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Quality of life of persons living with HIV and congruence with surrogate decision-makers

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Abstract

Purpose Physicians and caregivers rate patient quality of life (QOL) lower than patients rate their own QOL. This study investigated discrepancies between self-assessments of patient QOL by adults with HIV and their surrogate decision-makers.
Methods We collected baseline data from 223 adult dyads in the FAmily-CEntered (FACE) Advance Care Planning (ACP) clinical trial, consisting of HIV positive patients and their chosen surrogates. Participants independently completed the Medical Outcome Study-HIV Survey (MOS-HIV) and the Palliative care Outcome Scale (POS). We used Wilcoxon Signed-Rank Test to assess differences in overall patient–surrogate means. We used Prevalence Adjusted Bias Adjusted Kappa (PABAK) statistics to assess dyadic agreement, with surrogate HIV status and cohabitation status as grouping variables.
Results Patients were 56.1% male, 86.1% Black/African-American, aged 22–77 (mean = 50.83, SD = ± 12.33). Surrogates were 43.8% male, 84.1% Black/African-American, aged 18–82 (mean = 49.73, SD = ± 14.22). 46.2% of surrogates lived with the patient. 64.6% of surrogates reported negative HIV status. Surrogates were more likely to state patients were ill, $p = 0.032$. Among patient–surrogate dyads, most QOL assessments showed poor (0.00–0.39) or fair (0.40–0.59) agreement and agreement tended to be even poorer among patient–surrogate dyads where the surrogate had a shared HIV diagnosis.
Conclusions QOL discrepancies are said to arise from healthy surrogates overestimating the effects of chronic illness. In this novel assessment, many surrogates had a shared HIV diagnosis, without increased agreement. These findings highlight the challenge of accurately assessing patient QOL by surrogates, even when there is a shared HIV diagnosis. Improved communication is needed between patients and surrogates about the patients' representation of illness.
National Clinical Trial Number: NCT01775436.

Keywords HIV/AIDS · Health-related quality of life · Caregivers · Medical decision-making · Advance care planning · Disability paradox

Introduction

Although the life expectancy of people living with HIV (PLWH) has increased substantially since the development of combination antiretroviral therapy (cART), life expectancy is still shorter than in the general population [1]. PLWH commonly experience co-morbidities that affect both quality of life (QOL) and length of life [1, 2]. Healthcare professionals recommend planning for future medical decisions and end-of-life (EOL) care to increase understanding of the patient's representation of illness and goals for medical treatment [3].

Choosing an appropriate surrogate decision-maker (the person who will make medical decisions for the patient when the patient is not able to do so themselves) is vital.

Data presented previously in abstract form at the 2016 Annual Conference for the Society of Clinical Research Associates in Montreal, Canada and the 2017 Advance Care Planning and End of Life Care Annual Conference in Alberta, Canada. Data have not been published previously.

Our study sites were: Children's National Health System, MedStar Health Research Institute/Washington Hospital Center, MedStar Georgetown University Hospital, The George Washington Medical Faculty Associates and the Washington DC Veterans Affairs Medical Center/Institute for Clinical Research, Inc.

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Surrogate decision-makers should be familiar with the patient's diagnosis, current health status, and treatment preferences [3]. Understanding the extent to which the illness impacts the patient's functional ability and QOL is crucial, as these factors predict emotional well-being and willingness to undergo medical interventions [4]. However, published research demonstrates discrepancies between surrogate and patient perceptions of patient health and well-being [5, 6]. Despite functional limitations, patients with chronic illness rate their QOL as high or higher than healthy individuals [4]. Conversely, physicians and surrogates rate the QOL of patients lower than the patients rate their own QOL [7]. Subjective differences in QOL appraisals between chronically ill and healthy individuals constitute what is known as the disability paradox [8]. According to the disability paradox, assessing patient QOL from the point of view of a healthy individual may fail to consider how valuable life can be for a chronically ill patient because the general public does not recognize how a patient's illness appraisal changes over time, after reevaluation of life goals and priorities [9, 10]. Surrogates may share a diagnosis with the patient; however, it is not known how a shared diagnosis influences QOL agreement. Due to the nature of HIV transmission, it is likely that some surrogates are also living with the illness, yet the effects of surrogate HIV status on perceptions of patient QOL have not been explored.

In context of medical decision-making, discrepancies between patients' and surrogates' perceptions of patient QOL have important consequences. Accurately understanding how patients feel is critical to making medical decisions consistent with the patients' desires [4]. If a surrogate's understanding of a patient's QOL differs significantly from patient's self-assessment, there is potential for misdirected medical decision-making on the part of the surrogate. The negative consequences of misdirected medical decision-making include unmet care or delivery of unnecessary or unwanted care [11, 12], conflicts in the ICU about treatment choices or dismissing the importance of non-relative caregivers such as same-sex partners [3, 13–18], loss of respect for autonomy in the spirit of the Patient Self-Determination Act (1990), and the loss of decision-making capacity of the PLWH [19]. Disease-specific advance care planning (ACP) has demonstrated increased congruence in treatment preferences between patients and surrogates as well as an increased likelihood that patients' treatment preferences will be honored [5, 20–24]. The FAmily-CEntered (FACE) ACP clinical trial tests the implementation of ACP among adult PLWH in Washington, DC with a proposed aim of increasing congruence in EOL treatment preferences between patients and surrogates.

Objective & hypotheses

Our aim of the current analysis was to understand factors that influenced patient–surrogate congruence on perceptions of patient QOL during the baseline visit of the FACE ACP clinical trial [25]. We hypothesized that (H1) consistent with the disability paradox, patients would rate themselves as having higher QOL compared to surrogate ratings of patient QOL; (H2) a shared diagnosis (HIV positive surrogate) would increase QOL agreement; and (H3) surrogate cohabitation status (living with the patient) would increase QOL agreement.

Methods

Study design

The FACE ACP clinical trial for HIV positive adults was approved by the Institutional Review Board at Children's National (coordinating center) and the participating study sites. The Children's National Medical Center IRB's Federal Wide Assurance (FWA) number is FWA00004487. The institutional organization number is IORG0000245. This was a palliative care clinical trial that recruited HIV positive adults who were 21 years or older from five urban, hospital-based outpatient clinics in Washington, DC. Participants selected surrogates as their health care agents, who were adults 18 years or older. We initially recruited individuals based on the following criteria: (1) detectable viral load on two occasions over a 12-month period, (2) a CD4 count (< 200), (3) current opportunistic infection, (4) HIV infected with a co-morbidity that may significantly limit life expectancy, including malignancy, cirrhosis, cardiomyopathy, end stage renal/kidney or liver disease, diabetes or HIV Associated Neuropathy, or (5) in/outpatients with AIDS receiving dialysis. The inclusion criteria were broadened in year 3 of the study to increase enrollment to include all persons 21 years or older ever diagnosed with HIV at any age. This change in inclusion criteria is consistent with the consensus definition of ACP as appropriate for any age and any stage of health in understanding and sharing their personal values, life goals and preferences regarding future medical care.

Further inclusion criteria required that both patients and surrogates knew of and were willing to discuss the patient's HIV diagnosis. Exclusion criteria included signs of HIV dementia, homicidality, suicidality, or psychosis, as determined during screening by trained study staff. We also excluded patients who did not have a surrogate decision-maker willing to participate. There were

868 patients assessed for eligibility. 645 individuals were excluded: 192 did not meet initial inclusion criteria, 107 could not identify a surrogate decision-maker, 14 were screening failures (were suicidal, homicidal, or psychotic), and others declined to participate with the most common reasons being time issues ($N=85$) or did not want to talk about ACP ($N=24$). Data were not available for all who declined. 223 eligible and enrolled patient/family dyads were randomized. Further details about the study design and methodology are published elsewhere [11].

Trained study staff conducted screening and informed written consent with both the patient and the surrogate. Following consent, study staff collected baseline data from 223 patient–surrogate dyads in the FACE ACP trial. A trained research assistant verbally administered questionnaires to participants and recorded answers on the standardized paper forms. Patients and surrogates met with the research assistant independently. Data were later entered into the secure online database REDCap by study staff. Administration of baseline questionnaires occurred before randomization, so all participants completed these surveys regardless of group assignment. Participants were given monetary compensation to complete 15 baseline questionnaires in the course of 60 minutes. Two of the baseline questionnaires administered by the research assistants were the Medical Outcome Study-HIV Survey (MOS-HIV) and the Palliative care Outcome Scale (POS).

Materials

In this analysis we assessed six individual items from two dimensions of the MOS-HIV, general health perceptions and health-related QOL of patients with HIV in the past month. We chose these six items because we judged these were the most relevant to patient illness perception. Strengths of the MOS-HIV include that it is internally consistent, has good reliability and good validity—especially when used with African-Americans and individuals with low socio-economic status [2, 26]. We selected the POS to assess the physical, psychological, psychosocial, emotional, practical, and spiritual needs of palliative care patients in the past 3 days [27]. All POS questions are scored using a 0–4 Likert scale, which can be summed to create a total score. Advantages of the POS include good construct validity [28]. In a previous sample internal consistency of the POS was 0.65 [28].

Analysis plan

We used SAS 9.2 to analyze data [29]. We used descriptive statistics to characterize study participants by group (patients and surrogates). To determine if patients responded more positively to the QOL measures (H1), we compared mean scores of QOL measures reported by patients and surrogates using Wilcoxon Signed-Rank Test. This test was a non-dyadic analysis of overall patient and surrogate scores. To ensure that a higher mean score indicated a more positive health response across all QOL measures, we recoded two of the MOS-HIV questions, “The patient is somewhat ill” and “The patient is feeling bad lately”. Therefore, for these two questions a higher mean score indicated “The patient is NOT somewhat ill” and “The patient has NOT been feeling bad lately”.

We used Prevalence Adjusted Bias Adjusted Kappa (PABAK) statistics to assess dyadic agreement between patients and surrogates on responses to each QOL measure, following recommendations by Cicchetti for interpretation of PABAK: $<0.40=$ poor; between 0.40 and $0.59=$ fair, between 0.60 and $0.74=$ good; between 0.75 and $1.00=$ excellent [30]. For the PABAK analysis, we dichotomized MOS-HIV questions into positive and negative responses using the following criteria: a positive response was defined as (1) agreeing the patient was in excellent health or was as healthy as anyone; (2) disagreeing that the patient was ill or feeling bad; and (3) rating general health and QOL as good (Table 1). We dichotomized POS questions the following way: (1) high QOL = 0–13 total score; (2) low QOL = total score 14–26,

Table 1 Dichotomization of MOS-HIV and POS responses

Question	Positive response	Negative response
The patient’s health is excellent	Definitely true; mostly true	Not sure; mostly false; definitely false
The patient is somewhat ill	Mostly false; definitely false	Not sure; mostly true; definitely true
The patient is as healthy as anyone	Definitely true; mostly true	Not sure; mostly false; definitely false
The patient has been feeling bad lately	Mostly false; definitely false	Not sure; mostly true; definitely true
The patient’s general health	Excellent; very good; good	Fair; poor
The patient’s quality of life	Very well; pretty good	Good & bad equal; pretty bad; very bad
POS total	Score 0–13	Score 14–26

This table describes how we categorized responses to the MOS-HIV and POS as positive or negative for the dyadic PABAK analysis. These questions were given to the patient and surrogate independently as no patients or surrogates scored higher than a 26 on the POS (Table 1). We chose to dichotomize MOS-HIV and POS scores into positive and negative responses because we wanted to accurately capture discrepancies between patient and surrogates regarding illness perception. In some instances, a patient may have stated their own general health was "very good" while the surrogate stated the patient's general health was "excellent". Labeling this as a discrepancy is not quite meaningful because both answers indicate a positive QOL appraisal, and so we dichotomized measures into strictly positive and negative categories as described in Table 1. We conducted two dyadic PABAK analyses, one grouping by surrogate HIV status and one grouping by surrogate cohabitation status (H2 & H3). We calculated a *p*-value comparing the difference between patient and surrogate PABAK statistics based on 1000 bootstrap resamples.

Results

Patients ($N=223$) were 56.1% male, 86.1% Black/African-American, aged 22–77 (mean = 50.83, SD = ± 12.33). Surrogates ($N=226$) were 43.8% male, 84.1% Black/African-American, aged 18–82 (mean = 49.73, SD = ± 14.22). Additional participant demographics are represented in Table 2 and patient clinical data represented in Table 3. There were more surrogates than patients because some patients ($N=3$) choose to have multiple surrogates participate in the research study. In this manuscript, all dyadic-analyses used data from the primary surrogate only. About half of the surrogates lived with the patient ($N=103$, 46.2%); most surrogates reported negative HIV status ($N=144$, 64.6%); and most patients reported a non-biological relationship to their surrogate ($N=165$, 73.9%). However, there was some discrepancy between the nature of the relationship

Table 2 Participant demographics

Demographic	Patient ($N=223$) *N* (%)	Surrogate ($N=226$) *N* (%)
Gender		
Male	125 (56.1)	99 (43.8)
Female	94 (42.1)	126 (55.8)
Transgender	4 (1.8)	1 (0.4)
Age (years)		
22–39	44 (19.7)	60 (26.5)
40–60	128 (57.4)	112 (49.6)
61–77	51 (22.9)	54 (23.9)
Race		
American Indian or Alaska Native	1 (0.5)	2 (0.9)
Asian	0 (0.0)	1 (0.4)
Black or African-American	192 (86.1)	190 (84.1)
White/Caucasian	19 (8.5)	21 (9.3)
Bi-racial	5 (2.2)	4 (1.8)
Declined	6 (2.7)	8 (3.5)
Ethnicity		
Hispanic/Latino	8 (3.6)	9 (4.0)
Non-Hispanic/Non-Latino	202 (90.6)	205 (90.7)
Declined	13 (5.8)	12 (5.3)
Sexual orientation		
Heterosexual	148 (66.4)	156 (69.0)
Non-heterosexual	75 (33.6)	70 (31.0)
Education		
High school or lower	93 (41.7)	103 (45.6)
Some college or higher	130 (58.3)	123 (54.4)
Income		
Equal, below federal poverty line	86 (39.5)	67 (29.6)
Higher than federal poverty line	87 (39.9)	105 (46.5)
Unknown/unreported	45 (20.6)	54 (23.9)

This table describes the demographic information about the patients and surrogates in the FACE ACP clinical trial for adult PLWH

Table 3 Patient clinical data

Clinical data	Patient ($N=223$) N (%)
Source of transmission	
Behaviorally infected	156 (70.0)
Perinatally infected	6 (2.7)
Unknown	61 (27.3)
Time since diagnosis of HIV positive (years)	
Mean (SD)	17.5 (8.2)
CD4 count < 200	
Yes	21 (9.8)
No	193 (90.2)
Advance directive in chart	
Yes	29 (14.0)
No	178 (86.0)
Is patient prescribed HIV medication?	
Yes	208 (94.5)
No	12 (5.5)
Adherence score	
≥ 90%	171 (81.4)
< 90%	39 (18.6)
Viral load undetectable (< 50)	
Yes	167 (75.2)
No	55 (24.8)
Dialysis	
Yes	6 (2.7)
No	213 (97.3)
Currently drug and/or alcohol dependent	
Yes	9 (4.1)
No	212 (95.9)
Current cigarette smoker	
Yes	82 (36.9)
No	140 (63.1)
Co-morbidities	
Liver disease including hepatitis b & hepatitis C	63 (28.3)
Diabetes	35 (15.7)
Cancer or malignancies	25 (11.2)
Heart disease or heart failure including heart attack or stroke	25 (11.2)
Renal disease (kidney disease)	18 (8.1)
HIV associated neurocognitive disorder (HAND)	3 (1.3)

This table describes the clinical information about the patients in the FACE ACP clinical trial for adult PLWH

as reported by the patients and surrogates. Upon review we determined most of these discrepancies were reporting errors: the patient said the surrogate was their parent and the surrogate said they were the child of the patient, when they meant the patient was their child ($N=39$). In some instances ($N=8$) one participant described the relationship romantically and the other platonically.

Cronbach's alpha for the POS scale during the baseline visit for this sample was 0.68 for the patients and 0.67 for the surrogates. In this analysis, we analyzed two dimensions of the MOS-HIV: MOS-HIV general health perceptions and MOS-HIV health-related QOL. The former is a subscale with five items and the latter is measured by a single item. Cronbach's alpha for the MOS-HIV general health perceptions subscale during the baseline visit for this sample was 0.82 for the patients and 0.84 for the surrogates.

Analysis of non-dyadic MOS-HIV and POS mean scores across all seven QOL questions demonstrated that patients responded more positively to questions about their health than their surrogates; however, the results were not statistically significant other than for the question “Is the patient somewhat ill?”, $p = 0.032$ (Table 4). Rather than dyadic comparisons, this analysis compared overall means of the patient sample and surrogate sample using the Wilcoxon Signed-Rank Test.

We found poor or fair agreement on most MOS-HIV outcomes when grouping dyads by shared diagnosis and by cohabitation status [30]. On the MOS-HIV question, ‘In general the patient’s health is good/bad’, we found either fair or good agreement. On the POS question, ‘Overall score for patient QOL’ we found good agreement. PABAK statistics, which represent dyadic patient–surrogate agreement, were lower on five of the seven MOS-HIV and POS questions among surrogates who were HIV positive and higher on four of seven MOS-HIV and POS questions among surrogates who cohabitated with patients (Table 5). According to the bootstrap these differences were not significant, $p > 0.05$.

Table 4 Comparing patient and surrogate sample means of QOL measures

QOL measures	*N* Patient	Patient Mean (SD)	*N* Surrogate	Surrogate Mean (SD)	Range	Wilcoxon Signed-Rank Test *p*-value
POS total score	215	7.01 (5.74)	194	6.26 (5.16)	0–40	0.13
MOS-HIV patient general health	223	3.49 (1.1)	223	3.39 (1.06)	1–5	0.30
MOS-HIV patient is somewhat ill	223	3.05 (1.58)	222	2.77 (1.57)	1–5	0.032*
MOS-HIV patient is healthy as anyone	223	3.31 (1.48)	223	3.3 (1.5)	1–5	0.99
MOS-HIV patient’s health is excellent	222	3.01 (1.48)	223	2.92 (1.48)	1–5	0.47
MOS-HIV patient feeling bad lately	223	3.67 (1.46)	223	3.61 (1.32)	1–5	0.46
MOS-HIV patient QOL	223	3.88 (0.89)	223	3.87 (0.82)	1–5	0.80

Note that two of the questions were recoded to ensure that a higher mean score indicated a more positive health response across all QOL questions. Those questions were, “The patient is somewhat ill” and “The patient has been feeling bad lately”. See “Analysis plan” for details

*Significant at the $p < 0.05$ value

Table 5 PABAK statistics by surrogate HIV status or by cohabitation status

Group		Outcome						
		POS QOL, high/low	MOS-HIV In general, the patient’s health, good/bad	MOS-HIV The patient is somewhat not ill, true/false	MOS-HIV The patient is as healthy as anyone I know, true/false	MOS-HIV The patient’s health is excellent, true/false	MOS-HIV The patient has been feeling good lately, true/false	MOS-HIV Overall QOL for patient, good/bad
Surrogate HIV status								
Positive ($N = 71$)	PABAK	0.64	0.49	0.14	0.21	0.24	0.10	0.35
Negative ($N = 144$)	PABAK	0.64	0.57	0.18	0.39	0.28	0.14	0.31
p-value*		1.00	0.51	0.76	0.21	0.77	0.77	0.71
Cohabitation status								
Cohabitate ($N = 103$)	PABAK	0.60	0.63	0.26	0.40	0.32	0.07	0.28
Don’t cohabitate ($N = 120$)	PABAK	0.68	0.47	0.11	0.27	0.23	0.18	0.35
p-value*		0.41	0.13	0.22	0.29	0.49	0.36	0.60

We used PABAK to measure dyadic congruence between patient and surrogate assessments of patient QOL at the baseline visit of the ACP clinical trial. We grouped dyads by shared HIV diagnosis and cohabitation status, comparing patient and surrogate answers based on 1000 bootstrap resamples. Cicchetti [30] gives the following often quoted guidelines for interpretation of PABAK: < 0.40 = poor; between 0.40 and 0.59 = fair, between 0.60 and 0.74 = good; between 0.75 and 1.00 = excellent

*Significant at the $p < 0.05$ level

Discussion

Even though patients tended to respond more positively to QOL questions, overall differences in patient and surrogate sample means were not statistically significant across MOS-HIV and POS measures as we had hypothesized (H1). However, there was a significant difference between non-dyadic patient and surrogate sample means on the MOS-HIV question, “Is the patient somewhat ill?”. This finding reflects results from previous studies, which found patients responded more positively when appraising their QOL [4, 7, 9, 31, 32]. It is interesting that patients were significantly more likely to disagree to the MOS-HIV question about illness perception. This finding may touch upon the foundation for QOL appraisal discrepancies and the disability paradox, in that patients rate their QOL differently than surrogates because, unlike surrogates, they do not view themselves as ill.

Perhaps patients report a higher QOL due to being cared for and the caregivers report a lower patient QOL due to being the caregiver of someone who is ‘ill’. Receiving care could be a form of social support, which we know improves physical QOL and decreases morbidity and mortality [33, 34]. In the future, researchers should address this possibility.

Previous studies found illnesses that are more visibly disabling, such as paraplegia, cancer, and kidney failure elicited significant differences between non-dyadic patient and surrogate health ratings [4]. While some HIV positive patients in this study were visibly ill (in a wheelchair, difficulty speaking due to stroke), many were not. The results of the current analysis may speak to changing self-perceptions of health status of PLWH, from a terminal illness to a manageable chronic disease [1]. Additional research is needed to determine the extent that physical dysfunction influences QOL appraisal in an HIV population.

Patients and surrogates had poor agreement on most MOS-HIV measures of patient QOL. However, agreement was fair or good for the MOS-HIV question ‘In general, the patient’s health is good/bad’. It is unclear why there was higher agreement on the MOS-HIV question assessing the patient’s general health but poor agreement on the question assessing patient QOL. Perhaps this is related to the surrogate tendency to describe patients as ill, which influences QOL appraisal. Furthermore, agreement was good on the POS score of patient QOL. There were a few major differences between the MOS-HIV and POS that may have influenced results. The MOS-HIV is specific to HIV patients, is divided into ten unique dimensions, assesses QOL for the past month, and has been shown to have acceptable reliability with injection drug users, African-Americans and lower SES patients [26]. The POS is not specific to HIV patients, is used in palliative care, is summed into a total score and assesses QOL in the past 3 days. Perhaps patients and surrogates had better agreement on the POS because it was easier to recall patient QOL from the past 3 days than from the past month. Conversely, because the MOS-HIV was specific to our population (HIV positive, largely minority) and not all of our participants were in palliative care, it’s possible the MOS-HIV questions highlighted areas of QOL appraisal that were more relevant to our participants (i.e., ‘Is the patient somewhat ill?’). If this is the case, than the MOS-HIV may have revealed discrepancies in QOL appraisals between HIV positive patients and their surrogates that the POS did not. It is important to note that in this sample internal consistency of the POS was low ($\alpha = 0.68$ for patients, $\alpha = 0.67$ for surrogates). Future research should consider how disease-specific questionnaires may differ from more general questionnaires in regards to QOL appraisal.

Results of the bootstrap demonstrated that differences in PABAK statistics grouping by shared diagnosis (surrogate HIV positive or negative) were not significant. Contrary to our hypothesis (H2), a shared surrogate HIV diagnosis did not increase congruence levels. Previous research theorizes healthy individuals rate patient QOL more negatively because they overestimate the emotional impact of chronic illness [4]. Based on that reasoning, individuals with a shared diagnosis should have a better understanding of the patient’s experiences and therefore increased congruence in QOL appraisals; our results do not support this theory, however. This is the first published study that we know of to assess QOL of PLWH with one-third of the surrogates having a shared diagnosis. Further research is needed to determine if a shared HIV positive diagnosis influences patient–surrogate congruence in other settings.

We additionally analyzed surrogate cohabitation status to determine if it influenced congruence levels, with the hypothesis that if a surrogate cohabited with a patient he/she would see them on a regular basis and have increased QOL agreement with patients (H3). Results of the bootstrap showed cohabitation status did not influence QOL agreement. It is important to note that without establishing measurement invariance across patient and surrogate versions it is unclear whether the differences in scores are due to actual differences in perceived QOL or are present due to differences in response scale use. Additional research is needed to determine what factors influence QOL agreement in this population. The FACE researchers plan to assess if ACP planning (the FACE intervention) influenced QOL agreement in post-baseline visits upon the conclusion of the clinical trial.

Most of participants in this study were minorities: 86.1% of patients were Black/African-American and 84.1% of surrogates were Black/African-American. While these participants represent a minority in the general population, they represent the majority of PLWH in urban centers in the US. Historically, medical research has not had large minority populations. However, it is crucial that we report on these groups. It is important for clinicians to understand how cultural issues impact EOL with minorities: African-Americans are half as likely as non-African-Americans to use any advance directive, prefer to discuss religion during ACP, and prefer to use less pain medication, if dying [35]. Given that ACP increases QOL congruence [36, 37] and that ACP attitudes and completion differ by racial groups [35], it is possible that QOL congruence rates between patients and surrogates also vary by racial group. Future investigation of patient–surrogate QOL congruence in other racial groups could provide insight into whether minority populations are at risk for increased discrepancy about patient EOL care and are in need of additional support with ACP facilitation.

Conclusions

While assessing the cause of patient and surrogate QOL appraisal discrepancies is important, it is equally important to understand the implication of those discrepancies. Surrogate decision-makers, by definition, are the individuals responsible for making medical decisions for a patient when that patient is no longer able to make their own decisions. The nature of this relationship is intimate, as the surrogate has the ability to continue or end life-sustaining treatment for the patient. Ideally, the surrogate decision-maker has a good understanding of the patient's self-assessment of their QOL and health status. The results of this study, however, show that is not the case. Although most non-dyadic differences between patient and surrogate QOL appraisals were not significant, dyadic congruence was low for most of the QOL questions during the baseline assessment of this clinical trial. Patients and surrogates had poor agreement, particularly when regarding whether they thought the patient was ill. It is this tendency for the surrogate to view the patient as 'ill' that negatively influences their perception of the patient's QOL [4]. Such differences in appraisal can be dangerous, as surrogates are more likely to underestimate how valuable life can be for a patient with a chronic illness and are at risk for making misdirected medical decisions [4, 10]. As previously stated, the negative consequences of misdirected medical decision-making include unmet care or delivery of unnecessary or unwanted care [11, 12], conflicts in the ICU about treatment choices or dismissing the importance of non-relative caregivers such as same-sex partners [3, 13–18], loss of respect for autonomy in the spirit of the Patient Self-Determination Act (1990), and the loss of decision-making capacity of the PLWH [19]. In palliative care or chronic illness cases where the surrogate underestimates patient QOL, clinicians or medical staff should consider facilitating structured conversations between patients and surrogates about ACP and medical decision-making, as it has been shown to increase congruence of treatment preferences [34, 35]. The FACE researchers plan to assess if ACP planning (the FACE intervention) influenced QOL agreement in post-baseline visits upon the conclusion of the clinical trial. Clinicians should be aware that minority populations have cultural views that influence their attitudes about ACP and completion of advanced directives, which means minorities should be given culturally-sensitive ACP interventions and increased support during EOL care discussions [33].

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Compliance with ethical standards

Conflict of interest The authors declare there are no conflicts of interest to report.

Ethical approval All procedures performed in studies involving human participants were in accordance with the ethical standards of the institutional and/or national research committee and with the 1964 Helsinki declaration and its later amendments or comparable ethical standards. This research was approved by the IRB at Children's National (coordinating center) and at all participating study sites. The Children's National Medical Center IRB's Federal Wide Assurance (FWA) number is FWA00004487. The institutional organization number is IORG0000245.

Informed consent Informed consent was obtained from all individual participants included in the study.

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