Asking the Question ‘What Matters to You?’ in a London Intensive Care Unit

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The origins of shared decision-making can be tracked to 1972 and Veatch’s article instructing readers on the models for ethical medicine.1 Veatch advocated that physicians need to understand “that the patient must maintain freedom of control over his own life and destiny when significant choices are to be made.”1 He described a contractual model for health care where the framework for clinical decision-making is based on the patient’s values. The concept of shared decision-making continued to develop over the following decades, including becoming a core principle of patient-centered care movements such as that established by The Picker Institute in 1986.2 In 2012, a perspective piece published in the New England Journal of Medicine proposed that clinicians could facilitate shared decision-making and move further toward patient-centered care by asking a simple question — “What matters to you?”3 In doing so, the authors suggested that patients’ experience of health care could be improved.3

The What Matters To You (WMTY) movement gathered momentum through its adoption by the international Institute for Healthcare Improvement (IHI). The concept was promoted by IHI President Maureen Bisognano and was launched in Norway in 2014. Bisognano described: “I was once walking through a long-term care home in Norway, and I noticed their whiteboards ... seeing these whiteboards filled me with joy. I saw pictures of the residents, the names they like to be called, their ages, and what matters to them. The interactions in this long-term care home are between human beings, not just between clinicians and patients.”4 In the United Kingdom, an emphasis on this move toward personalized patient care is a key aspect of the National Health Service (NHS) Long Term Plan,5 and in parallel, there has been growing involvement in the international WMTY movement.5,7 Evidence has demonstrated that the experience of the intensive care unit (ICU) can be dehumanizing.8 Dehumanization is defined as “treating and/or viewing another person as if she/he did not possess the attributes of other human beings.”9 Patients in the ICU are especially susceptible, as they frequently have impairment of human qualities such as consciousness and autonomy.9 This is amplified by patient and environmental factors: exposure

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**Purpose**
At the heart of the paradigm shift in approach to patient care from paternalism toward shared decision-making lies the international “What Matters To You?” (WMTY) movement. However, WMTY principles are not frequently applied to the critical care setting. The aim of this quality improvement project work was to design and integrate a tool for all patients admitted to the intensive care unit (ICU) that helped answer WMTY.

**Methods**
Using Plan-Do-Study-Act (PDSA) methodology across 8 cycles, a multidisciplinary team designed and integrated a bedside poster into the ICU. Quantitative and qualitative data were collected via a bedside audit process on a regular basis during each of the study phases comprising PDSA cycles.

**Results**
Project results confirmed that the introduction of this poster/tool, alongside resource- and staff engagement-focused interventions, enabled the ICU to offer more than 50% of patients a WMTY conversation, as compared to zero at the start of the project. Consistently, 100% of staff surveyed (n=46 over all cycles) felt the posters were a useful addition to the ICU and confirmed they learned something new about their patients that they didn’t know already.

**Conclusions**
This novel poster design successfully summarized patients’ responses to the question “What matters to you?” for ICU staff and would be transferable to other ICUs. (J Patient Cent Res Rev. 2022;9:166-173.)

**Keywords**
patient experience; intensive care unit; dehumanization; quality improvement; Plan-Do-Study-Act; bedside
for care, delirium, ambient noise from machines, frequent assessments, and limited visiting to facilitate rest and recovery.\(^5\) The COVID-19 pandemic placed an unprecedented strain on the U.K.’s NHS with a total of 25,843 ICU patients from September 2020 to August 2021, in England, Wales, and Northern Ireland.\(^10\) This led to increased patient to staff ratios, redeployment of staff into the ICU,\(^11\) and obscured physical interactions due to personal protective equipment.\(^12\) These factors contributed to an increase in dehumanization in ICU, with associated distress for patients and families and high burnout rates for staff.\(^13-16\)

Research conducted to combat dehumanization has demonstrated the benefit of simple strategies such as hand-holding and nonpharmacological interventions to relieve anxiety.\(^17\) A 2019 systematic review noted a need to respect patients’ individuality as a key element in humanization of care.\(^18\) Current practice to improve humanization focuses on long-stay ICU patients. For example, tools such as the post-ICU presentation screen inform the development of a personalized “rehabilitation prescription” once acute medical issues have resolved,\(^19\) whereas a focus on highlighting individuality at the time of admission to ICU is rare.

The aim of this quality improvement (QI) project was to design and integrate a tool to ask WMTY for patients admitted to the ICU at Royal Free Hospital in London, England. Importantly, the tool was designed for both short- and long-stay patients. A key focus of the project was to encourage humanization through displaying what matters to that patient in a format that was readily accessible to caregivers.\(^9\)

**METHODS**

Research participants of this QI project were patients admitted to the ICU, their families or friends, and the staff looking after them at Royal Free Hospital, a tertiary ICU in central London. The unit has 46 adult ICU beds with more than 1500 patients admitted yearly. It is a major referral center for the south of England and provided support for all in-patient specialties, including liver transplant, complex vascular surgery, and infectious diseases.\(^20\) All patients admitted could be included in the QI project over the 8-month study period. Questionnaire respondents were all ICU staff from a range of disciplines, including doctors, nurses, health care assistants, and allied health professionals.

The project utilized the Plan-Do-Study-Act (PDSA) methodology and included 8 cycles over an 8-month period that were subcategorized into two phases.\(^21\) The project was led by a core research team of a doctor, physiotherapy assistant, and QI advisor. Key stakeholders, including doctors, nurses, and allied health professionals, were recruited to form a WMTY-dedicated multidisciplinary team. WMTY team members were consulted by the core research team throughout each study phase of the project, and their feedback was the basis for further PDSA cycles.

This QI project was not human subjects research, therefore ethics approval was not required. Information gained about the patients was used solely to improve their care, and the questions asked are often part of routine assessments within the hospital, although not previously within the ICU. The project was sponsored by ICU leaders, and updates were reported to them. It was registered on the hospital system for recording QI projects, and updates were reviewed by the “what matters to patients” hospital committee chaired by the hospital’s director of nursing.

**Phase 1**

The focus of phase 1 of the project was designing a tool — namely, a bedside poster — based around the concept of WMTY. Phase 1 was conducted from January to March 2021 and encompassed PDSA cycles 1–4. The initial bedside poster was developed from an existing poster used sporadically within non-ICU wards within the hospital. The focus of cycles 1–4 was adapting poster content to the ICU setting. In each of the first 4 cycles, the poster was piloted on a small number of patients.

In cycles 1–4, information for the posters was collected from patients and families by the core research team and a small number of volunteer medical students, doctors, nurses, and therapy assistants. If patients and families offered comments on the project, these were noted as quotes of patient and family experience and recorded by the research team.

A simple bedside questionnaire was utilized to gain feedback from staff caring for these patients. Staff were asked 3 questions:

1) Did you learn something you didn’t know about your patient?
2) Did you feel that this was helpful for the staff caring for the patient to know?
3) Have you changed something you’ve done today as a result?

We also included a free-text box for further comments, and these responses were collected using Google Forms on a smartphone by the core research team. All questionnaire responses were distributed throughout the research team in person on the day the staff had used the
poster and then fed back, alongside the patient and family quotes, to the WMTY multidisciplinary team in monthly face-to-face meetings where the collected data were used to adapt the poster.

The poster was tested on 2, 5, 4, and 8 patients in cycles 1, 2, 3, and 4, respectively. The questionnaire was completed by 31 staff members across these first 4 cycles. Details on changes made to the poster over these cycles can be seen in Table 1. The first poster iteration was noted to be “too busy” and “difficult to read” and required frequent updating because of the box for video calls. This feedback helped us to streamline the poster and make each box clearer, larger, and more colorful (Figure 1). Through testing and developing the tool in our ICU before finalizing it, a poster that staff directly contributed toward was created. This helped to bring a sense of ownership to the project and increased awareness of the project’s value.

**Phase 2**

The focus of phase 2 of the project was the integration of the poster into routine clinical practice at the time of admission to ICU. Phase 2 was conducted from April to August 2021 and encompassed PDSA cycles 5–8, and the aim was for all patients in the ICU to be offered a WMTY conversation using the poster. Our interventions concentrated on staff engagement and resources. Staff engagement was focused across all ICU staff — nurses, allied health professionals, psychologists, doctors, and administrative staff — and those with a particular interest in the project, 15 in total, were recruited as ambassadors to join the WMTY multidisciplinary team across cycles 6–8. Monthly meetings with the WMTY multidisciplinary team were continued to maintain momentum.

As shown in Table 2, over cycles 5–8, staff were instructed through various means on the following methods of the project: all bedspaces to have a poster; it can be written on by anyone (all staff, relatives, the patient) using the whiteboard marker provided; information can be collected when updating family if the patient is unable to communicate; and when the patient leaves the ICU, the poster should be wiped down and reused. The methods for disseminating this information included emailing all staff, introducing the concept as “topic of the week” at nursing staff handovers, including WMTY in staff inductions, and adding the task of completing the poster to daily consultant jobs lists.

Provision of resources included ensuring availability of posters, pens, a laminator, and paper copies of the poster in admission document packs. In cycle 7 we saw that creating a restock cupboard was essential to ensuring the ongoing use of the poster. In cycle 8 we developed badges for ambassadors to help make them easily identifiable and serve as a visual reminder for staff of the project.

The core research team completed regular audit cycles to assess how many bedspaces had resources and the percentage of occupied beds with completed posters. We checked for a balancing measure of the accuracy of posters in relation to whether they were filled out for the current patient in the bedspace. This was checked by confirming the details of the poster with the patient, if able, or the bedside nurse. This was done to assess whether staff were accurately wiping down the posters when patients left bedspaces. These were assessed using a simple in-person counting method by the same auditor and recorded in an Excel spreadsheet (Microsoft). The auditor also took the opportunity to record verbal feedback from staff on the unit, which was discussed at the monthly WMTY multidisciplinary team meetings to inform future cycles.

At the end of cycle 8, we resurveyed staff with a new Google Form by emailing the link to the survey to all clinical staff in ICU. Staff were asked:

1) Do you think the WMTY posters are a useful addition to the ICU?
2) Did you learn something new about your patients you didn’t already know?
3) Does the WMTY poster help you in your care of patients?
4) Have you ever filled one of the WMTY posters out?
5) Can you share a time the WMTY posters have helped your care/changed something you have done?
6) Any other comments or suggestions for improvement.

A total of 15 survey responses were received. Thematic analysis was performed on responses to question 5 to ascertain common themes.

**RESULTS**

**Phase 1**

Cycles 1 through 4 consistently demonstrated that 100% of respondents (31 staff surveyed over cycles 1–4) learned something they didn’t know about the patient because of the poster (Figure 2). Depending on the cycle, between 55% and 90% of staff reported that they changed something they did that day in caring for that patient directly because of what they’d learned from the poster. For example, staff used a patient’s preferred name, played a patient’s favorite music during a procedure, or were able to facilitate a visit with a patient’s pet after being noted as their “support team” on the poster.
Table 1. Plan-Do-Study-Act Phase 1 Project Cycles

<table>
<thead>
<tr>
<th>Cycle</th>
<th>Plan</th>
<th>Do</th>
<th>Study</th>
<th>Act</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>WMTY MDT meet to decide key principles of the tool: bedside poster; sections to include communication needs, likes, preferred name, support network; easy for anyone to complete</td>
<td>Tested poster 1 on 2 patients; medical students filled in the poster from patient notes</td>
<td>Questionnaire feedback with staff</td>
<td>Test on a wider group – 2 patients chosen were both long-stay and not representative of full ICU cohort</td>
</tr>
<tr>
<td>2</td>
<td>Same poster on a wider group of patients; doctor to fill in during clinical update and gather family feedback</td>
<td>5 patients had posters completed during family updates</td>
<td>Questionnaire feedback with staff and informal feedback from families</td>
<td>Edit poster and limit the boxes so text is easily readable from end of the bed</td>
</tr>
<tr>
<td>3</td>
<td>Redesigned the poster in WMTY MDT meeting, removing video-calling box, which staff had fed back was not useful as would need updating too regularly</td>
<td>Tested on 4 new admission patients, completed by doctors doing the admission clerking</td>
<td>Questionnaire feedback with staff</td>
<td>Test on higher volume of patients, with all posters laminated and “permanently” in the bedsape</td>
</tr>
<tr>
<td>4</td>
<td>Color on posters was adjusted so each section was unique, all posters were laminated and to be tested in one section of the ICU</td>
<td>3 doctors and 1 OT completed 8 posters when doing family updates in one day.</td>
<td>Questionnaire feedback with staff</td>
<td>Implement across the care unit</td>
</tr>
</tbody>
</table>

ICU, intensive care unit; MDT, multidisciplinary team; OT, occupational therapy; WMTY, What Matters To You

Table 2. Plan-Do-Study-Act Phase 2 Project Cycles

<table>
<thead>
<tr>
<th>Cycle</th>
<th>Plan</th>
<th>Do</th>
<th>Study</th>
<th>Act</th>
</tr>
</thead>
<tbody>
<tr>
<td>5</td>
<td>Increase awareness among staff of the project and implement for all patients</td>
<td>A pen and poster placed in each bedspace; email sent to all senior staff to be forwarded to all staff members explaining project</td>
<td>Audited number of bedspaces with accurately completed posters; ongoing WMTY MDT meetings on regular basis to obtain feedback</td>
<td>Good initial uptake with subsequent decline; after meeting, realized many staff missed off initial email and not checking emails regularly</td>
</tr>
<tr>
<td>6</td>
<td>Need to target nursing staff, in particular, with increasing awareness</td>
<td>Recruited 3 nursing staff ambassadors; sent emails specifically to all nursing staff; made it “topic of the week” at nursing handover; paper copy added to each admission pack, which nurses put into each bedspace when new patient arrives</td>
<td>A transient rise in uptake after “topic of the week” – WMTY MDT felt the need for further staff awareness given high numbers of staff turnover</td>
<td></td>
</tr>
<tr>
<td>7</td>
<td>Further nursing staff ambassador recruitment is needed and resources restock is required</td>
<td>5 more nursing staff ambassadors were recruited across grades; restock station created in each section of the unit with spare resources and instructions</td>
<td>From the drop in the number of posters, felt we needed to widen participation in the project further across the ICU MDT</td>
<td></td>
</tr>
<tr>
<td>8</td>
<td>Need ambassadors from throughout ICU MDT and a way for them to be identifiable on the unit; also made a topic at each new staff induction</td>
<td>Further, 7 ambassadors were recruited from PT/OT, SLT, medical team, and psychology; each given custom-designed badge to wear at work to represent project involvement; consultant team also included WMTY as part of daily jobs list</td>
<td>Audited number of bedspaces with accurately completed posters; emailed all staff a questionnaire to feedback on the project</td>
<td>Small improvement made; ongoing plans for project discussed and handover to the new team</td>
</tr>
</tbody>
</table>

ICU, intensive care unit; MDT, multidisciplinary team; OT, occupational therapy; PT, physiotherapy; SLT, speech and language therapy; WMTY, What Matters To You
Free-text responses from staff reflected that the posters helped to “give the patient a personality again” and “provide a new insight.” Some staff felt it helped them to view the patient “more compassionately” and that the poster “would always be helpful when looking after patients.” By cycle 4, staff had expressed that “every patient should have one” and that we were “giving that human touch that we sometimes miss.” Patients and relatives also recognized the project’s value, with some commenting that they “are really grateful and impressed” and “believe in this and think it will make such a difference.”

**Phase 2**

For cycles 5 through 8, the data collected are represented in a run chart that starts with a small number of posters already completed from the end of cycle 4 (Figure 3). The most notable improvement in numbers of charts filled out occurred after cycles 5 and 8; although each cycle did initiate a small improvement, this was consistently difficult to maintain. There is a generalized upward trend in results throughout. This demonstrates that the cumulative effect of the interventions throughout cycles 5–8 are beneficial to improving the percentage of completed posters.

Figure 3 also displays the percentage of completed posters by lengths of stay less than 10 days. As the project progressed, there was a shift toward a higher proportion of posters being completed for short-stay (<10 days) patients.

After cycle 8, staff were re-surveyed and 15 responses were received. Of the 15 respondents, 100% felt the posters were a useful addition to the ICU, 100% learned something new about their patients they didn’t know already, and 100% felt the poster helped them in their care of patients. Despite this, only 46% of the respondents had filled out a poster themselves. In total, 46 staff were surveyed over the course of the project (31 in phase 1, 15 in phase 2).

**Qualitative Data**

The free-text response box of the Google Form used in phase 2 asked staff to share a time the posters had helped their care/changed something they did. Responses demonstrated how the poster could impact day-to-day care. For example, there were numerous cases where using the information on the posters helped staff reorientate delirious patients by calling someone from their support system, using the patient’s preferred name, or calming them using their favorite music or TV program. The information on the poster also was used at the end of life — to play a meaningful song for a patient or to be able to gather all those important to the patient virtually or in-person as visiting allowed. It also helped to engage staff, patients, and families in conversations over shared interests.
Based on thematic analysis, common themes emerging from the answers provided included:

1. Communication: Knowing a patient’s first language, communication needs such as glasses or hearing aids, and preferred name all helped in clinical care.

2. Humanity: Understanding the patient as a person and knowing more about their personality allowed the provision of personalized holistic care. One staff member reflected that it was “building humanity amongst the machines.”

3. Preferences: Having patient preferences helped to provide entertainment for the patient (e.g., TV or music), which can be particularly useful during procedures.

These themes mirrored the findings from cycles 1–4 and demonstrated that the project was well regarded by the ICU team.

Balancing Measure
The balancing measure of any posters displayed for the incorrect patient occurred for 2 separate patients over the 8 cycles. In each case, through discussion with bedside nurses, the core research team found this to have occurred because a patient had been moved to another bedspace and the board had not been wiped down. The potential for this error was addressed in the instructions for staff and when raising awareness of the project methods.
DISCUSSION

This QI project successfully met its first aim of developing a tool to enable staff to learn more about patients, with 100% of the 46 staff surveyed across phases 1 and 2 reporting that the posters had helpful/novel information related to caring for patients. Qualitative reports from staff collected via surveys also demonstrated the impact that the project had on day-to-day care. Specific examples were noted that reflect how the project helped humanize ICU patients for staff, aided communication, and was used to ease patient distress. Through helping staff understand what is important to their patients, this tool demonstrated the core of the WMTY movement.4 Posters were being used to benefit patients across the ICU, including short- and long-stay patients equally, by the end of the project.

We achieved a maximum of 58% compliance with the number of posters completed. Although far from the aim set, this was a marked improvement from baseline. Reflecting on the interventions implemented, each was important to achieving this level of compliance. Particularly successful were the interventions introduced in cycle 8 — formalizing and expanding the role of WMTY ambassadors, presenting them with badges, and moving the project into the “everyday” of the unit by having it as part of physicians’ daily jobs lists.

Project findings add to a growing body of studies demonstrating how to use a WMTY approach to improve care in ICUs. In 2019, Healthcare Improvement Scotland published a case study on using WMTY to support daily practice and cited an example from the Glasgow Royal Infirmary ICU.22 Researchers supported a multidisciplinary approach to WMTY, using paperwork for accountability and normalizing a culture of open communication between staff and patients.22 Similarly, in a QI project published in 2020 by the British Association of Critical Care Nurses, researchers concluded that it was important to bring WMTY into daily practice, particularly in a ward round setting.23 These studies draw similarities with our methods and results, for example, we embedded WMTY into daily practice by adding the concept to daily jobs lists, also used a multidisciplinary team approach, and devised our poster system and its paper counterpart as a way of adding the WMTY concept to the patient’s paperwork.

There were several challenges to implementing this QI project. First, staff familiarity with the project is ongoing. There has been high staff turnover due to the COVID-19 pandemic, which has made it difficult to ensure that all staff understand the project.13 To enable sustainability moving forward, we have built the project into staff inductions for both doctors and nurses. The pandemic has had further effects on the project due to the number of patients moving around the unit for infection control reasons.12 We felt that this might have led to the wrong posters being displayed in the two beds picked up in the assessment of balancing measures.

Additional limitations of this project include its generalizability to other ICUs, particularly smaller centers at which there may be fewer staff members to contribute to a large project or in lower-income settings where it may not be possible to use resources in this way. Future work is required to expand the number of patients asked about what matters to them in the ICU.

CONCLUSIONS

A novel poster tool developed for use in the intensive care unit was able to successfully summarize patient responses to the question “What matters to you?” for ICU staff. Through the first 4 study cycles (phase 1), the poster was designed and refined in response to key stakeholder feedback. Study cycles 5–8 (phase 2) focused on its integration into routine clinical practice. Our results demonstrate that simple tools can be effective at increasing staff knowledge of their patients and that this can have a positive impact on the care delivered. The next phase of this quality improvement project will strive to extend the benefits of the WMTY tool to 100% of patients in the ICU, introduce patient and family surveys to formally measure their responses, and establish a control period to better assess potential benefits of the tool.

Patient-Friendly Recap

• The “What Matters To You?” movement strives for a patient-centered approach to care, but its humanistic principles are not often applied in a critical care setting.
• To improve practices within a London-based ICU, a multidisciplinary team used Plan-Do-Study-Act methods to develop a bedside poster to be filled in with patient preferences (nickname, music, family visitors, etc).
• Quantitative and qualitative data showed that use of the posters increased staff knowledge of their patients and that most felt they had a positive impact on the care delivered.
• While posters were completed for about half of all ICU patients by the project’s end, only 46% of staff surveyed had filled out a poster themselves, indicating more efforts are needed to sustain implementation across the ICU.

172 JPCRR • Volume 9, Issue 3 • Summer 2022
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Author Contributions

Conflicts of Interest
None.

References

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