix)	
 Backsliding (negative social interaction) Negative social influence can accumulate With a sufficient accumulation of negative points, agents can cross the threshold back into the previous stage 	 If move up stage, then reevaluate current stage If in Action- Maintenance stage, then turn designated color If not in Action- Maintenance stage, then retain color If interact with neighbor, decrease ACP propensity for higher neighbor
Susceptibility	Logic
 Not all agents are impacted by experiences and social interactions 	 If land on patch, then probability of gaining points

2.1 CONCEPTUALIZATION

We built an ABM depicting individuals (agents) who progress through the Transtheoretical Model's (TTM) stages of change. Based on statistics for a population aged sixty-five and older, we designed the model to replicate the distribution across the stages of change for communicating with loved ones about quality versus quantity of life. Variables were built into the model to represent the appropriate percentage of agents relative to the sample population found in the literature (19, 21). A description of the variables can be found in Table 2.

Baseline distribution of	Bounds	SIM 1	SIM 2	SIM 3	SIM 4	Expected*
agents across stages						Ĩ
pre-contemplation	0-100	100	40**	40**	40**	
contemplation	0-100	0	40**	40**	40**	
preparation	0-100	0	20**	20**	20**	
action-maintenance	0-100	0	0**	0**	0**	
Baseline point value for each s	tage					
pre-contemplation	0-100	0	100	100	100	
contemplation	0-100	0	50	50	50	
preparation	0-100	0	0	0	0	
action-maintenance	0-100	0	50	50	50	
Thresholds	_		_	_		
contemplation	0-100	60	100	100	100	
preparation	0-100	20	50	50	50	
action-maintenance	0-100	10	0	0	0	
Points						
Experiences ICU stay	0-10	4	5	6	6	
Experiences loved one's	0-10	3	1	4	4	
illness						
Interacts with other agents at	0-10	3	3	2	2	
higher stages						
Interacts with other agents at	-10-0	1	1	2	2	
lower stages						
Visits primary care (PCP)	0-10			1	1	
Globals						
1°-affected-patches	0-10	3	3	3	3	
2°-affected-patches	0-10	6	6	7	7	
Primary care (PCP)-patches	0-10			10	10	

 Table 2. Variables in the model.

Table 2 continued

Other Parameters						
Agents in pre-contemplation are not influenced by other agents' stages upon						
interaction						
Susceptibility 0-100 100 50 50 50						
Movement rate in local					0.15	
networks						
Outcomes						
%pre-contemplation	0-100	0	23	57.8	21.4	40
%contemplation	0-100	0	20.2	19	20.4	10
% preparation	0-100	0	3.2	3.6	6.8	3
% action-maintenance	0-100	100	53.6	19.6	51.4	47

*based on (21)**based on (19)

Each stage in the model consists of a 0-100 scale, where the number of points needed to cross into the next stages can vary within that point range. Those thresholds acted as a proxy for the difficulty in moving between stages. Given that different stages have barriers and facilitators of different strengths, the point thresholds are designed to predict the ease with which agents can move in to and out of different stages in the TTM. That is, the thresholds are designed to represent the size of the barriers to moving into subsequent stages in the stages of change model.

Time in the model is set to run for five years, where the unit with each move in the model is one day.

2.1.1 **Pre-Contemplation**

Agents in the pre-contemplation stage have never considered ACP. In the general population, these are people who have never been introduced to the ACP process, are not aware of related concepts, or have been introduced, but do not find ACP to be a worthwhile or relevant behavior Agents in the pre-contemplation stage are not engaged in ACP in any respects.

2.1.2 Contemplation

Agents in the contemplation stage begin to think about their treatment preferences and values. They are not yet ready to talk about their thoughts or take action with respect to planning behaviors. Barriers to entering this stage from pre-contemplation include the perceived irrelevance of ACP for various reasons, including the idea that one is too healthy. An additional barrier is the desire to leave determinations of life and death in God's hands.

2.1.3 Preparation

The preparation stage consists of those who have decided ACP would be an advantageous behavior for them. These people begin clarifying their values by talking to healthcare providers and loved ones. They develop a plan to formally discuss end-of-life decisions with their surrogate decision makers and healthcare team. Barriers to preparation include a lack of resources or education about what is required in the ACP process. Additionally, emotional and psychological barriers influence one's willingness to discuss these issues and prepare for end-of-life scenarios. As in contemplation, if individuals perceive themselves as too healthy, they may prioritize their follow-through with the ACP behavior below other aspects of their lives, citing that they are too busy.

2.1.4 Action-Maintenance

In the current ABM, the action and maintenance stages are combined into one, as they are quite inter-related, and can be modeled in a dynamic way that accounts for both aspects of the behavior. Once the ACP behavior is completed, agents enter the action-maintenance stage. If they fail to maintain it (i.e. not updating annually), they backslide out of action-maintenance, into preparation.

Agents in the action-maintenance stage have had active discussion with their family and physician. This discussion can be documented in the form of an advance directive. Wishes are then reviewed annually and amended as necessary. Barriers to entering the action-maintenance stage include the inaccessibility or unwillingness of loved ones or healthcare providers to discuss end-of-life wishes. Likewise, some do not have potential surrogate decision makers. Emotional and psychological barriers at this stage also include the desire to not burden loved ones with such a discussion. With respect to maintaining active status, some individuals disregard or are not aware of the need to review and update advance care plans.

2.2 DYNAMIC MODELING OF EXPERIENCES

Based on the theoretical model, we incorporated key barriers and facilitators into the ABM at each to mimic population behavior. Given evidence found in the literature and previously described barriers to end-of-life planning, we employed an ABM where individuals experienced end-of-life events that may influence barrier perception. Specifically, agents could survive a stay in an intensive care unit (ICU) with high probability of death or severe functional impairment or experience the death of a loved one. In the model, experiences were represented by patches that agents could physically, randomly land upon, potentially causing them to earn ACP points

2.2.1 Exposure to Personal Critical Illness

We built a simulated critical illness experience into the model to simulate its effect on perceived health. Previous literature has noted one of the major barriers to ACP is that people often perceive themselves as too healthy to do such a behavior (8). The personal critical illness occurred relatively infrequently in the overall population, as the average person over 65 years of age is likely to not experience an intensive care unit stay (for example) very frequently. Though infrequent, when these events occurred, they had a relatively high influence on one's development of an ACP.

In the model, the patches for personal illness are relatively small (in comparison for those representing the critical illness or death of a loved one, outlined below), given their relative infrequency. They also carry a larger weight, meaning susceptible agents who land on the personal illness patches gain relatively more ACP points given its presumably more salient influence on future behavior with respect to ACP.

2.2.2 Exposure to Personal Critical Illness

We also included the influence of a loved one's severe illness or death. Similar to personal experience, this encounter with illness or death is intended to address the barrier of applicability. Barriers presented by Schickedanz and colleagues include both perceived health (as noted above) and the perception that one is too busy to complete an ACP (8). Both of these concepts can be addressed by reexamination and reprioritization. If perceived necessity increases based on life events, a person may be more likely to develop an ACP. Therefore, we built the ABM that represents a loved one's critical illness or death relatively more probable than having a

personal encounter with critical illness (by default of the fact that individuals are only one person and they know more than one person, making the latter more probable). These secondhand encounters have less impact on propensity to develop an ACP by virtue of one's proximity to the situation in personal experience and the salience that comes with such an event.

2.2.3 Exposure to a Primary Care Provider

After a primary analysis based on the two aforementioned end-of-life experiences, we integrated a primary care influence, as that is the forum in which most advance care planning discussions occur with providers. These encounters are likely the least influential in prompting discussion of end-of-life preferences, as the sense of urgency is lessened, making the behavior seem less applicable to the current setting (8). Exposure to primary care is given the largest probability of all three experiences in the model. Although advance care planning is likely not discussed in each encounter with primary care, individuals over sixty-five encounter providers in this setting more frequently than they do in the ICU setting (24). The fact that advance care planning is not discussed in each encounter is captured by the low influence the patch has on agents in the model per encounter.

The primary care patch is also placed relatively nearer to the ICU patch than that representing the death or critical illness of a loved one. We intentionally placed configured the placement in this way to reflect that patients who were critically ill are more likely to seek out primary care. The same events in a loved one are less likely to prompt one's own visits to a primary care provider. Patients are often referred to primary care or other outpatient clinical care for follow-up after critical illness, during which providers are more likely to address ACP given the patient's previous exposure.

2.3 DYNAMIC MODELING OF SOCIAL INTERACTIONS

We wrote interaction into the ABM to signify individuals talking to one another about ACP with potential bias for or against. That is, individuals who were in higher stages (presumably in favor of ACP as a concept) were able to influence those in lower stages, making them more likely to complete an ACP. Likewise, those at relatively lower stages negatively influence those of higher stages. Influences of those in lower stages can result in backsliding, or agents returning to previous stages due to perceived barriers and changed perceptions, theoretically. These interactions are set to represent barriers and facilitators in social norms, social networks, family relations, and perceived self-efficacy based on the exchanges.

After a primary analysis in which agents moved in random networks, the model was expanded to allow agents to build local networks and move within a relatively more structured community. Given the impact of social structure on advance care planning—and the fact that social capital varies across the population—we integrated local networks that vary in strength, thereby effecting the rate at which individuals in that network structure completed an advance care plan (8).In the model, local networks were implemented by requiring agents to move one geographic space at a time (i.e. take one step up, down, left, right, or diagonally) in a random fashion. By moving one space at a time, each agent maintained a more constant environment with respect to the other agents surrounding it.

2.4 SUSCEPTIBILITY

We built susceptibility into the model to demonstrate observations that some individuals in the population will not complete an advance care plan regardless of influences or interactions. A subset of the agents will not be affected by the influencing factors in the model.

2.5 LOGIC

Experiences and interactions could affect an agent's propensity to develop an advance care plan, outlined below (Figure 1).

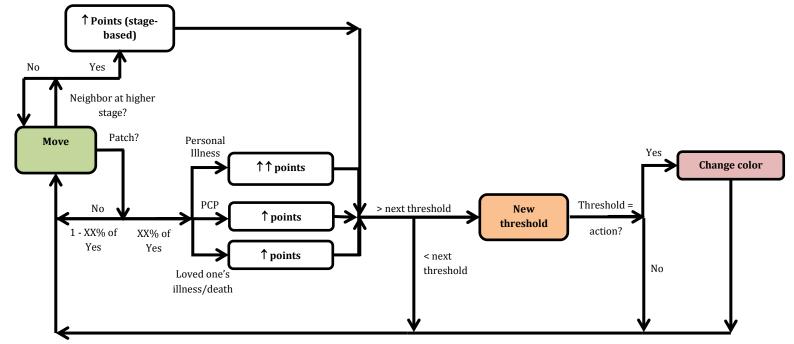


Figure 1. Model flow diagram.

Below, we describe the logic for gaining and losing points in the model for the agents who are susceptible to changing stages. Logic for the model is expressed in Table 2.

At the start of each step in the model, agents randomly move within the simulation grid. Upon their move, neither, one, or both of the influences can act upon the agent. If the agent land by itself on a non-descript grid square, it neither gains nor loses points. If the agent lands on a patch (indicating one of the two experiences of critical illness or that of primary care) it gains the appropriate number of points for that type of experience.

Likewise, if an agents lands on a grid square with another agent, they can influence each other; the agent at a lower stage gains points, and the agent at a higher stage loses points. Agents at the same stage do not influence one another. If an agent both lands on an experience patch and shares a space with another agent, both influences can affect the points for that agent.

The ABM then calculates each agent's total points and compares them to the threshold for moving in subsequent stages. Any agents that crossed a threshold moves into the next stage and changes colors accordingly. Then the agents move again, and the pattern continues until the run is finished (at approximately five simulated years).

2.6 EXPERIMENTS

We ran experiments systematically to simulate four different dynamics: (1) a model in which all agents developed an advance care plan, (2) a model in which the agents developed advance care plans under the influence of each other, ICU stay, and loved ones' illness or death, (3) a model in which the agents are influenced by primary care in addition to those in the second model, and (4) a model in which the agents developed advance care plans at the rate found in the

general population by developing local networks and potentially encountering all three of the life experiences (discussion of advance care planning in the primary care setting, ICU stay, and serious illness of death of a loved one). Below, an examination of each is outlined in detail.

For each of the three experiments, we systematically manipulated five sets of variables in the model: initial distribution across stages, initial scores within each stage, percent susceptible, points for experiences and interactions, and score thresholds to move between stages.

3.0 **RESULTS**

Upon evaluating the resulting distributions across the stages of change, we were able to determine the sets of parameters that best match those found at the population level for each of the four simulations (Table 2).

3.1 SIMULATION 1

The first simulation aimed to represent the means by which our ABM can appropriately reflect the progress of a population of individuals who all complete the ACP process as a baseline for comparison. A graph of the transition rates can be found in Figure 2.

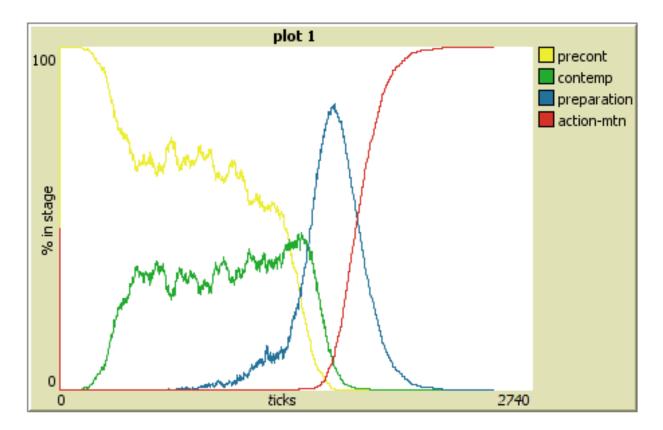


Figure 2. Results from Simulation 1.

As a baseline for comparison, all agents started in pre-contemplation, and all were susceptible to behavior. We found all agents progressed from pre-contemplation to actionmaintenance and remained there. Agents wavered between pre-contemplation and contemplation before progressing into preparation and subsequently moving rather quickly from preparation to action-maintenance. The ABM plausibly shows progression through stages at the individual level.

Starting in pre-contemplation (yellow), some agents are affected by interactions and life events relatively early and start to move into contemplation (green). As the number of agents in contemplation increases, interactions between the first two stages become more relevant, producing stochastic interactions between the two, indicating high interaction influence early in the behavioral process. Agents move through preparation (blue) relatively quickly, as the threshold to enter it is high and the threshold to move out of preparation is low, based on the nature of the barriers and facilitators for the stage found in the literature. Once preparation begins, backsliding due interactions with those in pre-contemplation becomes less likely. This is likely due to a relatively low threshold in ACP to complete the behavior (action-maintenance; red) once a decision has been made to do so. That is, once an agent decides to complete the ACP behavior during contemplation, that agent does not have to expend much effort to prepare and move quickly to action-maintenance.

We were able to accurately reflect the relative rates at which individuals move through the stages of change when all complete the process. In this experiment, all agents were susceptible to the events and interactions, meaning they all progressed to action-maintenance. Additionally, all agents started in pre-contemplation. These two factors in conjunction forced all agents through all four of the stages in the model. The rate and pattern with which agents made the transition offers one illustration of the barriers and facilitators associated with ACP and how certain experiences and social interactions may alter individuals' progression through the TTM's stages of change.

3.2 SIMULATION 2

The second simulation aimed to represent the means by which our ABM can appropriately reflect the distribution of individuals across stages of the ACP process found in the population. A complete description of agents' progression through stages can be found in Figure 3.

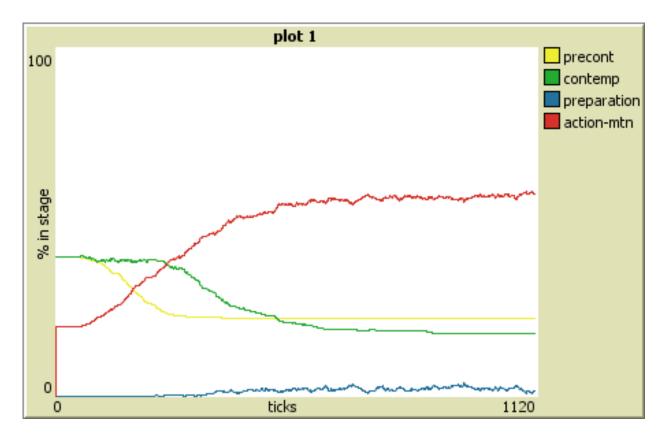


Figure 3. Results from Simulation 2.

In this simulation, all of the parameters in the model to mimic ACP dynamics found in the literature with respect to the general population. A complete breakdown of the observed and expected values for each stage can be found in Table 2. We set 50 percent of agents to be susceptible to behavior change. Agents moved through the stages of change until they reached a dynamic equilibrium that mapped onto the relative distribution of the general population across the stages of change in ACP behavior. Fifty-three percent of the agents completed the advance care plan, compared to 47 percent of the general population over 65 years of age. Precontemplation at the opposite end of the stage continuum had the second-highest representation.

Starting with a distribution typically found in the general population for multiple health behaviors (19), agents gradually redistribute across the stages of change, better representing population values (17). That is, as the number of agents stabilizes across the stages, the relative quantity in each stage corresponds with expected values from the literature. The first two stages (pre-contemplation and contemplation; yellow and green, respectively) occupy the middle two distributions, reflecting their close relationship prior to the enactment of any advance care planning behavior. The fewest individuals are in preparation (blue) given the relative speed with which agents complete the advance care planning after deciding to continue from contemplation, indicating either ease in moving out of preparation, difficulty entering it, or some combination of both. This finding is supported by the plot of preparation in the first simulation where agents appeared in preparation for a brief period of time. The plurality of individuals complete the behavior (action-maintenance; red), as is the case in individuals over 65 years of age. Approximately and appropriately, half of the agents completed the ACP process and entered action-maintenance.

We were able to accurately reflect the relative rates at which individuals complete the ACP process relative to population values. The observed and expected values for each stage relative to the general population can be found in Table 2.

3.3 SIMULATION 3

Again starting with a distribution typically found in the general population for multiple health behaviors, agents gradually redistribute across the stages of change, better representing population values. The distributions across stages and justifications remain similar when the primary care clinic was added to the model as an experience for agents. A complete description of agents' progression through stages can be found in Figure 4.

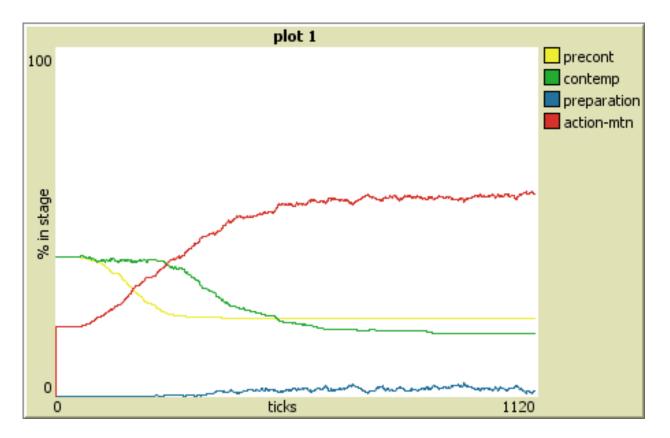


Figure 4. Results from Simulation 3.

In this simulation, all of the parameters in the model to mimic ACP dynamics found in the literature with respect to the general population. A complete breakdown of the observed and expected values for each stage can be found in Table 2. We set 50 percent of agents to be susceptible to behavior change. Agents moved through the stages of change until they reached a dynamic equilibrium that mapped onto the relative distribution of the general population across the stages of change in ACP behavior. Fifty-three percent of the agents completed the advance care plan, compared to 47 percent of the general population over 65 years of age. Precontemplation at the opposite end of the stage continuum had the second-highest representation.

Though the relative distribution of agents across stages remains the same with the addition of primary care, the rates more accurately reflect the expected values from the literature for advance care planning in individuals over 65 years of age.

We were able to accurately reflect the relative rates and more accurately reflect the distribution within the stages of change at which individuals complete the ACP process relative to population values. The observed and expected values for each stage relative to the general population can be found in Table 2

3.4 SIMULATION 4

Again starting with a distribution typically found in the general population for multiple health behaviors, agents gradually redistribute across the stages of change. The fourth simulation incorporated local network structures intended to represent social contacts. A complete description of agents' progression through stages can be found in Figure 5.

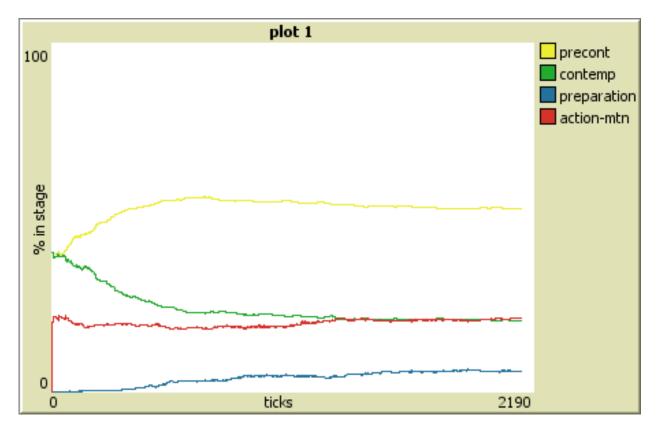


Figure 5. Results from Simulation 4.

After integrating a local network structure and simulated primary care setting into the model, the relative distribution across the stages of change was retained, while the completion rate (action-maintenance) dropped. Refinement of the model taking complex parameters into consideration may produce more nuanced results that more accurately represent the population.

Though the relative distribution of agents across stages remains the same with the addition of primary care, the rates more accurately reflect the expected values from the literature for advance care planning in individuals over 65 years of age.

We were able to accurately reflect the relative rates and more accurately reflect the distribution within the stages of change at which individuals complete the ACP process relative to population values. The observed and expected values for each stage relative to the general population can be found in Table 2.

The fourth simulation also aimed to represent the means by which our ABM can reflect ACP practices in the population. Integrating local networking (in contrast to the random network structure in previous simulations), allowed the model to potentially represent dynamics more similarly to those found in the population. Agents did achieve a distribution among the stages of change relatively representative of population values, though the accuracy decreased when compared to those simulations without local networks. The decreased accuracy possibly can be attributed to the integrated social networks neglecting some of the nuances of real-world social network structures.

25

4.0 **DISCUSSION**

Given the current literature in ACP that utilizes the Transtheoretical Model in human populations, our model provides a plausible representation of how individuals make decisions to complete an advance care plan (8, 21).

We aimed to answer two questions. Firstly, can we build an agent-based model that incorporates relevant barriers, facilitators, and behavioral variables in an agent-based model for advance care planning that demonstrates a causal dynamic? Secondly, can we accurately reflect the relative rates at which agents complete the ACP process relative to population values in individuals age 65 and older? Ultimately, we hope to provide one model of potential mechanisms of ACP to improve conceptual understand of ACP behavior and eventually be used to assess inferences about ACP behavior change interventions that address different stages of the Transtheoretical Model.

We were able to integrate relevant barriers into the model, represented by the varying thresholds required to move between stages. The barriers vary for each stage of change, and those barriers carry different weight in contributing to individuals' reluctance to complete ACP behavior. For instance, barriers to entering contemplation include emotional readiness, family readiness, and reluctance to make God's decisions. For some, these emotional and psychological barriers are more influential than the logistical barriers encountered later in the process. The emotional nature of these barriers may lend to why individuals oscillate between precontemplation and contemplation for some time before overcoming these barriers to enter preparation (in Figure 2). Likewise, in the remaining simulations (Figures 3-5), it may contribute to why so many individuals remain in precontemplation and contemplation, never moving to preparations.

Barriers to preparation (though still some emotional and psychological) are more logistical than those found in earlier stages. Obtaining ACP materials and finding time to discuss values and preferences with family and/or physicians seems not to be as difficult. Additionally, once agents have these theoretical materials, they are ready and able to complete the behavior relatively quickly, as there are few barriers to conducting the behavior once materials are obtained; therefore there is a low threshold to move from preparation to action-maintenance.

Interaction with those in precontemplation also acts as a barrier to some in higher stages, causing them to backslide (particularly from contemplation). Theoretically, the influence is likened to societal discomfort talking about the topics that arise in advance care planning discussions.

Facilitators include the experiences of the agents: (1) visiting primary care and a clinician assessing readiness, providing materials, or otherwise prompting ACP; (2) spending time in and ICU due to critical illness; and (3) having a loved one who dies or spends time critically ill in an ICU. The latter two experience may act as facilitators by increasing the salience of the need to develop an advance care plan for oneself.

With the exception of precontemplation noted above, interactions largely act as facilitators, Conceptually this represents social support and family availability to overcome barriers of emotional reluctance and time with family. This influence is effective, perhaps for different reasons, across different stages of the model.

27

We also incorporated behavioral variables to make the model more accurately reflect the population. Only a subset of our agents are susceptible to completing the ACP behavior. A lack of susceptibility to ACP may indeed be present in some individuals who refuse to develop an ACP. Contributing factors may include emotional or psychological barriers and religious or spiritual belief that end-of-life decisions belong to God and not man.

4.1.1 Explanation of Observed Outcomes by Stage

In the ABM individual agents moved through the four modified stages of the Transtheoretical Model as one would expect based on previous use of the stages of change model in population settings (Figure 2).

Starting in pre-contemplation (yellow), some agents experience the life events relatively early and start to move into contemplation (green). As the number of agents in contemplation increases, interactions between the first two stages become more relevant, producing stochasticity between the two as self-efficacy and social norms fluctuate. Eventually, contemplation is able to overcome pre-contemplation as some of its constituents reach the threshold for the third stage, preparation (blue).

As preparation is a relatively fast stage to move through once it has been entered, backsliding from interactions with those in pre-contemplation becomes less likely. This is likely due to a relatively low effort in ACP to complete the behavior (action-maintenance) once a decision has been made to more forward (represented by presence in preparation), that is, once an agent decides to complete the ACP behavior, during contemplation, that agent does not have to expend much effort to prepare and move quickly to action-maintenance. As individuals are able to move through the preparatory stage quickly, action maintenance (red) increases as subjects create ACPs.

4.1.2 **Progression of the Model**

Simulation 2, as the most basic model, demonstrated the model's relative accuracy in reflecting the distribution of agents across the stages of change. The addition of primary care made the model more accurate with respect to reflecting the percentile distribution of agents across the stages. The addition of primary care makes the model more realistic with respect to how patients make advance care planning decisions in the population. The added complexity allowed to model to more effectively reflect the population of individuals over 65 years of age.

The addition of a basic local network structure were theoretically designed to make social connections in the model more realistic with respect to population communication. However, the outcome distribution of agents across the stages of change reflect population values less accurately than with a random networking structure, when agents moved randomly in the model. By forming random local networks, we likely underestimated the complexity of the influence of real social networks. Pockets (or subpopulations) of agents likely continuously negatively affected one another, preventing them from progressing to higher stages. Additionally, Segments of the agents were secluded, and did not encounter any of the experiences (PCP, ICU stay, or death of a loved one).

We also added baseline distribution across the stages to start in some of the simulations. (Figures 3-5). Though this may or may not affect the outcomes of the model, it perhaps lends to the model being more realistic to the population context.

4.2 STRENGTHS OF THE MODEL

The ACP model offers a generalizable method for integrating the Transtheoretical Model into an ABM. The novel application of ABM can be adapted to other health behaviors by adjusting the barriers and facilitators affecting movement through the stages of change.

ABM facilitates the presentation of potentially causal pathways for a behavior. We were able to find a sufficient mechanism in the model for recreating at least some of the empirical results. Though it is unknown if this mechanism drives ACP behavior, the model's strength lies in its ability to integrate, vary, and test potentially causal factors of a behavior, giving it high internal validity.

4.3 LIMITATIONS OF THE MODEL

Our model offers one potential, sufficient mechanism for achieving the ACP rates found empirically. There are likely other mechanisms sufficient to produce the same results. The mechanism of ACP has yet to be determined empirically, and we provide only one framework by which the action-maintenance rate can be achieved. We found potentially significant variables, though these variables must be tested empirically, outside of a simulated setting. The limitation of knowing what variables are causal empirically and having relatively few variables in the ABM lends less ecological validity to the model when applied to real populations. Additionally, we named and built our variables to reflect what we feel are reasonable mechanisms, though those mechanisms and effect sizes in the population have not been determined. Many factors influence propensity to develop an advance care plan. We only included three in this model. Likewise, agents move and interact blindly, as they do not have families or individualized networks, nor do they have demographic or other sociologic characteristics such as age, socio-economic status, race, religion, chronic health status, and attitudes toward medicine.

The degree to which the selected experiences actually influence ACP was determined arbitrarily, as population influences are unknown. The effects of all of these variables can be better described empirically and integrated into the ABM to provide a clearer picture of health behavior change. The integration of additional barriers and facilitators of ACP may help the model better reflect population-level decision making. Interventions and additional variables can be integrated into the model to assess their effects on barriers and facilitators prior to implementing community-level programs.

The lower levels of action-maintenance rate found after integrating local network structure as compared to a random network may be due to the lack of complex relations and community-level networks within the model compared to real-world local networks. Social networks are complex, and the current model may not fully capture the dynamics found in real population. However, it is at least as likely that the model's other behavioral dynamics also do not reflect actual population dynamics. The localized network, which is more complex than the random network, may also be a more realistic depiction of how individuals interact. It may be that a different set of behavioral variables combined with a localized network would produce action-maintenance rates that more closely match those found in empirical studies.

4.4 SUGGESTIONS FOR FUTURE STUDIES

To the authors' knowledge, studies on advance care planning behavior have been cross sectional, capturing one time point in the process. Future studies can be longitudinal in nature, capturing individual behavior across a time period. Such studies will lend insight with respect to the advance care planning process and individuals' dynamic movement through it. Individual differences can be compared, and data can be collected on each person's social contact structure to build more informed local networks. Detailed data on the influences and execution of behaviors can aid in the development of interventions designed to prompt advance care planning behavior in the population.

Studies can apply the information gathering in a longitudinal study to inform both structural and behavioral interventions. Longitudinal data can inform investigators of potential intervention points to introduce effective facilitators or intervene on existing barriers. Such interventions may include increasing the prevalence with which ACP is discussed in primary or specialty care clinics, providing resources in skilled nursing facilities or community centers. Likewise, decisional support tools and workshops may prompt individuals and their families to learn about ACP and complete the behavior.

4.5 CONCLUSION

ABM is a plausible way to represent the dynamics of ACP behavior change and the results reflect population level distribution of ACP readiness. Barriers and facilitators of ACP can be successfully integrated into such a representation, and the Transtheoretical Model offers a

conceptual model for movement through the ACP process. ABM may allow for the testing of ACP interventions prior to community implementation as a way of testing for effectiveness prior to time and money allocation. Additionally, the use of the Transtheoretical Model in an agent based model provides opportunity for the integration of other health behaviors into such examination.

APPENDIX:

NETLOGO CODE FOR HEALTH BEHAVIOR CHANGE IN ADVANCE CARE PLANNING

globals [primary-affected-patches secondary-affected-patches **PCP-patches** %precontemplation %contemplation %preparation %action-maintenance total-action-maintenance %primary-affected %secondary-affected %PCP 1 turtles-own [ACP-proclivity-count duration contemplation-score precontemplation-score preparation-score action-maintenance-score precontemplation? contemplation? preparation? action-maintenance? susceptible? ; either yes or no or change this to be a continuous variable e.g. 0-100 then probabilistic] patches-own [primary-affected-here? secondary-affected-here? PCP-here?

```
1
```

to setup clear-all setup-patches create-turtles NumberTurtles setup-turtles reset-ticks end

to setup-turtles ask turtles [setxy random-xcor random-ycor] set-default-shape turtles "person"

ask turtles [ifelse random 100 < %susceptible [set susceptible? true] [set susceptible? false]]

;; initialize all as false first.

ask turtles [

set precontemplation? false set contemplation? false set preparation? false set actionmaintenance? false

set color white ;; white means no stages. Sliders should add to 100%.

set precontemplation-score initial-precontemplation-score

set contemplation-score initial-contemplation-score

set preparation-score initial-preparation-score ;; could change this to zero for all, but more flexible to set some initial value

set action-maintenance-score initial-action-maintenance-score

]

ask turtles [if who < initial% precontemplation * count turtles / 100

[set precontemplation? true set color yellow]]

ask turtles [if who >= initial%precontemplation * count turtles / 100 and who < (initial%contemplation * count turtles / 100) + (initial%precontemplation * count turtles / 100) [set contemplation? true set color green]]

ask turtles [if who >= (initial%contemplation * count turtles / 100) + (initial%precontemplation * count turtles / 100)

and who < (initial%preparation * count turtles / 100) + (initial%precontemplation * count turtles / 100) + (initial%contemplation * count turtles / 100)

[set preparation? true set color blue]]

ask turtles [if who >= (initial%preparation * count turtles / 100) + (initial%contemplation * count turtles / 100) + (initial%precontemplation * count turtles / 100)

and who < (initial% action-maintenance * count turtles / 100) + (initial% preparation * count turtles / 100) + (initial% precontemplation * count turtles / 100) + (initial% contemplation * count turtles / 100)

[set action-maintenance? true set color red]]

;; Sliders must add to 100%

;; update globals here as well as in 'go' to see proportions in each stage displayed in four monitors.

```
update-global-variables
update-colors
end
to setup-patches
clear-all
ask patches [set primary-affected-here? false set secondary-affected-here? false set PCP-
```

here? false

```
ifelse pxcor < 0 [set pcolor black] [set pcolor black]]
```

```
set primary-affected-patches patches with
[pxcor > (16 - primary-affected-patch) and pycor < (-16 + primary-affected-patch)]
ask primary-affected-patches [set primary-affected-here? true set pcolor pink]
```

```
set secondary-affected-patches patches with
```

[pxcor > (16 - secondary-affected-patch) and pycor > (16 - secondary-affected-patch)] ask secondary-affected-patches [set secondary-affected-here? true set pcolor orange]

```
set PCP-patches patches with
```

```
[pxcor < (-16 + PCP-patch) and pycor > (16 - PCP-patch)]
ask PCP-patches [set PCP-here? true set pcolor violet]
end
```

```
to update-global-variables
```

```
if count turtles > 0
```

[set %precontemplation (count turtles with [precontemplation? = true] / count turtles *

100)

```
set % contemplation (count turtles with [contemplation? = true] / count turtles * 100)
set % preparation (count turtles with [preparation? = true] / count turtles * 100)
```

```
set %action-maintenance (count turtles with [action-maintenance? = true] / count turtles * 100)
```

]

```
end
```

to affect-score-turtles

ask turtles with [susceptible?] [if [primary-affected-here?] of patch-here and precontemplation? = true [set contemplation-score contemplation-score + primary-points]]

ask turtles with [susceptible?] [if [primary-affected-here?] of patch-here and contemplation? = true [set preparation-score preparation-score + primary-points]]

ask turtles with [susceptible?] [if [primary-affected-here?] of patch-here and preparation? = true [set action-maintenance-score action-maintenance-score + primarypoints]] ask turtles with [susceptible?] [if [primary-affected-here?] of patch-here and actionmaintenance? = true and action-maintenance-score < 100 [set action-maintenance-score actionmaintenance-score + primary-points]]

ask turtles with [susceptible?] [if [secondary-affected-here?] of patch-here and precontemplation? = true [set contemplation-score contemplation-score + secondary-points]]

ask turtles with [susceptible?] [if [secondary-affected-here?] of patch-here and contemplation? = true [set preparation-score preparation-score + secondary-points]]

ask turtles with [susceptible?] [if [secondary-affected-here?] of patch-here and preparation? = true [set action-maintenance-score action-maintenance-score + secondary-points]]

ask turtles with [susceptible?] [if [secondary-affected-here?] of patch-here and actionmaintenance? = true and action-maintenance-score < 100 [set action-maintenance-score actionmaintenance-score + secondary-points]]

ask turtles with [susceptible?] [if [PCP-here?] of patch-here and precontemplation? = true [set contemplation-score contemplation-score + PCP-points]]

ask turtles with [susceptible?] [if [PCP-here?] of patch-here and contemplation? = true [set preparation-score preparation-score + PCP-points]]

ask turtles with [susceptible?] [if [PCP-here?] of patch-here and preparation? = true [set action-maintenance-score action-maintenance-score + PCP-points]]

ask turtles with [susceptible?] [if [PCP-here?] of patch-here and action-maintenance? = true and action-maintenance-score < 100 [set action-maintenance-score action-maintenance-score + PCP-points]]

end

to interact

ask turtles with [susceptible?] [if contemplation? and any? turtles-here with [preparation? = true] [set contemplation-score contemplation-score + interact-points]]

ask turtles with [susceptible?] [if contemplation? and any? turtles-here with [actionmaintenance? = true] [set contemplation-score contemplation-score + interact-points]]

ask turtles with [susceptible?] [if preparation? and any? turtles-here with [actionmaintenance? = true] [set preparation-score preparation-score + interact-points]]

ask turtles with [susceptible?] [if preparation? and any? turtles-here with [preparation? = true] [set preparation-score preparation-score + interact-points]]

;;ask turtles with [susceptible?] [if action-maintenance? and any? turtles-here with [action-maintenance? = true] [set action-maintenance-score action-maintenance-score + interact-points]]

ask turtles with [susceptible?] [if contemplation? and any? turtles-here with [precontemplation? = true] [set contemplation-score contemplation-score - negative-interact-points]]

ask turtles with [susceptible?] [if preparation? and any? turtles-here with [precontemplation? = true] [set preparation-score preparation-score - negative-interact-points]]

ask turtles with [susceptible?] [if action-maintenance? and any? turtles-here with [precontemplation? = true] [set action-maintenance-score action-maintenance-score - negative-interact-points]]

ask turtles with [susceptible?] [if action-maintenance? and any? turtles-here with [contemplation? = true] [set action-maintenance-score action-maintenance-score - negative-interact-points]]

end

to ACP-affect-score-turtles ;;move turtles up in stage based on stage-specific point accumulation; theshold determined by stage-specific sliders

ask turtles [if precontemplation? and contemplation-score > score-threshold-contemplation - 20

set contemplation? true set precontemplation? false set preparation? false set action-maintenance? false]]

ask turtles [if contemplation? and preparation-score > score-threshold-preparation - 20

set preparation? true set precontemplation? false set contemplation? false set action-maintenance? false]]

ask turtles [if preparation? and action-maintenance-score > score-threshold-action-maintenance - $20\,$

[

set action-maintenance? true set precontemplation? false set preparation? false set contemplation? false]]

```
ask turtles [if contemplation-score < 0 [set contemplation-score 0]]
ask turtles [if preparation-score < 0 [set preparation-score 0]]
ask turtles [if action-maintenance-score < 0 [set action-maintenance-score 0]]
```

ask turtles [if action-maintenance? and action-maintenance-score <= 0 [set precontemplation? false

```
set contemplation? false
  set preparation? true
  set action-maintenance? false
  11
ask turtles [if preparation? and preparation-score \leq 0
  ſ
   set precontemplation? false
  set contemplation? true
  set preparation? false
  set action-maintenance? false
  11
ask turtles [if contemplation? and contemplation-score \leq 0
  set precontemplation? true
  set contemplation? false
  set preparation? false
  set action-maintenance? false
  11
```

```
end
```

to affect-ACP-score

ask turtles with [susceptible?] [if [primary-affected-here?] of patch-here and precontemplation? = true [set contemplation-score contemplation-score + primary-points]]; if random 100 < 50 [

ask turtles with [susceptible?] [if [primary-affected-here?] of patch-here and contemplation? = true [set preparation-score preparation-score + primary-points]]

ask turtles with [susceptible?] [if [primary-affected-here?] of patch-here and preparation? = true [set action-maintenance-score action-maintenance-score + primary-points]]

ask turtles with [susceptible?] [if [secondary-affected-here?] of patch-here and precontemplation? = true [set contemplation-score contemplation-score + secondary-points]]

ask turtles with [susceptible?] [if [secondary-affected-here?] of patch-here and contemplation? = true [set preparation-score preparation-score + secondary-points]]

```
ask turtles with [susceptible?] [if [secondary-affected-here?] of patch-here and preparation? = true [set action-maintenance-score action-maintenance-score + secondary-points]]
```

ask turtles with [susceptible?] [if [PCP-here?] of patch-here and precontemplation? = true [set contemplation-score contemplation-score + PCP-points]]

ask turtles with [susceptible?] [if [PCP-here?] of patch-here and contemplation? = true [set preparation-score preparation-score + PCP-points]]

ask turtles with [susceptible?] [if [PCP-here?] of patch-here and preparation? = true [set action-maintenance-score action-maintenance-score + PCP-points]]

end

to move-turtles ;;ask turtles [move-to one-of patches]

```
if encounters = "correlated"
```

```
[rt random 360
fd moving-rate ]
if encounters = "random" [move-to one-of patches]
if link-up [link-up-turtles]
end
to link-up-turtles
if any? other turtles-here [create-links-with other turtles-here]
 end
to update-colors
 ask turtles [if precontemplation? = true [set color yellow]]
 ask turtles [if contemplation? = true [set color green]]
 ask turtles [if preparation? = true [set color blue]]
 ask turtles [if action-maintenance? = true [set color red]]
end
to go
 ask turtles
 [move-turtles]
 affect-score-turtles
 ACP-affect-score-turtles
 interact
 update-colors
 update-global-variables
 tick
end
;;setting totals
to update-globals;
; set % contemplation (count turtles with [contemplation? = true]) / count turtles
; set % precontemplation (count turtles with [precontemplation? = true]) / count turtles
```

```
;end
```

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