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**Title: How important is compassionate healthcare to you? A comparison of the perceptions of people in the United States and Ireland**

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*All authors, qualifications, designations and place of work (upload separately to the manuscript to facilitate blind peer review). Authors should include a short (100-150 words) biography with their submission.*

**Abstract –**

**Introduction**

All human beings want to be treated with respect and compassion, especially when ill and vulnerable. We define compassionate care as a process that involves understanding and empathic concern for another's concerns, distress, pain or suffering, coupled with action to ameliorate these conditions. Healthcare professionals recognize and endorse compassion as one of their primary responsibilities as evidenced by its inclusion in professional codes of ethics. Yet the lack of compassion has been cited as a critical problem in healthcare organizations and systems, The ability to address organizational and systemic deficiencies requires measurement of issues that are important to patients and professionals alike, reporting of patients' experiences, and translation of measurement into meaningful quality improvement. Examples of measurement of patient- reported experiences include the Consumer Assessment of Healthcare Providers and Systems (CAHPS®) in the United States (U.S.) and the NHS Adult In-Patient Survey in England. Important aspects of compassionate care however, such as emotional support and contextual knowledge of the patient, are not routinely measured. The myriad causes of compassionate care deficiencies require systemic approaches and solutions; nonetheless, compassionate organizations begin with compassionate people. Explorations of public and professional perceptions of the compassionate behaviors of healthcare professionals could serve the aim of enabling healthcare organizations and systems to identify barriers that inhibit the flourishing of these behaviors.

The Schwartz Center for Compassionate Healthcare conducted a study of the importance and successful demonstration of sixteen elements of compassionate care among a nationally representative sample of 800 recently hospitalized patients and 510 physicians in U.S. Physicians and patients generally agreed on the importance of these elements. However, while 78% of physicians agreed that most healthcare professionals provide compassionate care, only 54% of patients agreed that they do. A psychometric analysis of the data from this survey resulted in the creation of a unidimensional 12-item scale, the Schwartz Center Compassionate Care Scale (SCCCS), which has high internal reliability, item-total correlation and factor loading

onto the central concept of compassion. Responses to the SCCCS correlated with patient satisfaction. Because we concluded that a better understanding of patient's perceptions of compassionate care, and the gap between patient and professional perceptions could provide useful information for quality improvement efforts, the authors have pursued additional assessment of the validity and reliability of this scale.

## **Methodology –**

Patient Opinion Ireland and The Irish Society for Quality and Safety in Healthcare (ISQSH), with permission, adapted and distributed in Ireland the Schwartz Center's original survey, including the 16 behavioral elements of compassionate care, to query public perceptions about the importance and healthcare providers, and if recently hospitalized, respondents' perceptions of the successful demonstration of these behaviors [Appendix]. The purpose of the current analysis is to further examine the face validity of the originally identified sixteen compassionate care items and their reliability by comparing the perceptions of people in Ireland with those in the U.S. We also report recently hospitalized Irish patients' ratings of their doctors' and healthcare teams' compassionate care and variables that influenced these perceptions.

ISQH distributed a request to participate and a link to the survey using their internet-based social media sites. The survey asked participants to rate the original sixteen behaviors in terms of the importance of the healthcare team's ability to demonstrate each behavior (version 1), and if hospitalized within the previous 12 months, the successful demonstration of each behavior by the healthcare team (version 2) and by the doctor in charge of their care (version 3).

Principal axis factoring was used to examine the factor structure of the Schwartz Centre Compassionate Care Scale (SCCCS). Student t tests and analysis of variance were used to compare scores between groups and across surveys. Pearson correlation was used to examine the relationship between scores. All results were also checked using non parametric alternatives and only significant results on both reported.

## **Results**

Demographic information is available for hospitalized patients of whom 19 were male, 127 female; 39 did not report gender. The median age was 47.

### **Basic psychometric analysis**

[INSERT TABLE 1]

#### *Reliability*

The Cronbach's alpha for analysis 1 (importance of the 16 behaviors) was high at .925 with all 16 items, but better when just the 12 items of the SCCCS were included at .949. As in the U.S. data, items 6, 11,

13 and 16 had the lowest item-total correlations, hence the improved alpha for the 12 item version. For analysis 2 (successful demonstration by the patient's team) the pattern of results overall was similar in that the alphas were high for the 16 items at .967, and .970 for the 12 item scale. For analysis 3 (successful demonstration by the doctor in charge) the alphas were .983 for both scales. As there seems good evidence that the 12 item scale is at least as good as the 16 item scale, the rest of the analysis reported here will concentrate on that scale.

#### *Factor analysis.*

For version 1, the items load onto one factor which accounts for 63.47% of variance, with a minimum factor loading of .7 onto that factor. For version 2, the items load onto one factor which accounts for 73.16% of the variance, with a minimum factor loading of .62. For version 3, the items load onto one factor which accounts for 82.92 % of the variance, with a minimum factor loading of .86. Overall the results suggest that all versions of the scale are measuring one factor.

#### *Ceiling and floor effects for total scale scores:*

For version 1, 31% of participants gave top endorsement to all items; for version 2, one person gave the lowest endorsement for all items and 13% gave the highest; for version 3, the same people repeated their endorsement pattern.

#### **Score comparisons among different versions of the compassionate care survey**

A repeated measures analysis of variance with total scores on the 12 item scale across versions revealed significant differences between versions 1, 2 and 3 ( $F(2, 164) = 38.45, p < .001$ ). Eighty-three participants completed all three versions of the scale. Mean total score was 109.89 (SD 15.11) for version 1, 86.90 (SD 27.56) for version 2, and 85.19 (SD 32.95) for version 3. Version 1 is significantly different from both of the other versions on post hoc tests. Versions 2 and 3 however, in which participants rated successful demonstration of compassionate care by their health care team and then their doctor respectively were not significantly different ( $t(85) = .69, p = .45$ ).

One hundred twenty seven participants completed ratings of versions 1 and 2. In a direct comparison of ratings on version 1 (importance) and 2 (successful demonstration by healthcare team), there was a significant difference between total scores ( $t(126) = 9.98, p < .0005$ ). The mean total score for version 1 was 110.06 and for version 2 it was 84.20. There were also significant differences for each individual item in versions 1 and 2. The largest mean difference (2.65;  $t(155) = 12.18, p < .0005$ ) was on item 4, "Listen attentively to you."

There were no significant differences between any of the items between version 2 (team) and version 3 (doctor). The survey also asked recently hospitalized patients to rate overall levels of compassion provided by nurses, and in another question, overall levels of compassion provided by doctors/consultants. There were significant positive correlations between the ratings of the compassion of both nurses ( $r = .53, p < .001$ ) and doctors ( $r = .58, p < .001$ ) and the score on the SCCCS.

We also compared importance rating scores of recently hospitalized and non-hospitalized people. The total rating score by recently hospitalized patients on version 1 (M =110.24, SD = 14.95) was not significantly different from the non-hospitalized people (M = 110.33, SD = 15.45;  $t(384) = -.06, p = .96$ ).

### **Irish and U.S. ratings of compassionate behaviors**

We could not compare Irish and U.S. overall scale results as participants in the U.S. survey were initially presented with two different sets of 8 items each rather than a single set of 16 items as in the Irish survey. We therefore compared differences on individual survey items. Table 2 compares the Irish and U.S. ratings of the importance of each compassionate behavior.

[INSERT TABLE 2]

[INSERT TABLE 3]

### **Variables influencing patients' perceptions of compassionate healthcare**

Continuity of care and frequency of contact were associated with higher SCCCS ratings. Those who met the doctor in charge of their care (M = 88.43, SD =27.15) had significantly higher SCCCS ratings than those that did not (M= 68.48, SD = 31.29;  $t(124) = 2.99, p = .003$ ). This was reinforced by the finding of a significant positive correlation between the question asking "How often did your doctor come to speak to you" and SCCCS rating ( $r = .34, p = .001$ ). Those who were checked regularly by a member of their health care team (94.93, 22.84) also endorsed significantly higher SCCCS ratings than those who were not (56.16, 26.41;  $t(108) = 7.72, p < .001$ ). Further, those who had their pain managed (96.37, 21.77) endorsed significantly higher SCCCS ratings than those who did not (63.65, 29.37;  $t(100) = 6.25, p < .0$  vs.1).

Patients' desire for connection and contact was further demonstrated by their responses to a question related to their relationship with the care team. Those who answered 'nothing' to the question 'What is the single most important thing that the health care team could have done to improve their relationship with you?' (105.8, 13.52) scored significantly higher on SCCCS than those who endorsed some possible improvement (77.74, 29.21;  $t(124) = 5.08, p < .001$ ). Those who wanted their concerns to be more closely listened to had the lowest SCCCS ratings (70.21, 32.65), followed by those who wanted more consideration about how the illness affected them and their family's lives (75.52, 28.04). These concerns received the most endorsements (28 and 21 respectively).

The value of an apology was shown among those who believed a mistake was made in their care (n = 45). Those who received an apology endorsed significantly higher SCCCS ratings (91.44, 21.23) than those who did not (66.67, 33.91;  $t(43) = 2.08, p = .04$ ). Only 20 percent of those who believe a mistake was made received an apology.

There was no significant difference in ratings on the SCCCS among those who had been treated in a public hospital (84.53 vs. 29.89) and a private hospital (85.0 vs. 25.14;  $t(114) = -.07, p = .95$ ).

## **Discussion**

This study adds to our understanding of the validity, reliability and potential utility of the SCCCS. It also provides a glimpse into public perceptions of the provision of compassionate healthcare in Ireland. It is clear that for the most part there is no difference between Irish and U.S. respondents' views on the importance of the elements of compassionate care. The Irish survey found that, whether recently hospitalized or not, the importance of the compassionate care elements was similarly endorsed. This suggests that these elements may be generally important to the public regardless of health status.

As healthcare is increasingly provided by teams, the Irish survey added queries about team compassion. The finding that there was no significant difference in ratings between recently hospitalized patients' perceptions of compassionate behaviors of their doctors and their healthcare team suggests that the SCCCS could be used to assess team as well as individuals' behaviors and to explore how the team influences perceptions of compassionate care. This was further substantiated by the finding that there were significant correlations between overall ratings of compassionate care by nurses and overall ratings of compassionate care by doctors with overall SCCCS score. We can only speculate on the implications of these findings, but they suggest that each and all members of the team influence such perceptions; i.e. that the perception of compassionate care is "averaged" over the sum of its parts by patients.

As in the U.S. survey, Irish respondents indicated that the demonstration of compassionate behaviors, whether by providers or healthcare teams, falls short of what they consider important and desirable. Because of the differences in the way the Irish and U.S. surveys were implemented, we do not here report a comparison of Irish and U.S. patients' overall perceptions of successful demonstration of compassionate behaviors. However, we did find significant differences between U.S. and Irish ratings on individual behavior items suggesting that the SCCCS may be able to discriminate the relative success of compassionate care performance in different countries.

## **Conclusion**

This study adds to the evidence that the SCCCS is a valid and reliable measure of patients' perceptions of compassion and correlates with questions designed to measure fundamental aspects of compassionate healthcare. We again note a gap between patients' perceptions of the importance of the compassionate behaviors included in the scale and their successful demonstration in a recent hospitalization. The finding that there are no significant differences in SCCCS scores when used to assess individual or team performance also adds to our understanding of patients' perceptions of compassionate care and, further, suggests that all healthcare professionals bear both individual and collective responsibility for its provision.

We hope to stimulate further use and investigation of the SCCCS by other researchers. Studies in progress will further clarify and standardize the wording of the behaviors included in the scale. We hope others will use the SCCCS as an instrument to assess patients' perceptions of quality improvement efforts designed to improve compassion in healthcare.

**Key points**

The Schwartz Center Compassionate Care Scale functions well with a sample of patients in a different country and healthcare system beyond where it was originally tested.

Recently hospitalized and non-hospitalized people agree on the importance of the elements of compassionate care.

There is a significant gap between the compassionate care that the majority of patients desire and feel is important, and their perceptions of the care they are receiving.