Piloting A Self-Reported Symptom Assessment Tool In Three Outpatient Oncology Palliative Care Clinics

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Abstract

Background: Palliative care outpatient clinics should assess patients' symptoms and quality of life prior to visits to guide care and response to treatments. We describe the implementation of a quality improvement initiative to increase symptom and quality of life screening in the outpatient oncology palliative care (OOPC) clinics of one National Cancer Institute-designated Comprehensive Cancer Center.

Method: Our quality improvement project structure was based on the RE-AIM framework. Guided by the Plan-Do-Study-Act (PDSA) approach, we focused on assessing effective implementation of the Edmonton Symptom Assessment Scale (ESAS-r) and one Quality of Life (QoL) question at each OOPC visit. At the end of each 3-week PDSA cycle, barriers and facilitators were recognized and addressed. The implementation's effectiveness was determined by percentage of adherence using the following formula: [(number of ESAS-r +1 QoL forms completed per clinic/Number of OOPC completed patient appointments per clinic) x 100].

Results: A total of 372 patient appointments were completed during the four PDSA cycles, with overall 59% adherence. The first PDSA cycle compliance was 69%, 58% in the second, 52% in the third, and 65% at the last PDSA cycle. The primary barrier was staff turnover.

Conclusion: We were able to implement the ESAS-r + 1 QoL form in a complex clinical outpatient setting. We identified barriers for sustainability, including staff turnover. We addressed these barriers by providing robust instructions that outlined an overview of the clinic workflow and education for all staff members involved in the implementation process. Based on our experience, we suggest integrating this form into the electronic medical record to monitor patient outcomes in the outpatient oncology clinics.

Introduction

The goal of introducing palliative care (PC) early in the advanced cancer disease trajectory is to manage refractory physical symptoms and complex psychological issues while enhancing patient QoL [1-4]. PC involves symptom assessment and management, advance care planning engagement, coping facilitation, and communication to promote concordance between patients' care goals and treatment received [3, 5]. PC is provided to patients with advanced cancers, significant side effects, and functional status losses [6]. The American Society of Clinical Oncology (ASCO) and National Comprehensive Cancer Network (NCCN) state that PC improves health-related quality of life (HRQoL), reduces symptom burden, reduces health care resource use, improves provider-patient relationship, and may lengthen survival [1, 7]. NCCN developed guidelines to ensure that each patient with cancer experiences the best QoL throughout their disease trajectory [1]. The guideline includes recommendations for screening, assessment, and management of PC needs.

A gap exists, however, because PC clinicians may not routinely screen for and assess PC needs in oncology outpatient clinics. The recommendation for intensifying PC interventions is based on evidence-based patient outcomes demonstrating reduced distress, optimized quality of life (QoL), relief of

caregiver burden, strengthened relationships, acceptable sense of control, personal growth, and enhanced meaning [1]. Ongoing reassessment of these outcomes is recommended by NCCN [1], but specific time intervals for assessments are not included in the guideline. ASCO recommends that comprehensive cancer care should offer PC to patients with metastatic cancer within 12 weeks of diagnosis because of multiple randomized trials demonstrating improved outcomes, including quality of life, for individuals receiving PC. Previous studies have also assessed higher symptom burden and lower quality of life during hospitalization of patients with metastatic cancer [8] and undergoing *Hematopoietic Stem Cell Transplantation [9, 10]*. A consistent method for symptom and QoL assessment is needed in the outpatient PC setting to better understand patients' PC needs and to help create an individualized treatment plan and improve patient outcomes. Our quality improvement project addresses this need by implementing an approach to collect symptom and QoL information prior to patients' outpatient oncology palliative care visits.

Re-aim Framework

The Reach, Effectiveness, Adoption, Implementation, and Maintenance (RE-AIM) framework [11] served as the conceptual framework for our project and was used to evaluate the success of the intervention. We used RE-AIM as a planning and evaluation framework model for our study.

Iterative quality improvement approach

The Institute for Healthcare Improvement Model for Improvement PDSA was used to help facilitate a PC needs assessment by providing the structure for testing the change at a small scale prior to implementing it more widely [12]. The first step was the "Plan," which defined a clear purpose, formulated the desired outcome, and established a means of putting the plan into action. The second step was the "Do," during which the implementation plan was rolled out into action. The third step was the "Study," in which the DNP student monitored the outcomes to assess progress and barriers to implementation. The last step was "Act," in which the thorough evaluation of barriers and lessons learned were examined to adjust future PDSA cycles [12].

Methods

Our primary goal was to pilot the use of the ESAS-r + 1 QoL form in three palliative care outpatient clinics. Our expected outcome is continuous improvement in meeting PC needs, which was accomplished via a process in which patients completed the ESAS-r + 1 QoL form at each OOPC visit by end of the 12-week pilot project in all three clinics.

Setting. This quality improvement project was conducted at a large

Southeastern National Cancer Institute-designated comprehensive cancer center with a specialty outpatient oncology palliative care (OOPC) service within its three geographically discrete clinics. OOPC does not have discrete clinic space and is instead embedded within the Surgical Oncology, Multi-disciplinary Oncology and Hematology-Oncology clinics. The PC team included two attending physicians, three palliative medicine fellows, one nurse practitioner, one clinical pharmacist, and a nurse clinical coordinator. The PC team shared nursing and support staff with these oncology clinics. The three outpatient PC clinics did not have a standardized process in place for symptom assessment prior to this project.

Sample. The project population consisted of all patients seen by OOPC in these three clinics during the 12-week pilot period. There were three check-in desks staffed with a Health Unit Coordinator (HUCs) to check in patients. HUCs handed patients a piece of paper with questions to complete while they waited to be seen. However, each HUC had a different workflow at each clinic. The project was submitted to and approved by the University of North Carolina at Chapel Hill Institutional Review Board (IRB).

Measures

Edmonton Symptom Assessment Scale (ESAS). The ESAS is a well-established measure of physical and psychological domains that asks patients to rate nine common symptoms (pain, tiredness, drowsiness, nausea, appetite, shortness of breath, depression, anxiety, wellbeing) and one fill in the blank symptom they would like to address with their provider. The measure uses a 0 to 10 numeric rating scale to rate severity of the symptom, with 0 being absent of symptom and 10 being worst possible severity. ESAS was validated in PC, hospice patients, and to measure symptom severity in adults with cancer seen by a PC service [13]. ESAS has been revised to make it easier to complete, with added description for symptoms [14]. The scale does not require recall, as it assesses the timeframe of “now.” The ESAS-r is the revised ESAS measure and includes a body diagram to identify the pain site [14]. The ESAS-r has been used extensively in cancer PC, inpatient, and outpatient studies [15].

European Organization for the Research and Treatment of Cancer (EORTC) – Quality of Life in Palliative Care Patients (EORTC-QLQ-C15-PAL). The single QoL question has been validated and was found to be comparable to multi-item questionnaires [16]. It has been used extensively in the PC population with cancer [14, 17-23]. Based on extant literature and our communication with the PC team, there was mutual agreement that the ESAS-r with the global QoL question (ESAS-r + 1QoL) would be used for the assessment.

Plan-Do-Study-Act (PDSA)

Plan. Approval from clinic nurse managers was obtained prior to proceeding with the project planning. The project introduction, project timeline, and instructions were shared via information flyer with the HUCs, Certified Medical Assistants (CMAs), nurses, and clinicians that were involved in caring for the patients seen by OOPC. Flyers were posted at the HUCs’ desk and nurses’ station to serve both as a

resource and as a reminder to have the patient complete the ESAS-r + 1 QoL form for each PC patient appointments. The HUCs were able to see on their worklist if the patient was scheduled to see a PC provider at the time of check-in.

Do. The piloting of the ESAS-r + 1 QoL form took place in each clinic at the same time. The existing HUC workflow was used to pilot the assessment form. There were already several different general forms distributed at the time of the clinical appointment. For example, a yellow symptom inventory form was given to patients with breast cancer in the clinic. The same workflow was used to distribute the ESAS-r + 1 QoL form. The HUCs handed out the ESAS-r + 1 QoL form to the patient when they checked in. Clipboards with attached pens were already available at the HUC desk and the exam rooms. The completed ESAS-r + 1 QoL forms were collected by the support staff at the time of rooming and placed in a bin outside the room. Additional time was allowed to a patient who had not completed the questionnaire at the time of rooming. Those forms remained in the exam room and were collected by PC clinicians at the time of the visit. All ESAS-r + 1 QoL items were collected from the patient the end of the visit, regardless of completion status.

Study. Data were collected at weekly intervals. The number of OOPC scheduled and ESAS forms completed were tracked using an excel spreadsheet. At the end of each three-week cycle, the data were analyzed for each clinic separately. The DNP student met in person or via phone call with HUCs to assess barriers and facilitators at the end of each PDSA cycle. Prior to rolling out the project, we worked with the OOPC clinics to secure a designated area to store completed assessment forms. We totaled the number of completed ESAS-r + 1QoL forms and compared it with the total number of completed visits under PC service in a given time period. The denominator was set as the total number of patient visits. If a patient visited the clinic twice in a given time period, then each visit was counted independently in the denominator. The nurse coordinator for the PC team agreed to keep a printed list of appointments for the day and to cross out “no show” patients or patients seen outside the three-clinic area listed above. This information was collected weekly during the pilot period. An Excel data sheet was used to track this data for each clinic. No personal identifier of patients was logged into the data sheet.

Act. The assessment of barriers was performed for the clinic that did not maintain or surpass the set compliance benchmark of 50%. Changes to the pilot project process were made to address barriers observed during each PDSA cycle. Staff input was incorporated when making these changes.

Implementation

It was important to engage stakeholders early in the process. Gaining not only cooperation but also the support from all of the clinic staff was critical for the success of this project. The stakeholders of the intervention included the organization’s executive directors, unit managers, administration personnel, and PC clinicians that provide direct care to the patient (including the physician, advanced practice providers, clinician pharmacist in the PC team, nursing staff, and patients/caregivers). The ongoing update on the

progress and data collected up to that point was shared with stakeholders at the end of each PDSA cycle via e-mail.

Reach. The number of patients seen by the OOPC clinic during the DNP project from October 7, 2019 to December 29, 2019 was the total sample. The baseline benchmark at the end of initial PDSA cycle was set at 50% for each of the three clinics. The goal for each cycle thereafter was to continue to look for ways to maintain or surpass the previously reached compliance rate, or 50%, whichever was highest.

Effectiveness. The Plan-Do-Study-Act (PDSA) cycles did facilitate piloting of the ESAS-r + 1 QoL item. The PDSA cycles provided opportunities to make necessary changes to address noted barriers at each PDSA cycle.

Adoption. The clinicians (PC advanced practice providers, PC physicians, clinical pharmacists, and PC nurse clinical coordinators) and support staff (HUCs, CMAs, and nurses) received project information via staff meetings and group email. The contact information was included in the email for further questions. At the end of each PDSA cycle, we performed a site visit to interact with support staff to assess barriers, if any. Adjustments were made to the implementation plan based on feedback from clinicians and support staff.

Implementation. A total of four PDSA three-week cycles were completed during the project time period. We re-educated clinicians and support staff, provided resources, and made adjustments as needed for each clinic that did not meet the set benchmark as described above at the end of each PDSA cycles. Education and changes to the pilot project took place in the first week of new PDSA cycles.

Maintenance. We did not include the maintenance portion of the framework within the project timeline but instead plan to present maintenance as a recommendation for the future.

Results

The majority of the patients seen were located in either the Multidisciplinary clinic or the Hematology Oncology clinic. Prior to this QI project, the clinic did not utilize any standard tool to assess HRQoL or general QoL to align with NCCN guidelines and the content areas identified by an ASCO expert panel.

PDSA Cycle 1 consisted of 3 weeks, including a kick-off day (first day of the project) to acquaint the HUC staff with the ESAS-r + 1 QoL tool distribution process. The initial introduction was given at a RN and CMA staff meeting during September 2019. Unfortunately, HUCs are not present at these staff meetings because they focus on checking in patients that arrive early for their scheduled oncology visits. The project was also introduced to the OOPC during their Thursday team meetings in April and July 2019, where HUCs were present. The author (MP) was present at the clinic two to three times a week supervising and supporting the front-line staff with distribution of the ESAS-r + 1 QoL tool in the first cycle. The support included the following: 1) daily reminders of how many patients were scheduled to see an OOPC provider in a specific clinic for the day, 2) the names of providers covering OOPC patients for the

day, and 3) follow-up with HUC to see if patients received the ESAS-r + 1 QoL form at the time of check-in at least twice a week. A total of 54 ESAS-r + 1 QoL tools were completed by patients in the first PDSA cycle of 54/82 appointments (for a baseline rate of 66%). The following changes were made after PDSA cycle 1 including updating the PC team of the progress and challenges, written instructions posted at each desk with the image of the form and who should receive it, direct daily supervision and guidance for two weeks in the clinic, and reminding patient to hand completed form to the provider.

The Overview of each PDSA cycle and associated modifications to the process were logged (see Table 2, Appendix E(Appendix files are not available with this version),). PDSA Cycle 2 began after the end of cycle 1 adjustments were made. The cycle consisted of ongoing remote engagement with support staff via phone because the DNP student was unavailable in-person due to personal reasons. The data collection process continued uninterrupted and we were able to educate the OOPC providers to collect the form after each visit and place this in the data collection bin in the secure OOPC office. A total of 58% of patients completed the ESAS-r + 1 QoL during Cycle 2. There was a 29% increase in number of total OOPC visits completed in Cycle 2 compared to Cycle 1. Of note, compliance significantly dropped for the Surgical Oncology clinic from 50% Cycle 1 to 14% in Cycle 2 (Appendix E). This significant decrease is based on provider input about difficulty locating the ESAS-r + 1 QoL tool because it blended in with other white forms used by the clinic. To address this barrier, the color of the form was changed from white to dark green.

Table 1
PDSA Data Collection Overview

PDSA 3-week Cycles				
Cycle 1		# Appt	# ESAS-r + 1 QoL	Compliance %
	Surg-ONC	2	1	50%
	Multi-D	40	23	58%
	Hem/Onc	40	30	75%
	Total	**82**	**54**	**66%**
Cycle 2		# Appt	# ESAS-r + 1 QoL	Compliance %
	Surg-ONC	7	1	14%
	Multi-D	49	26	53%
	Hem/Onc	50	34	68%
	Total	**106**	**61**	**58%**
Cycle 3		# Appt	# ESAS-r + 1 QoL	Compliance %
	Surg-ONC	8	1	13%
	Multi-D	55	30	55%
	Hem/Onc	46	26	57%
	Total	**109**	**57**	**52%**
Cycle 4		# Appt	# ESAS-r + 1 QoL	Compliance %
	Surg-ONC	3	1	33%
	Multi-D	40	27	68%
	Hem/Onc	32	21	66%
	Total	**75**	**49**	**65%**
Total		# Appt	# ESAS-r + 1 QoL	Compliance %
	Surg-ONC	20	4	20%
	Multi-D	184	106	58%
	Hem/Onc	168	111	66%
	Total	**372**	**221**	**59%**

Note: Surg-ONC: Surgical Oncology; Multi-D: Multi-disciplinary; Hem/Onc: Hematology/Oncology

Table 2
PDSA Cycle Overview (10/07/2019-12/29/2019)

PDSA Cycle	Problem	Plan (P)	Do (D)	Study (S)	Act (A)
Cycle 1 Dates: 10/07/19 to 10/27/19	The OOPC team is not administering any self-reported symptom severity tool such as ESAS-r with 1QoL. The data can help provider guide the focus for the visit for that day and help assess quality of care.	Distribute ESAS-r + 1 QoL tool to patients scheduled for New/Routine OOPC clinic visit	Distribute ESAS-r + 1 QoL tool to three clinics and provide staff direction of the flow	2/3 of the clinic HUC thought ESAS-r + 1 QoL tool should be given to returning patients only and not new encounters. Lack of HUC knowledge regarding who should receive the ESAS-r + 1 QoL Patients comfort level when rating symptom severity listed on the ESAS-r + 1 QoL	Written instruction posted at each desk with the image of the form and who should receive it. Distribution process effective (50% or greater) for two weeks under direct daily supervision and guidance and third week via phone.
Cycle 2 Dates: 10/28/19 to 11/17/19	Can the pilot site sustainably distribute ESAS-r + 1 QoL tool as part of 3 cancer clinics front desk process with supervision and guidance?	Provide support to HUC via phone.	Call in the morning to remind them of number of appointments for two consecutive days.	Lack of HUC knowledge regarding ESAS-r + 1. QoL clinical significance	Distribution process partially sustainable for three weeks under remote supervision via phone.

PDSA Cycle	Problem	Plan (P)	Do (D)	Study (S)	Act (A)
Cycle 3 Dates: 11/18/19 to 12/08/19	Can the pilot site sustainably distribute ESAS-r + 1 QoL tool as part of 3 cancer clinics front desk process without supervision and guidance?	No in person reminder or calls for the HUC.	The ESAS-r + 1 QoL tool form color was changed dark green color to easily recognize.	The clinic was using pink, yellow, and light blue color for other providers. There was another provider with green form but it was a Spanish version of the yellow symptom inventory form.	Different color folder with printed instructions taped to the front of the folder to differentiate forms.
Cycle 4 Dates: 12/09/19 to 12/29/19	Changing front line staff lack education on ESAS-r + 1 QoL related process.	Provide frontline staff update regarding modification to process and form appearance.	Laminated sheet given with name of providers and process given was placed at the HUC desk.	Similar process was being used by one of the HUC in the clinic. This helps to standardize the process throughout the three clinics.	Laminated sheet improved sustainability as it provided floating HUC and new HUC with information for workflow. Since clinic staff are not connected to the OOPC team directly, a member from OOPC team will need to update the HUC when new provider is hired.

PDSA Cycle 3 consisted of ongoing HUC education and engaging with OOPC clinicians on how to input the patient selected value from the ESAS-r + 1 QoL form into the encounter progress note using an the SmartPhrase, “ESAS into Epic.” The ESAS-r + 1 QoL tool completion percentage had a 52% average between all three clinics in cycle 3. There was another 10.2% decrease in completing the forms in Cycle 3 when compared to Cycle 2 data for the average of the 3 clinics. A face-to-face meeting occurred with two of the PC clinicians and the clinical nurse coordinator for an assessment of Cycle 3. The clinicians noted

that there had been a decrease in the Cycle 3 compliance due to hefty staff turnover throughout the month of November 2019 in two-thirds of the clinic.

PDSA Cycle 4 began with a HUC who served as a project champion notifying us during the first week of Cycle 4 that she was leaving her job effective immediately. No new champion was recruited for the remainder of the 2 weeks of Cycle 4. The focus was placed on creating a process that would not be heavily dependent on routine staff. On the second day of Cycle 4, each clinic received a laminated sheet with a list of providers covering OOPC patient visits and instructions for the process to follow for each visit. The percentage of compliance at the end of Cycle 4 was 65% (49/75) for all three clinics. The was a 25% increase in compliance when compared to Cycle 3, but there was a 31.2% decrease in the number of patients seen by OOPC clinic during Cycle 4, indicating the volume was slower and patients were more likely to complete the form. The contributing factors were the following: clinic being closed for three days in last week of the cycle due to Christmas and generally low census in the last weeks of Cycle 4.

Handwritten notes were taken periodically by the first author when making in-person visits during the project process to document observations and barriers throughout the PDSA cycles. Week one of Cycle 1 was met with resistance from HUC and frontline staff members stating, “we are doing all we can” and “I cannot add one more thing to my workload.” As Cycle 1 progressed, staff became more receptive to the new process but often missed distributing ESAS-r + 1 QoL tool to patients stating “Oh, I forgot about the sheet.” Engagement during Cycle 2 was done remotely via phone. The phone conversations were brief in nature, with minimum feedback from the HUC staff during Cycle 2. At the end of Cycle 3, the HUCs and PC clinicians shared the concern that another service provider had a similarly colored form to the ESAS-r + 1 QoL tool. During the Cycle 3 field visit, the DNP student noted two patients refused to compete the form because it was their second visit to OOPC clinic for severe symptom management in less than two weeks.

This intervention met with several barriers, primarily from overworked clinical staff who had a high turnover rate. First, new floating HUC staff were noted at the front desk of the Multi-Disciplinary Oncology clinic when making an in-person visit during Cycle 4. Second, brief interaction between the DNP student and frontline staff consisted of reminders about where the forms were placed, checking for adequate supply, and asking about barriers to the process.

Discussion

We conducted a QI project to 1) pilot the implementation of the ESAS-r with an added single global QoL question from EORTC-QLQ-C15-PAL in the OOPC, and 2) assess barriers and facilitators to improve future implementation of the tool in other OOPC setting for better sustainability. Overall, this project did not achieve its goal of surpassing or maintaining ESAS-r + 1 QoL form compliance benchmark of 50% set at the end of PDSA cycle 1, although subsequent PDSA cycles 2–4 maintained compliance rate between 52–65% with overall project compliance of 59%. This was due to a few factors that played a central role in lower adherence rates: turnover of clinic staff (HUCs, CMAs, nurses, and clinicians), typically crowded

clinic settings, and patient perceptions about completing a form about their symptoms. Also, an unpredictably higher than normal staff turnover in the PDSA cycle 3 and 4 was a contributing factor.

HUCs at the front desk of each three clinics made a significant impact on compliance rate. Initially, the supporting staff displayed resistance, but continuous education on the importance of practice change led to more buy-in. One of three clinics often reported forgetting to hand the form at the time of check-in to the patient. HUCs who encountered higher numbers of PC appointments were more likely to complete the process of distributing the ESAS-r + 1QoL tool compared to HUCs who encountered lower numbers of PC appointments in their clinic.

Patients' perceptions were an important aspect of this project. Generally, patients reported that the form was easy to navigate and required fewer than five minutes to complete. The lack of compliance from one patient with severe symptoms arose because of being asked to complete ESAS-r + 1QoL form multiple times in a week or on weekly basis. One patient reported that the form was redundant to complete it twice in a single week. This patient did not see the value in completing the form during their visit.

The three adult oncology clinics were part of this pilot project. The OOPC operates out of an office located in one of the clinics and patients are scheduled throughout these clinics. The OOPC provider template is available in two of the three clinics, resulting in a barrier for the other clinic.

Exploring facilitators and barriers to implementation in PC setting can help guide the process of implementation and its effect of routine use of PROs on patient outcomes in the outpatient clinics. Despite PC guidelines, PC clinical practices have been slow to adopt PROs due to time and lack of consensus regarding what outcome domains to include and what assessment measures to use [24, 25].

This pilot project supports the need to identify and address barriers when implementing the use of ESAS-r + 1 QoL tool in an OOPC clinic. There is a high need for obtaining patient and staff feedback at regular intervals when implementing a change in practice. This will assist in addressing a barrier at the early stage before it creates a negative impact on the compliance rate. The appropriate use of ESAS-r + 1 QoL tool can help initiate symptom management conversations and determine patients' course of treatment and follow-up. In order to address staff resistance, ongoing training and education are recommended for all clinic staff at set intervals. A small presentation or educational materials should be included in the new hire orientation package to introduce the process during staff training.

Conclusions

The OOPC team cares for a wide range of complex patient populations with different stages of cancer diagnoses, with the range of symptoms and intensity varying from patient to patient. We experienced challenges of practice changes for palliative care clinics embedded within oncology practices even when there's buy-in from all involved clinical and leadership staff, particularly when hand-collecting data for entry into an electronic health record. Future implementation for the ESAS-r + 1QoL tool needs to be

integrated within the electronic health record and be answered at the time of clinic check-in. This will allow more symptom data to be collected and symptom patterns determined.

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Availability of data and material: All data generated or analyzed during this study are included in this published article.

Code availability: N/A

Authors' contributions: All authors contributed to the design, data analysis, and manuscript writing.

Ethics approval: This study was reviewed by the University of North Carolina at Chapel Hill Office of Human Research Ethics, which has determined that this submission does not constitute human subjects research as defined under federal regulations and does not require IRB approval.

Consent to participate: N/A

Consent for publication: N/A

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