Meaning in life and quality of life: palliative care patients versus the general population

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ABSTRACT

Background and objectives Meaning in life (MIL) represent a key topic in palliative care. The aims of this study were to explore (1) the differences in perceived MIL and in the meaning-relevant life areas between a representative sample of the Swiss population and palliative care patients, and (2) to what extent MIL can be considered as a significant predictor of quality of life (QOL).

Methods A cross-sectional study was conducted separately for the patients (face-to-face interviews) and the general population (telephone survey). MIL was measured with the Schedule for Meaning in Life Evaluation (SMILE) and QOL with a single-item visual analogue scale (0–10). Sociodemographic variables were controlled for in the analyses.

Results 206 patients and 1015 participants from the Swiss population completed the protocol. Results indicated high MIL scores in both populations even if the difference was significant (patients 81.9 vs general population 87, p<0.001). Patients were more likely to cite 'family' (OR=1.78), 'social relations' (OR=1.9), 'spirituality and religion' (OR=3.93), 'social commitment' (OR=1.94) and 'growth' (OR=2.07), and less likely to cite 'finances' (OR=0.15) and 'health' (OR=0.21) as MIL-relevant areas. The SMILE scores and MIL areas explained 21.8% of the QOL variance for the patients and 15.1% for the representative sample.

Conclusions Our data emphasise the importance of MIL as a contributor to QOL in both populations. It highlights the importance of the life areas contributing to MIL, especially social interactions for both populations, and spirituality and areas related to growth in palliative care patients.

INTRODUCTION

The concept of quality of life (QOL) is the central outcome measure in palliative care research. The WHO defines QOL as 'the individual perception of the position in life in the context of the culture and value system in which they live, and in relation to their goals, expectations, standards and concerns'.[1] In palliative care research, focusing on a general individual perception of QOL by using a single-item question is still uncommon. Many instruments used for research were designed using either a health-related concept of QOL[2] or a multidimensional perspective.[3 4] Studies have shown in recent years that QOL at the end of life is linked to non-physical determinants.[5 6]

Among these, the spiritual domain is relevant for palliative patients.[3]

A paper of the European Association for Palliative Care Task Force on spiritual care defines spirituality as 'the dynamic dimension of human life that relates to the way persons (individual and community) experience, express and/or seek meaning, purpose and transcendence, and the way they connect to the moment, to self, to others, to nature, to the significant and/or the sacred'.[7] Meaning in life (MIL) represents a core element of spirituality, and loss of MIL represents an important clinical issue. It has been associated with important outcomes in the end of life context: anxiety and depression,[8] suicidal ideas,[9] the desire for hastened death[10] and various physical symptoms.[11]

From a clinical and research point of view, meaning and MIL have been widely discussed in the psychology literature. The meaning-making model explains how people adjust themselves by giving meaning to various stressful life events, as is the case with a life-threatening illness.[12] Several manualised interventions were developed in order to help people facing

a loss of meaning.[13 14] Victor Frankl, a pioneer in the development of psychological interventions centred on MIL, considered it as an individual construct, difficult to capture from an external standpoint. The individual identification of life areas considered as sources of MIL represents a crucial point when initiating a therapeutic process.[15] The Schedule for Meaning in Life Evaluation (SMILE) allows individuals to choose freely the life areas that they consider important for their own MIL.[16]

We have previously reported separately data obtained with the SMILE in a representative sample of the Swiss population and a sample of Swiss palliative care patients.[5 17] Relating a patient population with the general population may help to take a step back by contrasting what is normal from a developmental perspective and what is specific to a life-threatening disease situation. Identifying areas of life that may contribute to QOL can also provide interesting insights for interventions. In analogy to the study of Fegg et al,[18] we compare the two populations regarding MIL, but we go further by exploring to what extent MIL can predict QOL and what is the discrepancy between these populations.

METHODS
The data for this comparison study using an exploratory, cross-sectional design were collected separately for the palliative care patients and the representative sample of the Swiss population. Collection methods and part of the results have been published.[5 17]

Data from the general population in Switzerland were collected through a telephone survey performed by a professional company between November and December 2013, resulting in a representative sample across the three linguistic regions, age and sociodemographic characteristics. In the first step, households were drawn and the sampling was stratified by linguistic region and town size. The selected households were then called on the phone and the interviewer established their composition. The selection of the respondent among the household members happened by quota (sex–age interlocked). All interviewers of the survey company were trained by two study investigators and received a standardised protocol, including an assessment of MIL, QOL, health status and sociodemographic data: gender, age, education, employment, marital status, profession, self-evaluation of the socioeconomic status, residence (population size) and linguistic region.

For palliative care patients, a cross-sectional study, based on structured face-to-face interviews, was conducted in different palliative care contexts of the three Swiss linguistic regions (German, French and Italian) between 2012 and 2015. Inclusion criteria were (1) 18 years or older, (2) being treated by one of the specialised palliative care teams involved and (3) <6 months life expectancy according to the

treating physician. Exclusion criteria were (1) psychiatric disease, (2) significant cognitive impairment and (3) insufficient knowledge of the local language. Patients hospitalised in a palliative care unit or cared for by a palliative home care team who fulfilled the inclusion criteria were asked to participate in the study by a research collaborator who was not part of the palliative care team. After obtainment of informed consent, a meeting was scheduled with the research collaborator in order to complete the case report form assessing MIL, QOL, religiosity, psychological distress and attitudes towards hastened death.

For this specific study including both populations, assessment of MIL, QOL and sociodemographic data (gender, age, education, employment, marital status, residence and linguistic region) were considered.

Instruments
Schedule for MIL evaluation
This instrument was developed and validated by Fegg et al.[16] Respondents are first asked to indicate three to seven areas that provide meaning to their life. The relevant areas contributing to MIL were classified in 1 of 15 categories reported in a specific manual developed for this instrument (family, partnership, social relations, occupation/work, leisure time/relaxation, home and garden, finances, spirituality/religion, health, satisfaction, nature/animals, social commitment, hedonism, art and culture, and growth (see Simmons et al[6] and www.psychotherapie-muenchen.de/downloads/SMiLE_Manual.pdf).

The importance and the current level of satisfaction associated with each area are rated on Likert scales (seven points, from −3 to +3, for the satisfaction, and eight points, from 0 to 7, for the importance). An 'index of weighting' (IoW, range 0–100) and an 'index of satisfaction' (IoS, range 0–100) indicate the mean weighing score and the mean satisfaction score for the areas mentioned. A SMILE total score, 'index of weighted satisfaction' (IoWS, 0–100), indicates the global MIL satisfaction.

Subjective Single-Item QOL
In both groups, subjective QOL was measured after completion of the SMILE questionnaire with the Single-Item Quality of Life Scale–Numeric Rating Scale 0–10, ranging from 0 (worst imaginable QOL) to 10 (best imaginable QOL). This approach to measuring QOL was validated by de Boer et al and Idler and Benyamini.[19 20]

Statistics
Differences between sociodemographic characteristics of the two samples were assessed using the χ^2 test. The mean of the different SMILE scores was computed in both samples, and linear regression models were used to determine whether sample membership could explain

the scores, controlling for sociodemographic factors. The distribution of MIL areas cited by the respondents was computed separately for each sample. A logistic regression model was computed to assess the presence of each MIL area in function of the sample membership.

After having applied bivariate analyses (t-test and correlation), we built models explaining the subjective QOL from the SMILE scores. We began by considering the full sample, and then we built separate models for the patient and the general population samples. In each case, we proceeded in two steps: in the first one, we used only the three main scores of the SMILE as predictors (IoS, IoW and IoWS). In the second one, we also included indicator variables of the presence or not of the 15 different MIL areas, and we applied a backward selection procedure in order to identify the best model. All models were controlled for sociodemographic characteristics (age, gender, marital status and education). Controlling for sociodemographic variables allows keeping them constant and avoiding any influence on the dependent variable.

Sample size was estimated based on the planned use of multivariate analyses. According to the literature, 20 observations are needed for each independent variable considered in the regression analyses. Given the very small number of missing data in the sociodemographic characteristics (n=9 for the marital status and n=2 for education on 1221 participants), no special processing was carried out and all calculations were done with pairwise deletion. The number of missing data concerning MIL and QOL was also very small (n=9 for QOL and n=6 for MIL), and these participants were not considered in the regression analyses.

The type I error was set to 0.05 for all inferential computations. Statistical analyses were performed using the Statistical Package for the Social Sciences V.24.

RESULTS

Recruitment and descriptive results

For the Swiss population, 6671 telephonic contacts were realised, and 1015 (15%) individuals completed all questionnaires (405 French, 400 German and 210 Italian participants; see ref. 18 for details). Regarding the patients sample, in the three Swiss linguistic regions, 588 participants met the inclusion criteria, 206 participants gave their consent and completed the questionnaires (77 French, 89 German, and 40 Italian patients; see Bernard et al[5] for details).

Table 1 gives the sociodemographic and medical characteristics of the two populations. Results showed significant differences between the two populations regarding age, marital status and education level. However, effect sizes can be considered as small, given the Cramer's V (between 0.016 and

0.180). Cancer was the most common diagnosis among the palliative care patients.

Differences in MIL between palliative care patients and the Swiss sample

Results of the linear regressions indicated significant differences between the two populations regarding the IoS, the index of importance (IoW) and the SMILE total score (IoWS), with lower scores in the patients sample. On the other hand, no difference was found regarding the number of cited areas.

Differences in sources of MIL between palliative care patients and the Swiss sample

'Family' and 'social relations' were the two most cited areas in both populations (76% for family in the two populations and 49% vs 39% for the social relations in the patients and the Swiss sample, respectively). The relational dimension represents the most important dimension for MIL in the two populations. The results of the logistic bivariate regression model show that patients were significantly more likely to cite family (OR=1.78), social relations (OR=1.9), 'spirituality and religion' (OR=3.93), 'social commitment' (OR=1.94) and 'growth' (OR=2.07), and less likely to cite 'finances' (OR=0.15) and 'health' (OR=0.21) (see table 3).

Notice that the apparent inconsistency between the percentages and the OR for the family category is due to the fact that the regression model was controlled for sociodemographic factors, which was not the case for the percentages. In particular, there were significant associations between marital status, age and civil status.

MIL as a QOL predictor

The results of the independent samples t-test indicated a significant difference in QOL between the palliative care patients and the Swiss sample (M=5.03, SD=2.6; M=7.56, SD=1.7, respectively; t=17.549, p=0.000). The correlation values between QOL and the SMILE scores indicated that these two dimensions were not independent and justified the use of linear regressions to test in which measure MIL was associated with QOL (Pearson correlation values were between 0.220 and 0.364, p=0.000).

The differences between the two populations clearly warranted a separate analysis to obtain a better identification of the QOL predictors. Therefore, we performed regression analyses on the two samples separately.

Palliative care patients

A first linear regression model (see top of table 4), including the three scores of the SMILE, showed that 13% of the QOL variance (adjusted R^2) was explained, but no predictor reached significance.

Table 1 Demographic characteristics in each sample and main diagnosis of the palliative care patients

Variables	Patients		Swiss sample		Total		P value	Cramer's V
	n	%	n	%	n	%		
Age (years)							<0.001	0.261
16–19	0	0.0	42	4.1	42	3.4		
20–29	0	0.0	99	9.8	99	8.1		
30–39	1	0.5	99	9.8	100	8.2		
40–49	12	5.8	144	14.2	156	12.8		
50–59	38	18.4	121	11.9	159	13.0		
60–69	65	31.6	244	24.0	309	25.3		
70–79	58	28.2	167	16.5	225	18.4		
80–89	28	13.6	88	8.7	116	9.5		
90–99	4	1.9	11	1.1	15	1.2		
Total	206	100.0	1015	100	1221	100.0		
Gender							0.575	0.016
Male	100	48.5	471	46.4	571	46.8		
Female	106	51.5	544	53.6	650	53.2		
Total	206	100.0	1015	100.0	1221	100.0		
Marital status							<0.001	0.180
Single	31	15.4	209	20.7	240	19.8		
Married/legal partnership	91	45.3	597	59.0	688	56.8		
Divorced/separated	45	22.4	92	9.1	137	11.3		
Widowed	34	16.9	113	11.2	147	12.1		
Missing	5	2.4	4	0.4	9	0.7		
Total	201	100.0	1011	100.0	1212	100.0		
Education							<0.001	0.149
Primary school	44	21.6	174	17.1	218	17.9		
Professional diploma	100	49.0	432	42.6	532	43.6		
Secondary school	5	2.5	102	10.0	107	8.8		
Highschool	30	14.7	92	9.1	122	10.0		
University	24	11.8	208	20.5	232	19.0		
Other	1	0.5	7	0.7	8	0.7		
Missing	2	1				0.2		
Total	204	100.0	1015	100.0	1219	100.0		
Region								
French	77	37.4	405	39.9	482	39.5	0.598	0.029
German	89	43.2	400	39.4	489	40.0		
Italian	40	19.4	210	20.7	250	20.5		
Total	206	100.0	1015	100.0	1221	100.0		
Primary diagnosis								
Cancer	197	95.6						
Heart disease	1	0.5						
Pulmonary disease	1	0.5						
ALS	5	2.4						
Missing	2	1.0						
Total	206	100						

ALS, amyotrophic lateral sclerosis.

A second linear regression model (see bottom of table 4), using the backward selection process with the 15 MIL areas in addition to the SMILE scores, explained 22% of the QIL variance. The results showed a positive and significant association with the index of importance (IoW) of the SMILE, and also the 'satisfaction' and the social commitment areas.

Swiss sample
The first linear regression model (see top of table 5), including the three scores of the SMILE, explained 13% (adjusted R^2) of the QOL variance, with a positive significant association with the index of importance (IoW) of the SMILE. A second linear regression model (see bottom of table 5), using the backward selection process with the 15 MIL areas, in addition to the SMILE scores, explained 15% of the QOL variance. The results showed a positive and significant association with the index of importance (IoW) and the total score (IoWS) of the SMILE, and also the satisfaction and the social relations areas.

Table 2 Descriptive characteristics of the different SMILE scores in both samples and linear regression models predicting these scores from group membership (patient vs Swiss sample, the Swiss sample being the reference)

SMILE indices	Patients Mean (SD)	Swiss sample Mean (SD)	Total R^2 adjusted	B	Beta standardised	P value
IoW	81.0 (14.3)	82.8 (12.5)	0.030	−2.230	−0.064	0.029
IoS	79.9 (17.6)	86.1 (13.4)	0.044	−6.715	−0.173	<0.001
IoWS	81.9 (17.2)	87.0 (13.5)	0.033	−5.463	−0.142	<0.001
Number of areas mentioned	4.0 (1.5)	4.1 (1.4)	0.000	−0.059	−0.016	0.584

Regression models are controlled for sociodemographic variables: age, gender, marital status and education.

IoS, index of satisfaction; IoW, index of weighting; IoWS, index of weighted satisfaction; SMILE, Schedule for Meaning in Life Evaluation.

DISCUSSION

To the best of our knowledge, this study is only the second one that aimed to explore differences in MIL between a palliative care population and a representative sample of a population from a national survey, after the study of Fegg et al.[18] The latter study took place in Germany, a more homogeneous sociocultural context than Switzerland with its mix of German and Latin populations. A novel purpose of our study was to explore the relationship between MIL and the QOL in these two populations.

Level of satisfaction in MIL: meaning-making hypothesis

The high levels reported in the SMILE total scores in both populations (>80) are comparable with those found in other studies, including different kind of populations: patients with cancer,[21 22] palliative care patients[23 24] and general populations.[18 25] This propensity towards high scores is also apparent in a study with Indian palliative care patients.[26] Fegg et al[16] already mentioned a ceiling effect of the SMILE to explain the

small difference between the samples. At first sight, these scores in MIL appear to be surprising, given the end-of-life context. However, the prevalence of mood disorders is about 30% in the oncological, palliative care and haematological settings.[27] This indicates that a majority of patients are able to adapt successfully to the constraints of an end-of-life situation.

Another explanation is the response shift phenomenon, which refers to a change in values, goals and expectations towards the remaining life.[28] Such a transformation process may occur, consciously or subconsciously, when people encounter adverse experiences during their lives. The announcement of a potential life-threatening illness and the subsequent confrontation with one's own death can certainly be viewed as a one of 'those events that have seismic impact on the individual assumptive world'.[29] A growing body of evidence exists on the psychological mechanisms employed by individuals in order to cope with adversity and difficulties (eg, see the review of Windle[30] on resilience).

Table 3 Percentage of participants listing each MIL area category in each sample and logistic regression model predicting the presence of each MIL area from group membership (patient vs Swiss sample (reference category))

	Patients (n=206) %	Swiss sample (n=1015) %	OR Exp (B)	95% CI		B	P value
Family	76.7	76.3	1.783	1.188	2.676	0.578	0.005
Partnership	18.0	16.4	1.468	0.949	2.270	0.384	0.084
Social relation	49.0	39.1	1.898	1.365	2.641	0.641	<0.001
Occupation and work	24.8	41.5	0.748	0.505	1.108	−0.290	0.148
Leisure time	33.0	37.7	0.872	0.617	1.232	−0.137	0.438
Home and garden	10.2	7.5	1.087	0.636	1.857	0.083	0.762
Finances	1.9	10.0	0.155	0.055	0.436	−1.862	<0.001
Spirituality and religion	32.5	10.6	3.933	2.621	5.901	1.369	<0.001
Health	14.6	36.1	0.213	0.136	0.333	−1.546	<0.001
Satisfaction	15.1	11.5	1.133	0.707	1.815	0.125	0.605
Nature and animals	29.6	20.7	1.219	0.839	1.771	0.198	0.298
Social commitment	8.3	3.9	1.941	1.015	3.715	0.663	0.045
Hedonism	7.8	8.9	0.800	0.436	1.468	−0.223	0.471
Art and culture	19.4	18.1	0.948	0.620	1.451	−0.053	0.806
Growth	16.0	7.9	2.065	1.279	3.333	0.725	0.003

Regression models are controlled for sociodemographic variables: age, gender, marital status and education.

MIL, meaning in life.

Table 4 Linear regression models predicting the subjective QOL among the palliative care patient sample

	Coefficient	Robust SE	T	P value	95% CI	
Regression from the SMILE scores						
IoS	0.073	0.046	1.575	0.117	−0.019	0.164
IoW	0.018	0.017	1.111	0.268	0.014	0.051
IoWS	−0.057	0.045	−1.268	0.207	−0.145	0.032
Regression by adding the MIL areas						
IoW	0.034	0.013	2.560	0.011	0.008	0.061
Partnership	0.932	0.515	1.810	0.072	−0.084	1.949
Home and garden	1.025	0.563	1.820	0.070	−0.087	2.137
Art and culture	0.827	0.475	1.743	0.083	−0.110	1.765
Satisfaction	1.511	0.526	2.872	0.005	0.472	2.549
Social commitment	1.814	0.644	2.815	0.005	0.542	3.086

Regression models are controlled for sociodemographic variables: age, gender, marital status and education; for the backward regression, only significant factors are displayed.

IoS, index of satisfaction; IoW, index of weighting; IoWS, index of weighted satisfaction; MIL, meaning in life; QOL, quality of life; SMILE, Schedule for Meaning in Life Evaluation.

Different psychological processes have been described and proposed in the meaning-making model, including, for example, assimilation and accommodation.[12] These processes contribute to decrease the discrepancy between a global meaning, consistent with the personal sense of identity, and a situational meaning arising in the context of a stressful life event. Such an adaptation or adjustment process may explain the low difference between our two samples. This adjustment hypothesis is plausible because most palliative care patients received their illness diagnosis several months prior to the study, thus allowing for a time frame for adjustment. This hypothesis requires confirmation in a longitudinal study.

Meaning-relevant areas: differences between groups as marks of an adaptation process

Family and social relations appear to be the most important domains contributing to MIL in both groups, with the addition of 'occupation and work', which is the second most cited area in the Swiss general population. Compared with the general population sample, patients were more likely to cite family and social relations as relational areas, and growth and 'spirituality' as psychoexistential areas.

A relative preponderance of family and social interactions as areas contributing to MIL in palliative care patients was also found in the study of Fegg et al.[18] Relationships are prominent in other studies exploring the sources of MIL using methodologies

Table 5 Linear regression models predicting the subjective QOL among the Swiss sample

	Coefficient	Robust SE	T	P value	95% CI	
Regression from the SMILE scores						
IoS	0.011	0.016	0.669	0.504	−0.021	0.042
IoW	0.017	0.004	3.932	0.000	0.009	0.026
IoWS	0.030	0.016	1.904	0.057	−0.001	0.061
Regression by adding the MIL areas						
IoW	0.019	0.004	4.376	0.000	0.010	0.027
IoWS	0.040	0.004	10.481	0.000	0.033	0.048
Social relation	0.264	0.104	2.547	0.011	0.061	0.468
Home and garden	0.338	0.191	1.775	0.076	−0.036	0.713
Finances	−0.312	0.167	−1.873	0.061	−0.639	0.015
Satisfaction	0.433	0.158	2.749	0.006	0.124	0.742
Social commitment	0.466	0.252	1.847	0.065	−0.029	0.962

Regression models are controlled for sociodemographic variables: age, gender, marital status and education; for the backward regression, only significant factors are displayed.

IoS, index of satisfaction; IoW, index of weighting; IoWS, index of weighted satisfaction; MIL, meaning in life; QOL, quality of life; SMILE, Schedule for Meaning in Life Evaluation.

other than the SMILE.[31] Correspondingly, the social integration dimension was found to be prominent in patients with cancer of different European countries and in India.[21 26] A systematic review reported the effectiveness of palliative care interventions enhancing social support on the patients' psychological well-being.[32] Our results also speak in favour of the development of compassionate communities that aim to strengthen this kind of support.[33]

The shift towards more 'inner directed' values and sources, such as spirituality and growth, is noticeable in our study. In the SMILE questionnaire, transcendence is a key element of the spirituality area. It refers to a feeling of connection with an entity that goes beyond our own self.[34 35] Growth refers to the experiences of self-realisation or self-development. Later stages of life have been shown to lead people towards deeper introspection.[36] Terror management theory has highlighted the importance of mortality awareness: while being confronted with finitude may induce anxiety, experiential reality of impending death may also elicit a so-called 'mortality-induced growth' associated with a transition from extrinsically oriented goals to intrinsic ones.[37]

Association between MIL and QOL

The finding that MIL represents a significant predictor of QOL, explaining up to 22% of the QOL variance, highlights the importance of the existential dimension for QOL in both populations studied and is consistent with previous findings.[5 17] While the association between QOL and sociodemographic variables has been assessed in the general population,[38] the majority of studies looking at the association of the existential dimension to QOL were realised in the oncology and palliative care settings.[4 6 39]

Interestingly, the part of explained variance increased in the palliative care patients when considering the life areas contributing to MIL (from 13% to 22%), more than in the general population (from 13% to 15%). Our results confirm the necessity to focus on the essential life domains in the end-of-life context, in line with the statements mentioned by Frankl in the introduction. These domains may be viewed as relevant to the patients' sense of coherence, allowing them not only to anchor themselves in the reality but also to identify new purposes in which to invest for the remaining time. This approach can also be used to initiate a discussion in order to address the MIL dimension with palliative care patients. Importantly, the use of the SMILE is not restricted to psychologists or chaplains but can encompass the entire healthcare team. In a subsequent step, a referral to a specific professional according to the areas of life mentioned may be appropriate (eg, chaplain, social worker and psychologist).

Limitations

First, the methodology used to assess MIL with the SMILE questionnaire was different in the two populations, which may account for divergences in the responses. Second, the categories associated with the areas were assigned a posteriori, which implies a degree of subjectivity by the investigators. Third, although a single-item scale for the assessment of QOL appears justified when considering the subjective approach to QOL advocated by the WHO, it does not allow an in-depth assessment of QOL. Concerning the patients, the fact that (i) the participant screening was not systematic in all the palliative care units, (2) only patients with less than 6 months of life expectancy were considered and (3) more than half of the patients who met the inclusion criteria could not participate in the study (which may have led to the exclusion of the most severely affected and unstable patients, not only from a physical but also from an emotional and socioeconomic point of view) contributed to a selection bias. Finally, the cross-sectional design of this study does not allow for a causal interpretation of the relationship between MIL and QOL.

CONCLUSIONS

Our data reinforce the notion of the importance of MIL for QOL in both clinical and non-clinical settings. From a clinical perspective, it highlights the importance of considering closely the concrete life areas contributing to MIL in every single patient, since they play an important role not only for MIL but also for their QOL.

For future research, it will be important to include health status and psychological and social indicators to improve our understanding of the QOL determinants. Different ways of exploring MIL, such as the search for meaning, could help in decreasing the large unexplained MIL variance, and thus contribute to a better understanding of QOL.

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