THE GOALS OF CARE PROJECT AT VANCOUVER COASTAL HEALTH

EXPERIENCE UNITING PATIENT & PUBLIC ENGAGEMENT (PPE) WITH LEAN THINKING

BACKGROUND

ACROSS THE VANCOUVER COASTAL HEALTH (VCH) REGION, SENIORS' RESIDENTIAL CARE FACILITES USE DIFFERNT APPROACHES TO ESTABLISH GOALS OF CARE – AN IMPORTANT CONVERSATION BETWEEN STAFF, RESIDENTS AND FAMILY/LOVED ONES. AS A RESULT, VCH HAS INITIATED A PROJECT TO DEVELOP A REGIONAL APPROACH FOR THE ESTABLISHMENT OF GOALS OF CARE WITHIN RESIDENTIAL CARE. THE PURPOSE OF THE PROJECT IS TO DEVELOP A PATHWAY REPRESENTING BEST PRACTICE IN ESTABLISHING GOALS OF CARE IN RESIDENTIAL CARE FACILITIES USING PATIENT AND PUBLIC ENGAGEMENT (PPE) AND LEAN METHODOLOGY.

THE GROWING NUMBER OF SERVICES TO SUPPORT SENIORS IN THEIR HOMES MEANS THAT PEOPLE ARE ENTERING RESIDENTIAL CARE FACILITIES LATER IN THEIR LIFE AND OFTEN IN POORER HEALTH. THIS TREND INDICATES THE IMPORTANCE OF INTEGRATING END OF LIFE PLANNING IN THE CARE PLANNING PROCESS WITHIN RESIDENTIAL CARE FACILITIES.

TO IMPROVE THE QUALITY AND RESPONSIVENESS TO RESIDENTIAL CARE AT END OF LIFE, WE SET OUT TO ASSESS THE CURRENT STATE OF PRACTICE AROUND ESTABLISHING GOALS OF CARE AT END OF LIFE, INCLUDING:

- IF, WHEN AND HOW GOALS OF CARE CONVERSATIONS ARE TAKING PLACE
- THE BARRIERS TO HAVING GOAL OF CARE CONVERSATIONS
- TYPES OF SUPPORTS THAT WOULD ASSIST STAFF IN GUIDING GOALS OF CARE CONVERSATIONS
- RESIDENT AND FAMILY EXPERIENCE OF GOALS OF CARE CONVERSATIONS.

DEFINITION

GOALS OF CARE AT END OF LIFE REFLECT PATIENT AND FAMILY VALUES, BELIEFS AND IDEAS OF QUALITY OF LIFE. THEY GUIDE ALL TYPES OF CARE, INCLUDING, BUT NOT LIMITED TO MEDICAL INTERVENTION. THEY ARE INTENDED TO DIRECT PATIENT CARE FOR THE DURATION OF STAY IN RESIDENTIAL FACILITIES, NOT SIMPLY THE FINAL WEEKS/DAYS/HOURS OF LIFE. THESE GOALS SHOULD BE OPENLY DISCUSSED, REVISITED WHEN NEEDED AND PROPERLY DOCUMENTED. GOALS OF CARE ARE DISTINCT FROM DEGREES OF INTERVENTION, WHICH SPEAK ONY TO MEDICAL INTERVENTION AT END OF LIFE.

METHODS

- USING LEAN METHODOLOGY TO GUIDE THE PROJECT, THE FIRST STEP OF THE THIS PROJECT, LED BY VCH COMMUNITY ENGAGEMENT, WAS TO GATHER INFORMATION FROM RESIDENTS AND FAMILY MEMBERS/LOVED ONES ABOUT THEIR EXPERIENCE SETTING GOALS OF CARE.
- INFORMATION WAS COLLECTED USING INTERVIEWS AS WELL AS A DISCUSSION GROUP WITH MEMBERS OF VCH'S COMMUNITY ENAGEMENT ADVISORY NETWORK (CEAN), REGIONAL PALLLIATIVE CARE COMMUNITY REFERENCE COMMITTEE AND PATIENT VOICES NETWORK.
- THESE RESULTS WERE THEN DISCUSSED WITH STAFF FROM RESIDENTIAL CARE FACILITIES AND LEARN ABOUT THE CHALLENGES THEY FACE AROUND GOALS OF CARE CONVERSATIONS.

WHY GOALS OF CARE?

- SIMPLY DOCUMENTS TREATMENT DECISIONS FAILS TO CONVEY A RESIDENT'S UNDERLYING VALUES AND END OF LIFE WISHES
- USE OF DEGREE OF INTERVENTION ALONG CAN BE DIFFICULT TO INTERPRET IN CRISIS SITUATIONS, & RESULT IN OVERLY AGGRESSIVE MEDICAL INTERVENTIONS & UNDERUTILIZATION OF PALLIATIVE/SPIRITUAL SUPPORTS
- RECORDED GOALS OF CARE CAN PROVIDE A FRAMEWORK WITHIN WHICH INTERVENTIONS CAN BE PROPERLY ASSESSED

KEY FINDINGS

1. CURRENT STATE OF GOALS OF CARE

- MANY HEALTH CARE PROFESSIONALS DO NOT HAVE A CLEAR UNDERSTANDING OF WHAT GOALS OF CARE MEANS IN TERMS OF END OF LIFE CARE
- GOALS OF CARE ARE OFTEN SEEN AS SYNONYMOUS WITH DEGREES OF INTERVENTION
- GOALS OF CARE CONVERSATIONS ARE OFTEN REPLACED WITH SIMPLE ASSIGNMENT OF A PARTICULAR DEGREE OF INTERVENTION
- IF THEY HAPPEN, GOALS OF CARE CONVERSATIONS GENERALLY TAKE PLACE UPON ADMISSION AND MAY BE REVISITED AT AN ANNUAL CARE CONFERENCE
- A CHANGE IN RESIDENT'S HEALTH STATUS IS THE PRIMARY OPPORTUNITY FOR GOALS OF CARE TO BE ADDRESS – OFTEN A DIFFICULT TIME FOR FAMILIES OR TOO LATE TO CARRY OUT WISHES

2. RESIDENT AND FAMILY EXPERIENCE

RESIDENTS AND FAMILY MEMBERS WERE ASKED ABOUT THEIR EXPERIENCE AND SATISFACTION WITH THE CURRENT PROCESS OF ESTABLISHING GOALS OF CARE IN RESIDENTIAL FACILITIES (INCLUDING END OF LIFE PLANNING) AND FOR THEIR SUGGESTIONS ON AN IDEAL PROCESS WOULD ENTAIL.

- MOST RESIDENTS/FAMILY MEMBERS HAD NOT HEARD THE TERM 'GOALS OF CARE' PRIOR TO THIS CONSULTATION AND VERY FEW HAD BEEN EXPLICITY ASKED ABOUT THEIR WISHES, VALUES AND BELIEFS RELATED TO THEIR CARE
- RESIDENTS/FAMILY MEMBERS WANT TO HAVE MORE OPPORTUNITIES TO DISCUSS THEIR VALUES AND PREFERENCES INSTEAD OF JUST BEING ASKED TO SIGN LEVEL OF INTERVENTION FORM
- MOVING TO RESIDENTIAL CARE IS A BIG TRANSITION FOR BOTH RESIDENTS AND THEIR FAMILIES SO THEY GOALS OF CARE PROCESS MUST BE WELL SUPPORTED WITH CARING STAFF, ADEQUATE TIME, CLEAR EXPLANATION OF WHAT STAFF ARE OBSERVING AND WHAT THIS INDICATES ABOUT THEIR LOVED ONES JOURNEY TOWARDS DEATH
- SOME RESIDENT AND FAMILIES ACKNOWLEDGED THEIR RELUCTANCE TO DISCUSS END OF LIFE CARE
- FAMILIES ASSUME THAT STAFF ARE COMFORTABLE AND SKILED WITH SETTING GOALS OF CARE FOR END OF LIFE

"READING THE *LEVELS OF INTERVENTION* FORM IS DIFFERENT FROM SEEING IT IN REAL LIFE… IT WOULD BE HELPFUL TO WALK THROUGH LIKELY EXAMPLES OF HOW THINGS PLAY OUT."

"IT IS IMPORTNT TO DISCUSS BEFORE CRISIS WHEN FAMILY IS ALREADY STRESSED. END OF LIFE PLANNING SHOULD BE EMBEDDED INTO REGULAR CARE MEETINGS"

"STAFF DIDN'ACKNOWLEDGE THAT MOM WAS AT THE END OF HER LIFE… SO I WASN'T READY. I WOULD WANT TO KNOW WHAT'S GOING TO HAPPEN."

FAMILIES NEED:

1. CLEAR AND COMPASSIONATE COMMUNICATION AROUND CONTINUUM OF PHYSICAL/MENTAL DECLINE; AVAILABLE TREATMENT/CARE OPTIONS
2. OPPORUNITIES TO DISCUSS THEIR UNDERSTANDING AND EXPECTATIONS, FUTURE WISHES AROUND MEDICAL INTERVENTIONS AND END OF LIFE CARE WITH STAFF AS WELL AS WITH OTHER MEMBERS OF THEIR FAMILY
3. ADVANCE PREPARATION FOR END OF LIFE, INCLUDING GUIDANCE AND SUPPORT FROM STAFF – ESPECIALLY AROUND WHAT CHANGES TO EXPECT IN DIFFERENT STAGES OF THE PROCESS.

3. STAFF BARRIERS TO GOALS OF CARE

- THE LACK OF UNDERSTANDING OF WHAT GOALS OF CARE MEANS AT END OF LIFE CARE
- RESIDENTS OFTEN MOVING INTO RESIDENTIAL CARE IN LATE STAGES OF ILLNESS, LEAVING NO TIME TO DEVELOP STRONG RAPPORT
- GOALS OF CARE CONVERSATIONS ARE TIME CONSUMING
- FAMILIES ARE SIMPLY NOT READY OR NOT INTERESTED IN TALKING ABOUT END OF LIFE
- STAFF LACK CONFIDENCE, TOOLS AND/OR SKILLS TO FACILITATE CONVERSATIONS WITH FAMILIES
- THE CULTURAL BELIEFS/PRACTICES OR STAFF AND/OR RESIDENT & FAMILY
- UNCERTAINTY AROUND WHO IS RESPONSIBLE FOR INITIATING GOALS OF CARE CONVERSATIONS
- INCONSISTENT OR LACK OF DOCUMENTATION FLOWING FROM GOALS OF CARE CONVERSATIONS

MOVING FORWARD

- THE CURRENT STATE AND FUTURE STATE MAPS WERE CREATED TO HELP ARTICULATE HOW VCH COULD IMPROVE THE PROCESS OF SETTING AND REVISING GOALS OF CARE WITH RESIDENTS AND THEIR FAMILIES
- VCH CONTINUES TO WORK WITH RESIDENTIAL CARE STAFF TO FAMILIARIZE THEM WITH THE CONCEPT, DEFINITION AND IMPORTANCE OF DISCUSSING GOALS OF CARE AT END OF LIFE AND TO PROVIDE STAFF WITH TOOLS TO GUIDE GOALS OF CARE CONVERSATIONS WITH FAMILIES
- MATERIALS FOR FAMILY MEMBERS ARE BEING DEVELOPED TO EXPLAIN END OF LIFE JOURNEY, THE DIFFERENT TYPES OF CARE AVAILABLE
- A PILOT TEST OF AN IMPROVED PROCESS IS UNDERWAY. THIS PROCESS PROVIDES GUIDELINES FOR STAFF ON WHEN AND HOW TO APPROACH GOALS OF CARE CONVERSATIONS; ENCOURAGES THEM TO FORMALIZES OPPORTUNITIES TO DISCUSS GOALS OF CARE INCLUDING DOCUMENTATION;
- AS PART OF THE COMMITMENT TO QUALITY, A SURVEY FOR RESIDENTS AND/OR FAMILY MEMBERS HAVE BEEN DEVELOPED TO ASSESS THE GOAL OF CARE CONVERSATION TO NESURE THE PROCESS AND RESOURCES ARE RESPONSIVE TO THE CURRENT NEEDS OF THOSE INVOLVED.

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Vancouver Coastal Health
Promoting wellness. Ensuring care.