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## Quality of life in the Palestinian context: An inquiry in war-like conditions

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#### Abstract

This study aims to elucidate the concept of quality of life (QOL) in a unique environment characterized by protracted and ongoing conflict, beginning with the utilization of the WHOQOL-Bref as a starting point for discussion. It works to determine important health-related quality of life domains and items within each domain, and evaluate issues pertinent to the Palestinian population's understanding of life quality in the Occupied Palestinian Territory.

Focus group discussions (FGD) were conducted with individuals living in the Gaza Strip and Ramallah District of the West Bank. Participants were asked if they understood the term QOL; and about the determinants of their own QOL, using openended questions. Participants were then presented with the WHOQOL-Bref questions and requested to assess their relevance and importance in determining their own QOL, and encouraged to suggest additional ones. A total of 150 men and women of various ages and socioeconomic classes participated in 13 FGD. A major finding is the all-encompassing impact of the political context on Palestinians' QOL assessment.

The study demonstrates that political freedom, self-determination, participation in democratic processes and feeling involved in political decision-making are considered important contributors to people's QOL. The study raises the option of adding a new domain to the WHOQOL-Bref, allowing the study of its psychometric properties and its relationship to the rest of the instrument. This contribution should be particularly relevant to societies and cultures in conflict-affected zones and locales where violence and insecurity constitute an important part of life. The documentation of QOL, beyond fatal and non-fatal health outcomes, must remain an important objective of all evaluations in order to guide policy and resource allocation decisions directed towards improving peoples' lives in general and their health in particular.

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Abbreviations: QOL, quality of life; WHOQOL, World Health Organization Quality of Life Instrument; WHOQOL-Bref, WHOQOL Brief version

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### 1. Introduction

Quality of life (QOL) measures are increasingly being used to assess health outcomes [1-5], with widening support for the hypothesis that the quality and value of an individual's life is what she or he considers it to be [6,7]. Conceptualizations of QOL and health and their measurement present researchers with theoretical and methodological problems [8–11]. A variety of generic and specific QOL tools have been developed [9,11-15]. The WHOQOL-100 is one of several generic instruments devised to assess OOL in health for cross-cultural use [16-19]. While the generic WHO instrument offers guidelines for assessing QOL in health in differing settings, this instrument requires cross-cultural adaptation and validation [1,6,16,19-21], especially as the international literature points to difficulties encountered in achieving universal validity for any life quality instrument [22].

Critics draw attention to various problems inherent in health-related QOL instruments: the term is hard to define [23]; construct validity requires underlying hypotheses about society, not possible to universalize; construct and content validity require complex and specific validation in relation to their use [21]. Additionally, the conceptualization of QOL is objective and subjective [24], offering to provide quantitative estimates of subjective attributes that are radically influenced by setting and refer to views derived from relative rather than absolute life conditions. The methodology moreover relies on epidemiological measures that involve considerable uncertainty beyond randomness and subjectivity [25], as subjective health complaints may be perceived differently by different people and may originate out of varied determinants. Health-related QOL instruments assess life quality at one point in time, merely unfolding a 'snapshot view of reality'. In fact, the impact of context on health and health-related QOL is cumulative, with many diseases emerging in adulthood having their origins earlier in the life course [26]. Critics have also drawn attention to the problems of age, class, gender and culture-related specificities in health-related QOL [27], implying the arduous and cost ineffective task of generating multiple instruments to capture the views and needs of various groups, even at the national level.

Life quality of Palestinians dramatically deteriorated since the Israeli army re-invasions of September 2000. Yet, adequate tools for the assessment of this deterioration that can inform both short-term emergency assistance and medium term policies have been lacking. Recent living conditions/health surveys in the Occupied Palestinian Territory (OPT) have not exposed the impact of long-standing conflict and appalling socio-economic situation of the Palestinian people in terms of measurable health and health-related indicators. Emphasis is placed on counting the dead and the injured and on morbidity and access to health and other services problems, with little attempts made to assess the consequences of intensified conflict, severe closures and siege and spiralling unemployment on life quality and health, nor to document the views, worries and needs, that is, the sheer suffering, of the bulk of the population. It is being increasingly realized that health systems must look beyond fatal and non-fatal health outcomes and examine the well-being of the population. This may have important implications for the development of policies and resource allocation decisions that take into consideration the needs of the living civilian population, and for acceptability and adherence to both preventive and curative health interventions. Studying OOL and well-being and their determinants may provide important clues for policy interventions that may have direct consequences for improving health outcomes.

In 2004, WHO West Bank and Gaza contacted the Institute of Community and Public Health, and the Gaza Community Mental Health Program, proposing a study on the QOL of Palestinians. The institute was already engaged in working to identify indicators, other than classical mortality and morbidity measurements, which capture the effects of protracted conflict on population's health, life quality and well being in better ways. The intention was to fill the gap between the 'social suffering' that people and communities are experiencing and the lack of scientific arguments to support the documentation of this experience, and to identify a tool that could be tested and adapted to the social and cultural Palestinian context.

This paper summarizes a Palestinian experience in testing and adapting, with the purpose of validating, a worldwide used QOL instrument: the WHOQOL-Bref [28,29]. Utilizing transcripts generated from focus

group discussions, we investigated whether the concept of QOL as defined by the WHOQOL group [30]: 'The individuals' perception of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards and concerns', is understood, has meaning, and is relevant and valid in the local Palestinian context. We also sought to assess the attitude of respondents to the WHOQOL-Bref. This study focuses on conceptualization and instrument design, taking into account the conceptual and contextual needs of the Palestinians. By focusing on the development of a national Palestinian OOL instrument, we hope to highlight the impact of current conditions on the living in ways that: go beyond classical mortality and morbidity assessments; can better capture the difficulties and tragic circumstances of daily life in the OPT; and can offer more substantive data than what is available for policy formulation and operational purposes. The output of this initial study will be used to develop a Palestinian-specific QOL instrument that can contribute to an international pool of items for cross-cultural comparison purposes, perhaps also relevant for use in comparable situations of ongoing conflict.

### 2. Methodology

Focus group discussions (FGD) were conducted with individuals living in the Gaza Strip and the Ramallah District of the West Bank, representing the two extreme living conditions in the OPT. FGD is a form of group interview that explicitly uses individual interaction, and capitalises on communication between research participants, in order to generate data [31]. FGD were chosen for this study since they provide participants with the best opportunity to express their views and experiences. Moreover, FGD have been advocated and used for the purpose of elaborating QOL instruments in a wide range of settings and cultural contexts [32-38]. A total of 13 FGD were completed: six in the Gaza Strip and seven in the Ramallah district. Sixtyfive males and 85 females were included in the study, with ages ranging between 14 and 70 years. The fieldwork was completed in 2 months, from mid-September to mid-November 2004.

The participants were purposively chosen to cover the different demographic and socio-economic characteristics as well as political realities present in the OPT. The participant groups were intended to reflect the current Palestinian realities (urban/rural/camp, women/men, young/middle-age/elderly, undergraduate/postgraduate students, employed/unemployed). After explaining the purpose of the study, different local associations were asked to recruit specific groups of participants. For example, women's centres in the villages and refugee camps helped to facilitate the participation of elderly and younger women. Eligible individuals were informed about the objectives of the study and encouraged to participate in the focus groups. Each group was limited to a maximum of 15 individuals to facilitate the flow of discussion. Since the study design is qualitative rather than quantitative by nature, no attempt was made to identify specific individual refusal. Two female facilitators, including one based in the Gaza Strip, and two male facilitators who were attached to the institute conducted the focus group discussions.

Discussions were divided into two parts. Participants were asked if they understood what the term Quality of Life' means, and how this should be expressed using local Arabic terminology. They were then asked to assess their own life quality, using an ordinal (excellent, very good, good, bad, very bad) and a visual analog (0-10 vertical line: with 0 representing the 'worst imaginable life' and 10 the 'best imaginable life') scale. Participants were also asked which of the scales was more comprehensible and easier to answer. Once participants scaled their own QOL, they were asked about the determinants they used to assess their life quality, using an open-ended question. Participants were then probed in order to identify the most relevant changes that could provide the best, and the worst, possible life quality. Part two entailed a discussion of the WHOQOL-Bref core items. This is a shortened version of the WHOQOL-100 instrument<sup>1</sup> [39]. It assesses life quality over four domains: physical, psychological, social and environmental. The objectives were to: ascertain the relevance of the internationally agreed upon core items; i.e., the extent to which they satisfy the conceptual and contextual needs of QOL assessment in the Palestinian

<sup>&</sup>lt;sup>1</sup> The two instruments are available at: http://www.who.int/evidence/assessment-instruments/gol/.

context; and ascertain the need for including new items, facets and/or domains to the current instrument, to more adequately capture local perceptions and realities. Participants were then presented with the exact questions as those appeared in a translated WHOQOL-Bref instrument. They were asked whether each of the questions was relevant and important in assessing their own QOL, and encouraged to suggest additional questions to add to the instrument. Two facilitators, and co-authors of this paper, were nominated to coordinate and run each of the FGD; and were aided by a note-taking person. Points to discuss were written on a board

or a flowchart to facilitate comprehension and guide the discussion.

The qualitative data were closely inspected through repeated readings for the purpose of familiarization, and gradually revealing patterns and themes. Those were then coded systematically in thematic tables, assisting in the clustering of responses, then categorized into grouped responses. Finally, working with the thematic tables, the results were interpreted and findings explained, based on the original research objective and the themes that have emerged from the data [40].

Table 1 Description of groups

Group code	Region	No. of males	No. of females	Total	Description	Age in years
G1	Ramallah	7	8	15	Post graduate students, middle and lower middle class professionals.	23–40
G2	Ramallah	0	12	12	Women's group, Birzeit village, middle and lower middle class.	30–45
G3	Ramallah	3	5	8	Birzeit University first year students—all classes.	17–19
G4	Ramallah	2	10	12	Administrative staff – ICPH – middle and lower middle class—mostly urban.	23–40
G5	Ramallah	0	14	14	Midia village women—mostly very poor.	25-50
G6	Ramallah	11	0	11	Ramallah district village men—all workers.	29-49
G7	Ramallah	14	0	14	Amari refugee camp men—all very poor, with very low educational levels.	20–70
G8	Gaza	0	9	9	The Islamic University students, middle and lower middle class, different residences:  Gaza city and Jabalia refugee camp.	19–23
G9	Gaza	0	9	9	The Women Empowerment Project (WEP-GCMHP) working/unemployed, high school students, and some vocational education, mostly very poor.	20–35
G10	Gaza	11	0	11	Undergraduate student from the Islamic al-Aqsa, and al-Azhar universities. Lower middle class and poor. Different academic. affiliations. Residences: Gaza and Khan Younis cities; and Jabalia, Nusairat and Maghazi refugee camps.	20–27
G11	Gaza	4	7	11	Students in school. Upper-middle class and well-off. Living in Gaza city.	14–16
G12	Gaza	7	5	12	Professionals, upper-middle class and well-off. Living in Gaza city.	22–53
G13	Gaza	6	6	12	Students-employees-unemployed graduates-mixed. Lower-middle and middle class. Residence: Gaza city and the Beach refugee camp.	19–27
Total	_					
West Bank	7	37	49	86	All classes in the West Bank	17–70
Gaza	6	28	36	64	All classes in the Gaza Strip	14–53
OPT	13	65	85	150	All classes and different locales	14–70

### 3. Results

### 3.1. Sample characteristics

Thirteen focus group discussions were completed in the Gaza Strip and the Ramallah District of the West Bank, six and seven groups, respectively. Sixty-five males and 85 females were included in the study, with ages ranging between 14 and 70 years (Table 1). Fieldwork was completed in 2 months, from mid-September to mid-November 2004.

### 3.2. The meaning and determinant of QOL

Focus group discussions revealed that participants knowledgeable of English understood what 'Quality of Life' means, when literally translated into Arabic: 'Jawdat al-hayat'. However, those who belonged to the poorer and less exposed sectors of society, especially women, neither understood the underlying meaning of the literal translation, nor the question related to its rating, 'How do you rate your quality of life?' When requested to state context-specific translations of the construct, the most frequently cited answers pertained

to the construct itself and its measurement simultaneously: 'To what extent are you satisfied 'radi' with your life?' and 'How would you assess your life quality?' Once this terminology was employed, the notion inherent in the WHO-QOI, definition, namely, a person's perception with regard to certain aspects of one's life given one's goals and expectations and context, was understood by all. The basic concepts embedded in the WHO definition were deemed the same as those of the participants.

With regard to the meaning of 'Quality of Life', participants' perceptions were directed toward two main connotations characterized by complex interactions. The first referred to respondent socio-economic status, 'Stable socio-economic conditions', 'Access to things needed', 'Having the minimum basics of life, work, food and security' or the 'Level of living (material)'. A second group of answers related to ongoing Israeli military occupation and its measures and consequences on people, 'Return to the homeland', 'Normal life with dignity' and 'No oppression'. Other answers were: 'Ease of life', 'Stability', 'Good health', 'Happiness in life', 'Psychological comfort/good mental health' and 'Belief and honesty with God and oneself'.

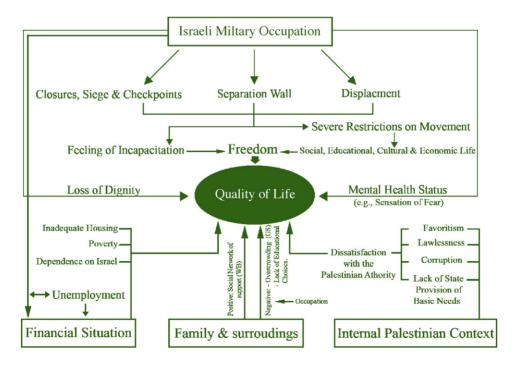


Fig. 1. 'Quality of Life' determinants in the Palestinian context.

Table 2
Themes and sub-themes emerging from the FGD

Theme	Sub-themes
Israeli military occupation	Closure, siege and checkpoints Separation wall Displacement
Internal Palestinian context	Lack of state provision of basic needs Lawlessness Favoritism Corruption
Family and surrounding	Over-crowding (-ve) Lack of educational choices (-ve) Social network of support (+ve)
Financial situation	Unemployment Poverty Dependence of Israel Inadequate housing

When asked to elaborate on the factors/determinants participants thought were most important in assessing their own life quality, they cited several inter-related themes and sub-themes. These are summarized in Fig. 1 and Table 2.

The *Israeli military occupation* and its measures (closures, siege, checkpoints and the erection of the separation wall) were strongly and unanimously identified as inhibiting a variety of ordinary/basic freedoms that severely negatively influence life quality, and leading to feelings of incapacitation, of being imprisoned because of severe restrictions on movement inhibiting normal social, educational, cultural and economic life. An example includes what a Ramallah village woman expressed:

"... the Wall! I cannot go to visit my family in Jerusalem anymore! All my brothers lost their work! Their shops were shut down because the Wall was built in-front of them".

A village worker stated:

'Life quality is about freedom'.

This entailed the freedom to move without restrictions, and being displaced and no longer able to live in the homeland of origin. An old man in a Ramallah refugee camp stated:

'Our situation was much better before 1948 ... we are under 'the feet' here in the camp ... they took our land when it was enough for our livelihood'.

These feelings were more strongly expressed by Ramallah participants compared to those from Gaza—a reflection of the specificities of the two distinct geopolitical contexts. Military occupation was also perceived to play a role in affecting life quality by causing a mix of life problems including, mental health status (e.g., a continuing feelings of fear) and loss of dignity, stated to negatively affect life quality. Examples include a Ramallah camp dweller's view:

'No peace of mind',

or that of a Gaza high-school student:

'Whenever I hear planes in the air, I say goodbye to beloved ones - friends in particular'.

A Ramallah camp dweller said:

'They [the Israelis] said that we are like animals, this is the most difficult part, more important than food and drink. They took away our dignity'.

A strong emphasis related to military occupation was placed on 'living in fear', fear over one's safety and the safety of loved ones, and what the future would bring, seen to be an important determinants of QOL. This was noted for both West Bank and Gaza, although more strongly expressed by Gazans, as the severity of Israeli army onslaughts during the period of fieldwork was severer there.

The second factor that played a major role in determining participant QOL was the 'bad' *financial situation*. Women from poor backgrounds emphasized this as due to unemployment, dependence on Israel and poverty – linked to occupation – and inadequate housing as important determinants of QOL. Narratives included:

'My life is bad due to the economic situation. I have 11 persons to support and my husband finds work only depending on the permission of the Israelis.' – a working class Ramallah urban woman.

A Gaza woman said:

'If money was found for me . . . the home environment would have been much better'.

In contrast, men downplayed financial difficulties, and tended to declare those as less important than other problems. Men associated their financial situation to what they believed was the determinant: occupation, as a Gaza undergraduate male student revealed:

'Money is not everything'.

Similarly, a Ramallah urban man emphasized:

'All financial, psychological, social, etc., problems are linked to occupation'.

The third major determinant was family and surroundings. These seemed to play two contradictory roles in the West Bank and Gaza. West Bank participants linked satisfaction with family and surroundings with their own life quality, implying positive preferences for family and social networks of support, and a sense of importance of the collectivity and social cohesion. West Bank women predominantly defined their life quality in terms of the life quality and health of their families and those around them. A Ramallah village woman declared:

'Life quality is about good health for my husband, family and myself'.

These findings contrast with the views expressed by some Gaza men and especially women, where the desire for individualism and longing for personal independence from family and elders was acutely expressed, as a Gaza woman nervously declared:

"... My family is confining me, even the extended family and others interfere with my life".

This may be partially due to the over-representation of young people in the Gaza focus group discussions, and *over-crowding* in Gaza, as demonstrated by a female Gaza university student:

'Over-crowding is reducing our levels of freedom and privacy.'

Over-crowding was also noted as important to life quality in the Ramallah refugee camp where a male participant maintained:

'We are living on top of each other'.

The interaction between perceived 'QOL' and 'the Family' was also seen to be influenced by political uncertainty and conflict, implying an interconnectedness between the domains of internal politics and conservatism in family and social life, pushing elders to dictate political affiliations to their families and thus affecting individual QOL. A Gaza male undergraduate student maintained:

'The political and social situation (are bad) ......... different political affiliations in the same house are intolerable and create problems for family members'.

Another finding that emphasizes the interconnectedness of the political and social contexts and their link to QOL is the strong views expressed by Gaza women students on the lack of educational choices (probably due to gender relations restricting the movement of women and favouring men for investments in education), and the strong sense of deprivation that arises as a result, an important QOL component in their view. A female Gaza university student declared:

'We are forced to study the specialties available in the Gaza strip ... we cannot move to study abroad due to closures'.

The contraction of these people's social worlds imposed by closures and siege seemed to have resulted in a general feeling of boredom, expressed by all, but more strongly by the younger generations, as expressed by a female Gaza university student:

'Every day is like the other day'.

Finally, an unexpected (due to respondents' forthrightness) finding is the emphasis on the *internal Palestinian political context* and dissatisfaction with

the Palestinian Authority, as an important determinant of QOL. This was more strongly felt in Gaza than Ramallah, emphasizing differences in political, demographic and socio-economic contexts between the regions. Lawlessness, corruption, lack of state basic needs provisions and favoritism were prominent themes. A male Gaza university student nervously declared:

'What did the Palestinian Authority do to us? They stole everything. The PA is not providing us with the needed security'.

# 3.3. Changes perceived to enhance a 'better' and a 'worse' OOL

Stated potential changes seen to shift the participants' assessment of their own QOL to the maximum best were wide, ranging from wishes for fulfilling basic needs to selflessness or humanitarian forms of preferences. Responses remained consistent with those of QOL determinants. The range of 'wishes' for better lives included: improvement in the political situation by ending occupation and enhancing internal political reform; improvement in economic conditions by creating job opportunities and improving working conditions to become 'just', stable, with no favouritism; enhanced income and secure future. Some participants emphasized a wider objective, linking these two factors and calling for improvements in the politico-economic situation. Many emphasized the limitations of social pressure imposed by tradition and family on individuals, perceived to significantly play-down QOL by limiting social equality and fairness, and called for enhancement of individual freedoms for QOL improvement. Others were more modest, limiting expectations to restoring dignity or merely eliminating imposed restrictions on movement. Finally, some participants asked for the sum total of life changes, while others aimed at fulfilling their basic needs including improvements in their own and others' physical and mental health. The following few words of a working class Ramallah urban woman summarizes most of the respondents' views:

'What would improve my life is peace, opening the checkpoints to having a better economic situation'.

3.4. Appraising the WHOQOL-Bref 26 questions for relevance to the conceptual and contextual needs of Palestinians

In the second part of the focus group discussions, participants were presented with the WHOQOL-Bref. Most questions were deemed important and relevant. There was a lack of discrimination between what item was more important than others, and an inability to prioritize issues important to QOL in the face of being presented with ready-made questions. This contrasts with the vibrant discussions that took place during the first part of the focus group discussions where issues and priorities were clear and strongly felt. These findings support the need to 'extract' additional relevant and important aspects of QOL, derived from the result of part one of this inquiry. However, interesting conclusions related the WHOQOL-Bref items can be noted.

With regard to the physical domain questions, participants emphasized the need to distinguish between 'suffering from physical pain' and 'the capacity of individuals to handle what needed to be done'. Women especially insisted that the burden of responsibilities overrides the weight of pain, obliging them to perform functions despite physical pain. Many linked the questions on the need for medical treatment, and the capacity of the individual to get around, with movement difficulties imposed by the political turmoil, suggesting a need to separate the two determinants. The question on one's satisfaction with sleep was revealed to be important for all, probably a reflection of sleep disturbances they experience, and an appropriate indication of their difficult life circumstances. A concern was raised with regard to the satisfaction with one's ability to perform daily activities question. The question was confusing, as respondents combined physical and mental health aspects. Indeed, in the local conception, physical and mental health are inseparable. Respondents highlighted the need to separate individual capacity to carry out activities from being prevented to carry out these activities by barriers in one's environment. It is worth considering dividing this question into two.

Some questions related to the psychological domain were found to lack conceptual coherence by participants, such as the question on enjoying life. This did not seem to be relevant to especially adults who are constrained by severe restrictions of movement, exposed to a variety of dangers and struggling for survival. Similarly, the question on life having a meaning was not compatible with the overall conceptualization of life in Palestinian culture, in face of views that life is 'dictated/written' and that you may accept it, be satisfied, but have to live it anyway. The questions on ability to concentrate and having negative feelings were revealed to be of utmost importance. The question on bodily appearance was understood differently by different people. Many young participants expressed interest in the question; some related it to the desire to take care of one's external appearance linking this to feelings of boredom or means of escaping from the difficult life circumstances.

The question on satisfaction with one's sexual life was not included in our study due to socio-cultural constraints. The other two *social domain* questions, personal relationships and social support, were found to be highly relevant to assessing QOL in the Palestinian context.

All *environmental domain* questions were deemed important, although to different degrees. Participants showed high interest in daily life safety, physical environment and living place appropriateness, money availability, accessibility to health services, adequate transportation availability and leisure opportunity questions. The physical environment healthiness question raised concerns over the rationality of this perspective in view of wanton destruction that is out of Palestinian control. More detailed examples and comments on the WHOQOL-Bref domain-specific 24 questions are presented in Appendix A.

### 4. Discussion

Developing a QOL assessment instrument in the Palestinian setting is a complex undertaking. In addition to previously noted difficulties, ongoing and intensified conflict poses particular challenges, including significant/abrupt changes in context and diverse impact of political events on increasingly differing zones of political reality (West Bank/Gaza Strip, North/Center West Bank, inside/outside the separation wall). The two regions represent the two extreme OPT living conditions in terms of proportion living in subsistence poverty, unemployment rates and decline in

real wages. Clearly, an international or national instrument assessing QOL needs to be responsive to such circumstances.

A major finding of this study is difficulties participants expressed in comprehending the literal translation of the term QOL, due to the complexity of locating conceptual equivalents to the terms 'rate' and 'quality' in colloquial Arabic. However, the implicit meaning intended by the construct was understood with a slight modification in translation, by substituting the word 'rate' with 'assess' and dropping the word 'quality'. These changes enhanced comprehension of what QOL means, deemed equivalent to the WHO-QOL core concept. Respondents felt that this was an important aspect of their lives that policy makers should appreciate and take into serious consideration when addressing needs over and above immediate health needs.

In trying to identify the most important factors determining participant QOL, our principal goal was ascertaining the degree to which the internationally agreed core items of the WHOQOL-Bref satisfied the conceptual and contextual needs of Palestinians. This is not merely a matter of concepts and semantics. Just as important is the overarching context of warlike conditions, economic crisis, insecurity and uncertainty, ongoing especially since September of 2000. We also sought to confirm or negate, our hypothesis on the primary QOL determinants in Palestinian society: the political domain as an ultimate determinant of the physical, psychological, social and environmental determinants, all affecting physical and mental health status. Findings indicate that Israeli military occupation/the lack of freedom and its consequences on life were clearly top determinants of QOL. The political context of military occupation was seen as an important cause of daily life problems, including mental health states, contributing to a negative impact on QOL. Similarly, the political context of closures, siege, checkpoints, roadblocks, the separation wall, instability and insecurity was strongly and unanimously identified as inhibiting a variety of ordinary/basic freedoms, thus influencing, in a severe and negative way, individuals' QOL. These political constraints and their impact on daily life, led to feelings of imprisonment and incapacitation. As described elsewhere, the deprivation of basic human rights, like freedom of movement, dignity and a minimum social life, leads to heavy tolls on health and suffering [41,42].

In contrast to participants from Gaza, those from Ramallah expressed these feelings more strongly, in part a reflection of the specificity of the geopolitical contexts of these regions. Displacement was an important issue among those living in the Ramallah refugee camp. This was not noted in Gaza probably because of the youthfulness of the respondents there, as Gaza young people know no other living place other than their current locales, in contrast to Ramallah participants, where the older generation still remembers the 'old country'.

Women from poor backgrounds emphasized unemployment, dependence on Israel, poverty and inadequate housing as important determinants of OOL. Moreover, West Bank women predominantly defined their QOL in terms of life quality and health of their families and those around them, emphasizing their inseparability from their social world and their primary responsibility as family caretakers, and highlighting a collective notion of life quality, as opposed to an individual one. In contrast, men did not emphasize financial problems as much. Instead, men seemed to associate their financial situation with what they believed was the determinant: Israeli occupation. These results underscore the impact of women and men's roles/responsibilities on individual assessments of QOL. They are also a reflection of the private-public divide that demarcates the social worlds and spaces accessed by men and women. Thus, women's concerns are mainly focused on household and family care-taking and survival, and consequently, the identification of OOL determinants related to these immediate and role defined concerns. Men's concerns on the other hand entail a wider perspective related to their expanded social world and access to the public sphere, and consequently, the broader economic and political contexts that influence and limit their abilities to fulfil their role as breadwinners/providers for the family.

The WHOQOL-Bref focuses on the QOL of individuals, a problem in its own right, as in the Palestinian context, individuals, especially women, tend to perceive, understand and express their views regarding their health primarily in relation to the collective (family, friends, neighbours, community). A strong interconnectedness exists between individual self-rated life

quality and the health and well-being of the others, especially the family. Such a sense of collectivity is partially determined by chronic ongoing conflict intertwined with acute intensifications and the absence of social safety nets. In times of uncertainty and turbulence, the family and social networks function to protect individuals in lieu of social security systems. This form of socialization contributes in real ways to the development of strong social support mechanisms that are especially important in times of conflict. Its downside, however, includes a restriction on societal freedoms, creativity and innovation, and can have negative ramifications on excluded groups, notably, women and young people.

These findings contrast with the findings from Gaza where the desire for individualism, longing for personal independence from family and elders, and longing for decision-making rights were acutely expressed, partially explained by the over-representation of youth in the Gaza groups. The Gaza findings are also related to over-crowding—an important QOL determinant for Gazans, and also noted as important to QOL in the Ramallah camp. The over-crowded conditions seem to have exceeded the tolerance limits of individuals, especially young people and women.

Women and young people are linked in status, rights and responsibilities through a patriarchal system of domination, as elders generally assume control over females and youth. The social domain narratives indicate a rising tension between old and young. There is evidence of a generation gap that has accompanied life changes, increasing exposure to the outside world accompanied by the information technology revolution and rapid rise in educational levels. These factors are pushing youth and women to call for more 'individualism' and higher levels of freedoms. Their narratives speak of 'privacy', decision-making rights and increasing rebellion against the control of older males and their wishes to reproduce themselves in their children. The rapid rise in educational levels without a corresponding liberalization in lifestyle appears to have contributed to these attitudes, especially among young people. Mounting pressures resulting from political oppression on the one hand, and over-crowding, poverty and lack of societal freedoms and space for participation on the other hand seem to articulate together to produce the enormous pressures and worries that youth have expressed.

Stated potential changes shifting QOL assessments to the maximum best were wide, ranging from wishes to fulfil basic needs to the humanitarian. Responses remained consistent with those obtained for QOL determinants, emphasizing including external and internal political domains in future QOL assessments; addressing issues of personal freedom and rights; and fulfilling the basic needs of the poor and unemployed, including adequate shelter, basic services and living space.

Some of the WHOQOL-Bref items were deemed not relevant or important. It seems that the instrument would fail in satisfying national conceptual and contextual needs without important additions. Findings indicate a strong justification for adding national items that can better capture national QOL perceptions. What complicates matters further is the rapidly changing demography in Palestine. The sharp drop in infant mortality and the continued high fertility is producing a considerable spurt in the youth population with 72.8% of the population under the age of 30 years [43]. Palestinian 'boomers' are caught in a transition. They are exposed to world events through remarkable access to information technology and satellite television. Hence, their passage to adulthood is considerably more multicultural than that of their parents and grandparents. In the process, they are re-examining long held assumptions. Exposure to the rest of the world has contributed to their search for their own space and change in their own lives. Yet, these young people are enduring an ever-widening gap between reality and their hopes and expectations. The clash between the misery of current life and increasing exposure and incorporation into a global world has served to highlight this discrepancy. Youth are caught in a paradoxical and transitional culture that is bound to influence QOL perceptions. Thus, their views and needs should be addressed in QOL research initiatives and future policy development.

The all-encompassing impact of the political context on Palestinian QOL is strongly supported by our findings. Some themes identified as relevant and important in the Palestinian context represent elaborations on themes already included in the WHOQOL-Bref. Yet, politically contextualized themes generated here contain quite different ideas. This raises the option of adding a new domain to the WHOQOL-Bref. Given that the introduction of a new domain introduces an important divergence from the WHOQOL-Bref, the generated political contextual items could be incorpo-

rated into existing domains, ensuring maximal crosscultural equivalence. Whether to introduce an entirely new domain to fill the gap in the instrument for a nationally specific context or to limit adaptation to adding new elements to the existing WHOQOL-Bref requires empirical investigation. This would ascertain the conceptual viability of a new facet as an independent entity rather than integrating its items within an existing facet.

This study has clearly shown that political freedom and self-determination are considered important contributors to people's OOL in the OPT. Perhaps this dimension should form a separate domain that can allow us to study its psychometric properties and its relationship to the rest of the WHOQOL instrument. This contribution to the WHOOOL-Bref structure should be particularly relevant to societies and cultures in conflict-affected zones and locales where violence and insecurity constitute an important part of life. By describing collective and individual human suffering associated with life conditions shaped by powerful socio-political forces, the development of such instrument may prompt a shift towards research documenting 'what political, economic, and institutional power does to people', that is, social suffering. The documentation of OOL, beyond fatal and non-fatal health outcomes, must remain an important objective of all evaluations in order to guide policy directed towards improving peoples' lives in general and their health in particular.

This study's findings may also be more widely relevant to other developing countries, especially Arab societies. Other than the importance of national political freedom in determining life quality in the Palestinian context, this study's findings also point to societal freedoms, participation in democratic processes and feeling involved in decision making as important QOL determinants. In this regard, one of the main findings of the Arab Human Development Report 2004 highlights the importance of political restrictions on human development as the most stubborn of all impediments to an Arab renaissance. Deficits of civil and political freedoms, the lack of participation of citizens, the disempowerment of various sectors of the population [44], resonating in this study in the youth narratives especially, are all elements that may well be defining features of OOL in the Arab World context, and as such, need to be addressed in future research.

### Appendix A. Comments, suggestions and selected answers to the WHOQOL-Bref 26 questions

Physical domain		
<u>F1.4</u> : To what extent do you feel that physical pain prevents you from doing what you need to do?	Important but pain does not prevent you from doing what you need to do, because the burden of responsibilities appears to override the weight of pain (for women to a larger extent). "Physical and mental health are related. Mental causes have physical manifestations"—a male Gaza upper middle class professional.	
	A middle class urban woman insisted that: "[There is a] need to change the question to: how many times you felt pain and did not go to the doctor".	
<u>F11.3</u> : How much do you need any medical treatment to function in your daily life?	Misconstrued to some extent to imply an accessibility problem to medical care rather than an absolute degree of physical need it may be worth the while to consider rephrasing to assess access to medical care, as it would seem that this is the item of relevance to the participants.  "There is no state to provide the needed treatment anyway"—A Ramallah Camp man.	
<u>F2.1</u> : Do you have enough energy for everyday life?	The question drew much attention from the participants.  It may be worth the while to consider dividing into two items: the physical exhaustion and the lack of energy due to stressful life conditions.  It was also suggested to change the term energy in Arabic (taqa) into Himmeh or Heil as those were better understood by the discussants to mean personal ability to function due to a general psycho-social and physical state, as opposed to the	
<u>F9.1</u> : How well are you able to get around?	absolute presence of physical energy.  This question also drew much attention, although meaning was quite clearly not linked to physical abilities, but to the inability to move around due to checkpoints, closures and siege instead. The discussants emphasized the need to include another question on ability to move around in relation to the latter.	
<u>F3.3</u> : How satisfied are you with your sleep?	Much interest was generated by this question among all groups In general, the participants reported their inability to sleep after witnessing tragic and traumatic events, reported to be associated with "fear of devastating political events" and "other internal insecurities" making the individual not sleep well, having bad dreams and nightmares, or not getting the needed rest from the sleeping period. On the other hand, some participants revealed that they started to sleep more as a form of escapism.	
<u>F10.3</u> : How satisfied are you with your ability to perform your daily living activities?	This question proved to be a confusing one, as respondents combined the biological aspects with mental health aspects.	
Psychological domain		
<i>F12.4</i> : How satisfied are you with your capacity for work?	This question was seen as a redundant question, especially to women who do not work outside the home, and where the previous question queried them already on daily activities which include work.	
	Some participants found that the question was not relevant as the concentration should be on the satisfaction with the	

achievements and not the capacity to do work.

It is suggested that this question should be dropped.

physical and mental health.

Others insisted again on the close inter-connected between

### Appendix A (Continued)

<u>F4.1</u> : How much do you enjoy life?	This was a difficult question to answer for some respondents, notably the older generation, as enjoying life is not very
	relevant to people who are constrained by severe restrictions of
	movement, exposed to a variety of dangers and simply
	struggling for survival. A lack of enjoyment in life was strongly felt by younger Gazans.
	It seems that, for many, especially the older generation, life is
	not conceptualized in terms of being enjoyable or not
	enjoyable, but rather in terms of people being happy, satisfied or
	acceptant of life instead.
	"The word satisfied is better to use than enjoy. Enjoying
	something means that we have reached the top, when in reality
	· ·
	we are not at the top, we are barely satisfied"—a middle class Ramallah village woman.
	On the other hand, some of the participants reported enjoying
	life in some situations or in certain social occasions.
<u>F24.2</u> : To what extent do you feel your life to be meaningful?	This question as well did not seem to be compatible with the
	overall conceptualization of life in the Palestinian culture. In
	the face of some views that life is "dictated/written" and that
	you may accept it, be satisfied, but have to live it anyway, this
	question does not seem to be very relevant for Palestinian life
	quality assessment.
	Moreover, the term meaningful was largely interpreted as
	important and of value to oneself, the others, or the nation in
	general, and in relation to fulfilling social roles.
	It was suggested that: "This question should be divided into
	two, one about the importance of one's life, and the other about
	self worth"—middle class Urban Ramallah woman.
$\underline{F5.3}$ : How well are you able to concentrate?	This question was perceived as important for different reasons,
	especially for students, but also for others. Most reported being
	unable to concentrate, but present their views in different ways.
	Political contextual challenges seem to be determinant.
<u>F7.1</u> : Are you able to accept your bodily appearance?	The question was rated as important mostly for the younger
	generations and women more than men.
	Some participants attributed the importance of the question to
	boredom or escapism; e.g., girls tend to pay more attention to
	their looks in times of political difficulties.
	Alternatively, it appeared that severe psychological distress
	could lead to the neglect of looks as well.
	Even attention to appearance, however, was linked the
E6 2. How satisfied are you with yourself?	difficulties encountered in crossing checkpoints daily.
<u>F6.3</u> : How satisfied are you with yourself?	This question does not seem to be relevant to the
	conceptualization of life quality and self in the local culture. It
	was not perceived as an interesting or relevant question
	generally. Some of the discussants, however, interpreted the
	question in relation to satisfaction with what one does or in
	relation to satisfaction with social relationships.
	It is suggested that this question is either dropped, or re-conceptualized to inquire about satisfaction with what one
	does.
F8.1: How often do you have negative feelings, such as blue mood,	This was almost unanimously reported as an important
despair, anxiety, depression?	question, to be divided into its component items, and to include
despuis, anniety, depression.	new items that were revealed as important in defining life
	quality in the local context (such as sadness, frustration, feeling
	captive, feeling hopeless, feeling helpless and fear).
	capare, reening noperess, reening nerpiess and rear).

### Appendix A (Continued)

The social domain

F13.3: How satisfied are you with your personal relationships?

F15.3: How satisfied are you with your sex life?

<u>F14.4</u>: How satisfied are you with the support you get from your friends?

The environmental domain

F16.1: How safe do you feel in your daily life?

F22.1: How healthy is your physical environment?

F18.1: Have you enough money to meet your needs?

"Mental Health? See . . . whenever I open a news channel, there isn"t anything but death, shelling and blood scenes"—a Gaza high school student.

It was strongly recommended to divide this item be divided into relationships with: family, neighbors, friends and others, because of the varying nature of relations of support and control that were revealed by the narratives.

Differences in views were detected between young women and young men. Women expressed interest in limiting the pressure imposed by the local customs and traditions, and the significant discrimination against females in the society. In contrast, some young women acknowledged the importance of the support they get from close relatives. Young men also protested against discrimination by older members in the family and the society. This question was dropped, as it was deemed inappropriate to include in the local cultural consideration.

All agreed that this was an important question generating a good amount of discussion. It may be worth the while to divide the question into: financial and social support, given the existence of financial networks of support that operate within the extended family, other relatives and among friends, and its importance for survival especially in times of crises. We noted the higher tendency of men to reach out to friends, compared to women, perhaps due to the cultural restrictions on the freedom of movement of women in Palestinian society. Support also comes as a result of being politically active.

This question generated much interest and discussion, and was interpreted in various ways, including: physical safety/security due to Occupation violence, to internal societal violence, financial security, warranting a possible division of this question into relevant items.

A female Gaza university undergraduate student declared: "I do not feel physically safe at all. I am not used to this, and will not get used to this. Whenever there is shelling, it is like the first time, and I panic".

The relevance of this question was strongly expressed, especially by Gazans and Ramallah village women.

Various types of environmental hazards were noted: pollution due to inadequate infrastructure and services, water quality problems and noise pollution which appeared to be an issue in

Some downplayed the problem of environmental pollution and pointed to the complicated political situation instead.

An important question to ask in a context of spiraling poverty, especially relative to the recent past.

The availability of money was expressed as associated with one's social rights, including education.

Others, mostly males, downplayed the importance of money and emphasized being able to study and work in influencing life quality instead.

### Appendix A (Continued)

<u>F20.1</u>: How available to you is the information that you need in your day-to-day life?

 $\underline{F21.1}$ : To what extent do you have the opportunity for leisure activities?

<u>F17.3</u>: How satisfied are you with the conditions of your living place?

F19.3: How satisfied are you with your access to health services?

F23.3: How satisfied are you with your transport?

It was recommended that the question should be asked instead as: "Do you have enough money to fulfill your basic needs"—Ramallah village women [that is, satisfaction is not the issue, however, basic survival is].

This question did not generate much discussion, and did not seem to be very relevant to the national context. With the information technology revolution sweeping the country during the past decade, the ready availability, indeed abundance of mobile phones, computers, internet access and satellite dishes have allowed for a remarkable general access not only to the needed information, but also to the outside world. It is recommended that this question is dropped from the national instrument.

The question deemed important for all, especially youth and women. It was construed as containing a multiplicity of factors that allowed, or did not allow, the opportunity for leisure to arise: as in the lack of free time, the absence of leisure schemes and entertainment centers, the lack of financial means or other social/systemic restrictions.

Some participants reported that leisure helps during trying times of political crisis...

This was deemed as a very important question, especially for villages and refugee camps dwellers, and Gazans.

Main housing problems, as stated by the participants, included: overcrowding, unhealthy environment (including an absence of sewage water proper disposal) and no territorial management or zoning and urban planning (houses are very close to each others mainly in refugee camps).

Access was viewed as multi-dimensional. Problems hindering proper and adequate access included: physical inability to reach the health services due to checkpoints, closures and siege, financial affordability, unavailability of transportation, low quality of services, absence of social security schemes or that access entails favoritism.

Transport was reported as a very important problem the discussants faced in managing their daily lives and due to several causes: a systemic lack of service in villages, an order and control problem and difficulties due to the checkpoints and road blockades.

It is recommended that this question be divided into its component items.

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