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## **Micro-Meso-Macro Practice Tensions in Using Patient-Reported Outcome and Experience Measures in Hospital Palliative Care**

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### **Abstract**

This article applies a micro-meso-macro analytical framework to understand clinicians' experiences and perspectives of using patient-reported outcome and experience measures (PROMs and PREMs) in routine hospital-based palliative care. We structure our discussion through qualitative analysis of a design and implementation project for using an electronic tablet-based tool among hospital-based palliative clinicians to assess patients' and their family caregivers' quality of life concerns and experiences of care. Our analysis identified three categories of practice tensions shaping clinicians' use of PROMs and PREMs in routine care: tensions surrounding implementation, tensions in standardization and quantification, and tensions that arose from scope of practice concerns. Our findings highlight that clinicians necessarily work within the confluence of multiple system priorities, that navigating these priorities can result in irreducible practice tensions, and that awareness of these tensions is a critical consideration when integrating PROMs and PREMs into routine practice.

### **Keywords**

Patient reported outcome measures; quality of life assessment; palliative care; macro-meso-micro; qualitative; Canada

## Introduction

Patient-reported outcome measures (PROMs) and patient-reported experience measures (PREMs) consist of standardized, validated questionnaires for assessing well-being, as well as their experiences with health care. The use of PROMs and PREMs in clinical practice has been studied for several decades, including primary studies and systematic reviews focused specifically on palliative care (Antunes, Harding, & Higginson, 2014; Catania et al., 2016; Catania et al., 2015; Etkind et al., 2015; Hughes et al., 2003; Simon et al., 2012). Although comparative effectiveness studies for evaluating the use of PROMs and PREMs in clinical practice have focused on benefits to different stakeholder groups (e.g., patients, clinicians, administrators, researchers, and policy makers), a lack of explicit theoretical grounding may mask heterogeneity within complex health care systems and assume shared perspectives across stakeholder groups. As a result, there has been limited development of comprehensive explanations for why expected outcomes are (or are not) achieved when integrating PROMs and PREMs into routine care. Consequently, although perspectives of organizational change (Antunes et al., 2014; Bausewein et al., 2016), complex interventions (Boyce, Browne, & Greenhalgh, 2014; Catania et al., 2016; Catania et al., 2015; Santana et al., 2015), and symbolic interactionism (Donaldson, 2008; Lohr & Zebrack, 2009) have provided critical insights, a further need remains for theoretical development that reflects the diversity of perspectives and experiences of stakeholders (Boyce, Browne, & Greenhalgh, 2014; Catania et al., 2015). In this article, we draw upon a micro-meso-macro framework to elucidate clinician-stakeholder perspectives of using PROMs and PREMs within system complexities specific to hospital-based palliative care. In so doing, we contribute a qualitative perspective to research on PROMs and PREMs implementation (Vandermause et al., 2017) by contextualizing clinicians' experiences in new ways that promote successful long-term integration of these tools in routine palliative care.

### *Micro-, Meso-, and Macro-Level Analysis*

Contemporary health care consists of many interdependent influences, relationships, and practices that together form a complex whole or system. One established way of studying the interconnections that constitute these types of social systems is by distinguishing between micro-, meso-, and macro-level considerations. Although these levels necessarily have porous boundaries in real life, they are useful in identifying differentiated yet interconnected stakeholders, organizational levels, and priorities in health care, and are commonly used in policy development and health research (Caldwell & Mays, 2012; T. Greenhalgh & Stones, 2010; Schultz & Kitson, 2010). Nearly 25 years ago, Sutherland and Till (1993) found this multilevel framework useful in identifying how quality of life assessments based on the use of PROMs and PREMs could inform decision making for allocating health care resources on individualized, group, and population-based levels.

Micro-level considerations in health care focus on *interactional individual user* experiences that take place inside and around clinical encounters. The priorities of palliative care at the micro level are concerned with facilitating person-centered care through individualized therapeutic relations that emphasize patients' and family members' choices, desires, and needs in treatment and care planning. Meso-level considerations in health care

focus on the *intermediate organizational aspects* of regulating health in specific populations, communities, and groups. The priorities of palliative care at the meso level are to improve the quality of life of patients with advanced life-limiting illness(es) and that of their families through the organization and regulation of specialist care teams, care settings, scope of practice understandings, and best practice initiatives. Macro-level considerations in health care focus on the highest levels of the *aggregate health care system* for organizing specific responses to structural and social determinates of health at the overall population level. The priorities of palliative care at the macro level are expressed through governmental priority setting mediated through, and transformed within, regional health authorities and professional regulatory bodies. At the macro level, palliative care standardizes, extends, and makes cost-efficient practices to organize compassionate and efficient care for those with advancing life-limiting illness.

A micro-meso-macro framework can contribute to theoretical development regarding the use and uptake of PROMs and PREMs in routine palliative care by foregrounding the contextual plurality of health care priorities. It attends to the situated positions of, and interplay between, heterogeneous stakeholders in health care provision as a necessary antecedent to designing and implementing interventions that seek to improve patient and family care and health outcomes, and thereby complements existing models for anticipating successful practice change. In the following section, we situate literature on PROMs and PREMs integration within a micro-meso-macro framework, and give particular attention to the palliative care context.

## Literature Review

Existing scholarship highlights how integration of PROMs and PREMs into palliative clinical practice can achieve concurrent health care goals for different stakeholder groups. At the micro level of day-to-day clinical encounters, the anticipated benefits of using PROMs and PREMs focus on individualized person-centered *processes* for patients and their social networks. At the meso level, palliative care clinicians' use of PROMs and PREMs is constructed as a *practice* to facilitate person-centered care, enhancing their ability to engage in whole-person care while simultaneously meeting organizational requirements to streamline workflow and advance administrative monitoring for quality improvement. At the macro level, expected benefits of integrating PROMs and PREMs into care center on aggregate *outcomes* data for evaluating and comparing outcomes, efficacy, and costs of caring for critically ill, multimorbid populations within and across health systems. Accordingly, PROMs and PREMs are increasingly advocated as standardized indicators of the quality of palliative care across all health systems levels.

Despite extensive research on their potential benefits, integration of PROMs and PREMs in all care settings remains limited, including palliative care. In turn, primary (Bausewein, 2011; Hughes et al., 2003; Simon et al., 2012; Tavares et al., 2017) and synthesis studies (Antunes et al., 2014; Catania et al., 2016) specific to palliative care have identified key considerations that shape implementation and have provided recommendations for fostering use that have subsequently been incorporated into best practice guidelines (Bausewein et al., 2016). Within these studies, micro-level considerations address individual clinicians'

personal perspectives, beliefs, and values about the use of PROMs and PREMs. Most commonly, this includes clinicians' skepticism regarding the efficacy of routine use of PROMs and PREMs to facilitate improved patient outcomes, clinical value in relation to existing assessment practices, and the validity and veracity of patient self-reports, fear of change, disinclination to engage with potentially difficult topics, and/or belief that use is primarily for performance surveillance (Antunes et al., 2014). Other micro-level considerations include clinicians' concerns that use decreases ability to develop therapeutic relationships, adds to patient burden, and/or can cause harm by triggering emotional distress in patients (Hughes et al., 2003). Finally, attention has been given to micro-level considerations from the patient perspective, including concerns about symptom burden, questioning whether all patients necessarily want to talk about their quality of life issues with health care providers, and/or have the literacy to do so (Bausewein et al., 2011; Simon et al., 2012).

Meso-level considerations emphasize clinicians' inexperience with using PROMs and PREMs, including their limited knowledge about routine implementation, interpretation of scores, and clinical and organizational benefits (Antunes et al., 2014; Bausewein et al., 2011; Catania et al., 2016; Simon et al., 2012). Other significant meso-level aspects address the perception that use complicates clinical workflow and increases workload (Bausewein et al., 2011; Hughes et al., 2003), and the need for resources and training in responding to information from PROMs and PREMs (Antunes et al., 2014; Bausewein, 2011; Catania et al., 2016; Hughes et al., 2003; Simon et al., 2012; Tavares et al., 2017). Resource and training recommendations for addressing these micro- and meso-level implementation concerns include pedagogical initiatives regarding assessment validity and benefits to clinical practice, practical training in use of measurements, increasing managerial support, engagement initiatives, developing shared protocols for acting on measurement results, and how to efficiently integrate use into workflow.

Embedded within these and broader discussions of PROMs and PREMs implementation in clinical care are varying degrees of emphasis on the need for a broader systems perspective that encompass micro, meso, *and* macro levels. One end of the spectrum focuses on the need for framing implementation within a whole systems approach (Greenhalgh, 2009), or as occurring within nested microsystems (Donaldson, 2008). Others mention divergent system-level or user priorities (Boyce, Browne, & Greenhalgh, 2014; Greenhalgh, Long, & Flynn, 2005; Valderas et al., 2008); point to the need for balancing standardization with diversity in care (Simon et al., 2012); identify implementation as a complex intervention (Catania et al., 2016); call for future research to attend to the wider social, cultural, and structural contexts that shape daily practice (Hughes et al., 2003); or acknowledge that clinical settings are "dynamic systems" populated by heterogeneous individuals (Antunes et al., 2014). At the other end of the spectrum, there remains little or no discussion of system or stakeholder heterogeneity, and macro-level health care system considerations center on practical and technical challenges regarding integration with records management systems, confidentiality of data, licensing fees, and in the United States, issues of reimbursement.

Further research on stakeholders' experiences of using PROMs and PREMs within complex health care systems has been articulated as a precondition for more robust understandings as to why integration into routine care, including palliative care, remains

elusive (Boyce, Browne, & Greenhalgh, 2014; Catania et al., 2016; Greenhalgh et al., 2005; Hughes et al., 2003). In this article, we present the findings of an implementation study that elicited clinicians' perspectives and experiences of integrating an electronic tablet-based tool into practice to facilitate routine assessment of patients' and family members' quality of life and experiences of care (using PROMs and PREMs). Here we frame local-level findings of our analysis within micro-, meso-, and macro-level health care systems considerations of practice tensions. In so doing, our aim is to contribute theoretical understandings of how hospital palliative care clinicians relate to different health care system priorities when integrating PROMs and PREMs into their practice.

## **Project Background**

This analysis is part of an overarching applied health services research initiative involving the design, implementation, and evaluation of an electronic Quality of Life Assessment and Practice Support System (QPSS) in community- and hospital-based palliative care settings (Sawatzky, Cohen, Laforest, Voth, & Stajduhar, 2014; Schick-Makaroff et al., 2017). The initiative combines implementation science, knowledge translation strategies, mixed qualitative and quantitative methods, and user-centered design to develop much-needed knowledge about the integration and routine use of electronic quality of life assessments, based on PROMs and PREMs, with patients who have chronic life-limiting illnesses and their family members.

The tablet-based QPSS provides a means for patients and their family caregivers to respond to well-established, standardized questionnaires about their symptoms; their physical, psychological, social, and existential/spiritual well-being; and their experiences with health care. Responses are immediately summarized and presented back to health care professionals who can use this information to monitor and address any revealed health care needs or concerns. The analysis presented herein focuses on clinicians' use of the QPSS within a hospital-based acute palliative care unit in Western Canada over a period of 18 months in 2014–2015. Ethics approval was obtained from Trinity Western University (14F05) and Fraser Health (FHREB 2014-032), and all participants provided written informed consent.

## **Method**

### *Setting, Sample, and Inclusion Criteria*

The 10-bed palliative unit serves patients with complex needs who require specialized interdisciplinary team support, and is part of a larger 300-bed suburban acute care hospital. Staff included nurses ( $n = 19$ ), a patient care coordinator, a unit clerk, a social worker, a pharmacist, and two palliative care physicians, totaling 25 clinician-participants. Clinicians had a median age of 43 years, most were female (80%), had a permanent position (76%) with a median of 8 years of experience (ranging from 1–26 years), and were born in Canada (72%).

All clinicians (including those in administrative or managerial positions) were eligible to participate and were offered the opportunity to use the QPSS with consenting patients and family members. We described the overall goal of the study to clinicians as obtaining input

on design and use of the QPSS to support improved person-centered care, including their perspectives about using PROMs and PREMs at the point of care. Participation in using the QPSS, focus groups, and/or interviews was voluntary.

### *Data Collection*

The project was designed in two phases. The first phase of the project involved conducting focus groups with the clinicians to ascertain the desired operational characteristics of the system and identify barriers and facilitators regarding its routine use in practice. The second phase involved obtaining feedback from clinicians through focus groups and individual interviews regarding the use of quality of life assessment instruments and, subsequently, the QPSS, to inform its ongoing development and use in practice. We conducted five clinician focus groups and 24 clinician interviews regarding the desirable features of the QPSS and its use in daily practice. Focus groups and interviews were recorded and transcribed verbatim. Clinicians chose three patient-focused assessment tools for use on the tablet: the Edmonton Symptom Assessment System– Revised Version (ESAS-r) (Bruera, Kuehn, Miller, Selmsler, & Macmillan, 1991; Watanabe et al., 2011), McGill Quality of Life–Revised Version (Cohen, Mount, Strobel, & Bui, 1995; Cohen et al., 2017), and the Canadian Health Care Evaluation Project Lite Questionnaire (Heyland, Jiang, Day, Cohen, & Canadian Researchers at the End of Life Network, 2013). The most commonly used was the ESAS-r, which assesses pain, tiredness, nausea, depression, anxiety, drowsiness, appetite, well-being, and shortness of breath. The tablet was used at least once by 11 clinicians registered on the system.

### *Analysis*

Analysis included all focus groups and clinician interviews. Initial data analysis for the overall project focused on QPSS design considerations, clinicians' experiences and considerations of initial QPSS use, and their perspectives regarding use of PROMs and PREMs in day-to-day palliative care. We employed an iterative process based on inductive principles and constant comparison within and between transcripts to generate codes that were subsequently developed into a thematic taxonomy and provisional codebook. To further refine emergent findings and to strengthen analytic rigor, two team members then revisited and double-coded the transcripts, which were then compared and discussed by the whole team. At the end of the project, team members met to mutually challenge the fitness of our themes across the data, to locate findings within the existing body of knowledge regarding PROMs and PREMs implementation, and to situate our explanatory framework with reference to broader literatures in health and social science. Transcripts were organized and coded using NVIVO 11.

This article reports on the concept of "practicetensions", a theme that arose from ongoing consideration of apparently contradictory data. We define a practice tension in two ways: (a) to describe the stretching or strain when clinicians concurrently hold and/or value differing perspectives, beliefs, and/or behaviors about a specific clinical practice, and (b) as an effect of clinicians' ongoing requirement to negotiate the, at times incommensurate, micro-, meso-, and macro-level goals and priorities expressed by heterogeneous stakeholders within complex health systems. We define practice tensions not as

contradictions but as ambivalences, situated in the lived experiences of hospital palliative care clinicians as they routinely attempt to balance considerations such as patient/family member's desires for aggressive treatment in relation to evidence-based practices, provide holistic care in contexts that prioritize task-based care and rapid discharge pressures, support families as part of the circle of care while wrestling with complex family dynamics, and develop individualized therapeutic relationships in tandem with increasing practice standardization.

The theoretical framework of this article emerged from our observation that clinicians' discussions of the QPSS were context dependent, and indelibly conflated with power dynamics and institutional priorities. Robust analysis of clinicians' perspectives about the QPSS therefore required both attention to inductive findings and theoretically situating them within a framework that referenced their situated context, including clinicians' perspectives of standardized assessments more generally. Consequently, we chose a micro-meso-macro framework as a theoretical perspective as it gives equal value to systems considerations and clinicians' considerations of lived practice.

## **Results**

Three main categories of practice tensions shaped clinicians' interest in, and capacity for, using PROMs and PREMs in routine care: tensions during initial QPSS use, tensions in standardization and quantification, and tensions that arose from scope of practice concerns. The nature of the tensions became increasingly nuanced as clinicians gained familiarity with the use of the QPSS. Clinicians' grounded their discussion within preexisting practice considerations; yet these considerations also appeared to evolve as the project unfolded. Consequently, we position the following tensions as practice oriented within a processual context.

### *Growing Recognition of Tensions in QPSS Use*

Although some clinicians had relatively fixed opinions about the effectiveness of using PROMs and PREMs throughout the QPSS project, the opinions of others were more fluid and influenced by different periods of initial use. In the first-phase focus groups, participants spoke spontaneously and enthusiastically about the desirability of statutory use, with particular reference to being able to simultaneously address micro-, meso-, and macro-level concerns.

Clinician 2: I think [formally assessing quality of life and care experiences] is super useful in our setting . . .

Facilitator: Can you anticipate any other type of benefit that you might see from this?

Clinician 1: Well, just the ultimate of better patient/family care.

Clinician 3: Satisfaction, job satisfaction. To know that you assessed your patient properly and were able to act on it.

Clinician 1: Really did your best.

Clinician 5: And maybe to see patient outcomes that you've implemented a certain type of treatment—oh my goodness, it's working.

Clinician 3: Yeah.

Clinician 5: Patient's feeling better. (Focus Group 1)

In later focus groups and in subsequent one-on-one interviews after initial use of the QPSS, clinicians increasingly framed QPSS use through referencing both the “ideal” of palliative care philosophy and the “real” of palliative care provision. In these instances, clinicians often oscillated between understanding PROMs and PREMs primarily as (a) tools to facilitate person-centered care to make visible patients' and family members' quality of life and experience of care considerations (to meet micro-level concerns), (b) clinician-driven tools for discretionary use to identify issues relevant to care and treatment (to meet meso-level concerns), and (c) administrative-driven data collection tools mandated by organizational and governmental policies (to meet macro-level concerns). In early focus groups, clinicians were enthusiastic about using the assessment tools and discussed the potential of PROMs and PREMs to bridge these different stakeholder priorities. In subsequent one-on-one interviews and later focus groups, however, clinicians increasingly referenced practice considerations that simultaneously supported and minimized their interest in using standardized quality of life assessment tools.

Clinician 4: It's [quality of life or experiences of care] being turned into a numerical digit that . . . that allows us to track in a potentially more accurate way . . . but sometimes [results] can be misleading as well. But I think that's where it's useful is over time because we know [a patient] might be feeling very distressed because she just had an argument with her husband [an hour] ago, and that can be an anomaly, seeing it over a week, that a certain thing is poor over a whole week, then that gives us the [bigger picture] . . .

Clinician 6: Well, it's always nice to have a resource, like to back up whatever you are saying you need to do. But we have been [doing this] a long time, so we know how the team works. [But] for me, it's always nice to repeat . . .

Clinician 7: Yeah, and even newer employee nurses on our unit wouldn't need it for long.

Clinician 8: And plus, the mentorship on the unit is pretty stellar in terms of new people coming to the unit. They're never left to just kind of figure it out, right? And even if somebody doesn't know how to do something, we often consult each other as to what to do next or, you know, “I tried this and this, but I can't think of any other options. What do you do?” . . .

Clinician 7: And if we didn't know, we would bring it up in rounds. (Focus Group 4)

This quote evidences how, during the latter project stages, considerations of ongoing use were ambivalently framed, with clinicians invoking practice experiences and/or hypothetical understandings that highlighted positive individual outcomes while expressing uncertainty regarding efficacy in statutory PROMs and PREMs use across their entire patient population. Clinicians also framed assessment use through ambivalent considerations about standardizing quality of life and care experiences.

#### *Standardization and Quantification Tensions*

Clinicians articulated many positive considerations when framing their perspectives of using PROMs and PREMs to standardize practices for assessing patients' (and family members') quality of life and care experiences. These considerations included PROMs and PREMs providing knowledge about individuals' unique (and changing) quality of life concerns, serving as a standardized conversation starter about potentially sensitive or overlooked concerns, consistently including family members in the circle of care, and as providing a tool for strengthening patients' and family members' capacity to direct care planning. Meso-level clinical benefits primarily centered on how PROMs and PREMs could make visible quality of life concerns within a biomedical setting dominated by physical symptom management priorities. Clinicians identified how use of PROMs and PREMs could improve patient care through identifying areas for clinical intervention, for tracking quality of life over time to determine the relationship between interventions and quality of life, for generating a shared understanding of issues within the interdisciplinary team setting, in aiding new staff who do not yet have established assessment skills, and for informing non-palliative health care providers. Organizational meso- and macro-level benefits referenced systematic collection of data for administrative tracking, quality improvement, and outcomes evaluation relevant to their ward, the hospital, and the larger health authority. In particular, clinicians identified how evidence of improved care outcomes could operate as a form of administrative justification for further infrastructure development and resource expenditure requests within the larger health authority. Finally, when mentioned specifically, macro-level benefits referenced how PROMs and PREMs use could enable larger cross-systems comparisons.

Although early focus group participants referenced some concerns about standardization of practice and quantification of quality of life and care concerns, these became increasingly predominant in later focus groups (as evidenced in the previous quote), and in subsequent one-on-one interviews once the QPSS had been put into practice. In these contexts, clinicians expressed significant reservations about the efficacy of PROMs and PREMs in routine clinical practice and, at times, referenced all experience and outcomes measurements as a unitary whole. At a micro level, some clinicians questioned relevance to individual patient outcomes given the limited routine integration of information from PROMs and PREMs in rounds or care planning by the multiprofessional health care team. Other micro-level considerations included concerns of patient burden (both physical and emotional), that many patients are not able to respond adequately due to confusion around instructions, fluctuating symptoms, or, at times, may consciously respond untruthfully to achieve inaccurate results to facilitate specific care outcomes (such as early or delayed discharge).

Simultaneous to these expressions of uncertainty and concerns, however, clinicians also continued to articulate how routine use of PROMs and PREMs could enhance their capacity to engage in person-centered care, including references to promoting patient voice, as evidenced in the following quote taken from an interview with a clinician near the end of the project.

For those who want another way to voice their experiences, it's fantastic because a lot of people . . . you know, by the time they kind of come to us within their journey of health care and transitioning through the disease process, a lot of people don't feel like they've been listened to.

Clinicians also expressed ambivalences in meso-level purposes of PROMs and PREMs use, asserting that their palliative expertise already encompassed routine conversational and observational quality of life assessments, and engendered robust interdisciplinary communication. Participants expressed meso-level concerns that mandated use could limit their clinical autonomy and skill building, predominantly in relation to developing therapeutic relationships. Finally, many expressed concern that routine use of standardized assessment tools may be driven by “misguided” macro-level policies and an example of yet another mandated “top down” initiative. All three levels of these concerns are highlighted in the following excerpt from an interview with a nurse near the end of the project.

Clinician: I do think that in nursing in general that we tend to rely too much on tools and protocols and not enough on personal communication and just quality assessments. And in my heart I think although these are validated tools, I think they're validated under certain conditions. Like for the ESAS for instance, a quality tool that's definitely been validated, but I think that [we use it] in a way that is not validated, for instance, and accreditation would be one reason . . . I don't think that any tool should be something that's a mandatory thing . . . And I think actually a lot of these tools are robbing nursing of the art of nursing . . . I can explore these things in a conversation that is far less clinical, probably more inviting to the person—although at times I think probably they would like the more anonymity of just interacting with a piece of paper or a tablet—but I find that I can do an assessment myself, talking to a patient, seeing their facial cues, you know, their body language and things like that, and get more out of it than somebody simply circling a scale of 0 to 10.

Yet, even as this particular clinician comprehensively lists concerns about use, she also, at the same time, acknowledges that some patients may appreciate the possibility of anonymity afforded by standardized tools. This ambivalence regarding the routine use of PROMs and PREMs was also echoed by clinicians in discussions about scope of practice in hospital palliative care.

### *Tensions in Scope of Practice*

In early focus groups, clinicians identified how use of PROMs and PREMs could

simultaneously support micro-, meso-, and macro-level improvement in palliative care. As evidenced in the quote below, clinicians articulated that use could further person-centered palliative care by minimizing clinical assumptions about patients, including family members in the circle of care, and enabling internal audits as well as larger research initiatives to support the development and expansion of palliative care.

Clinician 5: I can't remember how many times we come into rounds and we're making an assumption about how a person is perceiving themselves, in rounds, we do that *a lot* . . .

Clinician 2: And family, I think that's a huge piece too. (Several people chorus their agreement to this) . . .

Clinician 6: Because we're using this data to help us do our job better to help our patients and families, but it's also going in another direction for possible research, audit and all these other things . . . (Focus Group 1)

Clinicians also referenced general macro-level positives such as how results could showcase the benefits of palliative care, thereby generating wider interest in this form of care. With respect to the meso level, clinicians strongly identified that appropriate palliative care required consistent and explicit attention to patients' and family members' quality of life and experiences of care concerns to achieve adequate scope of practice. On a micro level, clinicians acknowledged that they—at times—make incorrect assumptions about patient experience, that consistent assessment did not always occur in their regular practice, and that using standardized tools could help to ensure their achievement of person-centered care.

References to scope of practice constraints became increasingly common by the third focus group. Macro-level tensions focused on working in resource-constrained health systems with increasingly challenging acute and multimorbid older adult populations. Correspondingly, on the meso level, clinicians identified acute palliative care as increasingly prioritizing physical symptom management, stabilization, and discharge which demands primarily task-based care, often leaving little time for patients' concerns about quality of life, much less family members'. Clinicians also identified their scope of practice as being shaped by ongoing restructuring and practice changes often lead to "burnout" and cynicism. They also cited increasing workloads, a lack of resources for efficiently sharing results and addressing patient and family member concerns once identified, discomfort in dealing with emotional distress, and/or belief that these issues are primarily the professional domains of social work and/or spiritual care. We offer a particularly strong articulation of these concerns taken from an interview conducted during Stage 2.

Clinician: I think it [quality of life and experience of care assessments] should be done maybe by either social worker or spiritual care coordinator, people that can sit down and talk about that, because I would feel that I'm not compassionate enough . . . Sometimes you ask one patient or one family member one question that requires a yes or no answer and they would go into like 10 minute conversation, which also pushes you back from what's waiting for you out there, the bells are ringing and stuff. I cannot relax in knowing that my

other people are having pain and I'm sitting here listening to a life story that has nothing to do with a patient. And I've learned, it's actually a learned skill, to kind of interrupt the conversation and say, "Oh, so sorry. I just need to run." But some of them are really hard. If somebody's really upset, struggling with like husband or father of three young kids dying, then . . . I just rather not put myself into those shoes that I ask the question and then I can't fulfill that, so I'd rather not even initiate that conversation, because I know if I do, and maybe it's not the best practice, but I feel if I start, I need to finish, and I can't, and then I feel really bad . . . [and] when I leave, I have to put that smile back on and go to next room and pretend that nothing happened in the next room.

Interviewer: So if you were to do assessments that would make your job harder?

Clinician: Definitely.

Finally, on the micro level, some clinicians questioned the assumption that all patients nearing the end of life want to discuss potentially sensitive issues and/or have the capacity to do so due to disease progression.

## **Discussion**

Our analysis reflects three categories of practice tensions that framed hospital clinicians' complex perspectives when discussing the considerations of using PROMs and PREMs in day-to-day palliative care: growing recognition of tensions in QPSS use, tensions in standardization and quantification, and tensions that arose from scope of practice concerns. Analyzing these findings within a local context that references the "complexity of the real palliative care world" (Catania et al., 2015) and employing a micro-meso-macro framework provides an innovative theoretical contribution to existing research. Of particular interest is that, in most instances, clinicians did not completely collapse their understanding of PROMs and PREMs to a unified position, either pro or con, but instead situated their perspectives within an explanatory framework that simultaneously, if differentially, referenced diverse characteristics and purposes of the tools within micro-, meso-, and macro-level considerations. We suggest that this positionality evidences clinicians' requirement to navigate multiple overlapping—but not always commensurate—understandings of practice purpose and outcomes among heterogeneous stakeholders in complex system environments. We consider and extend three aspects of our analysis and findings to suggest how they may be utilized to inform further research.

### *Awareness That Clinicians May Not Have Equal Familiarity With the Purpose of PROMs and PREMs Across Micro, Meso, and Macro Levels*

Clinicians primarily focused on meso- and micro-level considerations when framing their desires, concerns, and experiences of using PROMs and PREMs. As we highlighted in the literature review, this micro-meso focus is also reflected in much of the implementation literature with attention focused on developing engagement strategies, training sessions, management champions, and protocols and practice support aids to support PROMs and PREMs use. Further attention to macro-level considerations may help frontline clinicians

better understand how routine use of PROMs and PREMs supports person-centered care well beyond the immediate clinical context. We suggest that future integration initiatives ground clinicians' understanding within research that evidences the value and importance of PROMs and PREMs data to macro-level policy development and population health decision making for "improving quality, effectiveness, efficiency and availability of palliative care" (Bausewein et al., 2016) in an era increasingly influenced by big data. In turn, increased awareness of the benefits and drivers of PROMs and PREMs use at this level may help clinicians better understand that results from "top down" initiatives can facilitate macro-level resource allocation for service improvements that strengthens clinical practice at the meso level, and supports improved patients' well-being on the micro level (Lee et al., 2013).

*Recognition That Palliative Clinicians Negotiate Care Within Heterogeneous Micro-, Meso-, and Macro-Level Health System Priorities Which Generate Intrinsic Practice Tensions*

Concerns about patients' and family members' quality of life and experiences of care have been central features of palliative care since its inception, as evidenced in both its earliest and most recent definitions (World Health Organization, 2015), and have been instrumental in shaping contemporary understandings about appropriate care for those with advancing life-limiting illnesses. With the success and expansion of palliative care, however, clinicians are increasingly engaging with new and multimorbid populations and providing advanced treatment interventions that simultaneously increase quality of life *and* prognostic uncertainty. Promoting patient and family member involvement, while desirable, can also at times increase complexity in care. Complicating matters further, these changes are being enacted within the rise of economic priorities driving current health care systems, where the impetus for care is influenced by requirements for organizational efficiency and cost containment as much as by concerns to promote person-centered care. This framing valorizes a "bureaucratic model" of task-based care over therapeutic relationship building, where palliative clinicians are institutionally rewarded for adhering to economic and managerial priorities rather than patient or even clinician preferences in end-of-life care (Bruce & Boston, 2008). Hospital clinicians' ability to assess and address quality of life and care experiences are therefore shaped by systems that require them to simultaneously meet the needs of their patients, the patients' networks of relations, fellow health care providers, the institutions of care, their own professional regulatory bodies, and larger governmental interests. Due to this complexity, clinicians are often pulled in competing directions (Mikesell & Bromley, 2012; Röing, Holmström, & Larsson, 2018). Consequently, instead of situating clinicians' beliefs of PROMs and PREMs as uniformed or contradictory, our analytic framework provides insight as to how future implementation research may also be strengthened by attending to tensions embedded within the provision of care shaped by not always commensurate micro-, meso-, and macro-level priorities.

*Acknowledgment That Different Levels of Priorities Drive PROMs and PREMs Implementation and Use*

Previous research has identified that some groups of stakeholders are more interested in using PROMs and PREMs than others (Boyce, Browne, & Greenhalgh, 2014; Sutherland & Till, 1993; Valderas et al., 2008). The prevailing discourse, however, is

that systematic use of these tools unproblematically meets the needs of, and equally benefits, individual patients and family members, clinicians, institutions of care, researchers, and larger regulatory and/or governmental-level interests. Yet, in spite of slow uptake, little discussion has been given to exploring how PROMs and PREMs have emerged as a

best practice within specific social and historical contexts and economic demands that are not necessarily commensurate, including increased interest in person-centered care, the global rise of individualized surveillance in population health, the necessity of large datasets to undertake performance audits both locally and across geographic boundaries, and concerns for quality improvement and cost containment in organizing the health needs and out-comes of those with advanced life-limiting illnesses (Öhlén et al., 2017). These requirements have resulted, in some regions, in accreditation and health care funding becoming conditional on the provision of PROMs and PREMs data, even as some researchers suggest proceeding with caution due to insufficient and/or conflicting evidence (Boyce, Browne, & Greenhalgh, 2014; Santana & Feeny, 2014; Valderas et al., 2008). We suggest that implementation initiatives may benefit from publicly acknowledging that administrators, clinicians, researchers, patients, and family members may, at times, have legitimately different objectives and priorities in championing PROMs and PREMs. It is also important to acknowledge that those who are interested in using PROMs and PREMs do not necessarily have equal voice in deciding how and when they will be used. Without explicit acknowledgment and deeper understanding of situated motivations by different stakeholders, or what Boyce, Browne & Greenhalgh (2014) term “a high level of transparency,” we may exacerbate current tensions regarding the purpose and desirability of use to improve care outcomes.”

We believe that further attention to these three aspects of PROMs and PREMs use may facilitate clinicians’ interest in weathering the inevitable challenges that come from integrating new practices into routine care within complex, and at times, contradictory, health systems settings that are organized by unequal relations of power. We therefore end by advocating a starting point for future research, one based on a shared recognition that PROMs and PREMs are not a neutral technology, and that implementation into clinical practice is shaped by a range of considerations constituted by a polyphony of system contexts and differently enabled actors. We suggest that it is from this vantage point, where stakeholder and system differences are neither masked nor assumed, that we can best determine the possibilities for what the philosopher John Rawls (1987) has termed “overlapping consensus” to support successful implementation of PROMs and PREMs within routine clinical care.

## **Limitations**

Different health care sites have their own particular histories and cultures that are generalizable to a greater or lesser degree. This particular research site was one in which there was a contested history of mandated use of the ESAS-r and in which clinicians expressed significant comfort with their own, and their team’s, existing tacit assessment capacities. These are context-specific considerations which limit transferability of findings,

as is true of all small-scale qualitative analyses. However, we believe that institutional care provision occurs within organizational contexts that are always already constituted by these types of considerations, even as the specificity which constitutes them may differ.

Increasing variety in working patterns, ongoing restructuring, and workload constraints are challenges when conducting research with health care providers. Consequently, not all clinicians participated in all focus groups, or in both focus groups and interviews. We acknowledge this “patchiness” in representation and that gaps in representation are unavoidable when the hospital unit as a whole, rather than individuals, are the primary site of research. Another representation constraint we consider here is the semipublic “front stage” space created by focus groups, where clinicians may have felt compelled to engage in idealized and/or normative narratives of practice, particularly as our groups included clinicians with managerial responsibilities. However, the themes addressed in this article were also well represented within private one-to-one interviews. A final consideration is that our micro-meso-macro framework was articulated only through reference to clinicians’ perspectives. A comprehensive insight of practice tensions will require that others involved in the provision and uptake of hospital palliative care be included.

## **Conclusion**

Existing approaches to support PROMs and PREMs use in routine clinical care have generated a range of recommendations, with primary focus on a trifecta of educational initiatives, strong managerial involvement, and development of user protocols and practice support aids. We agree that these practical micro- and meso-level aspects are critical and necessary antecedents to successful implementation. We also agree that these considerations alone may not be sufficient, and introduce the concept of practice tensions within a micro-meso-macro framework to generate new analytical insights regarding clinicians’ perspectives and experiences of using PROMs and PREMs in routine clinical care and to make evident the relevance of systems theorizing in tandem with pragmatic considerations.

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The authors declared no potential conflicts of interest with respect to the research, authorship, and/or publication of this article

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