

## **Advances in developmental psychology and subjective vs objective patient and family centred QoL care: A case presentation.**

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### **Introduction:**

Quality of Life (QoL) clinical care is a fairly recent concept in medical psychosocial practice. QoL can be defined sociologically as a subjective perception by the individual of the fulfilment of one's basic human needs, and is quantified objectively by measuring a minimum of 4 basic domains: physical, emotional, social and vocational (H. Morsi et al 2016). QoL lies in the core of patient and family-centred care that health care systems are aiming to transform to (J. Arts et al 2012). The objective is to comprehensively inform patients and families of their health issues, empower them to take charge of their illness and participate in making choices about managing their health.

Nevertheless, when a family member is diagnosed with a serious illness like cancer, it turns QoL and stable family life upside down. All 4 domains are disrupted by persistent symptoms of disease, the involvement of several physicians, and patient urgency in contrast to the perception that the diagnostic process is slow. The 3-5 days needed to run all possible diagnostic tests to reach the exact diagnosis, staging of the disease and determining the degree of risk inherent in the form of cancer, might feel particularly acute to a parent when their son or daughter is the patient. Furthermore, normal life is shattered when the news of a cancer diagnosis is broken to parents.

When QoL is compromised, the harmonious connection between parents and their children kids is both interrupted and parents lose the sense of control over the care of their children (A. Stanton et al 2001). In fact, we have been running QoL research in Qatar for the last four years, and the results show that 30% of cancer patients between the age 0-25 have significantly compromised one or more QoL domains, 30% of parents have similar significant compromise, and in 30% of cases there is a discrepancy between the perception of the patient and parents.

The focus of this document is a recently observed pattern in our data illustrating an up and down, zigzagging conflict between both parents. Among a stable family with no seriously ill children, for a mother and a father who have managed to stabilize living circumstances after getting kids, a blend of patterns would probably exist as shown in Table 1.

Congruent understanding of mother by father	Congruent understanding of mother by father
+	+
Congruent understanding of father by mother	In-Congruent understanding of father by mother
In-Congruent understanding of mother by father	In-Congruent understanding of mother by father
+	+
Congruent understanding of father by mother	In-Congruent understanding of father by mother

*Table 1: Possible congruencies between parents in a stable partnership. There will most likely be issues that fall under each quadrant of the above matrix, and despite normal tensions, stable marital life is not at risk. Congruencies are enjoyed and*

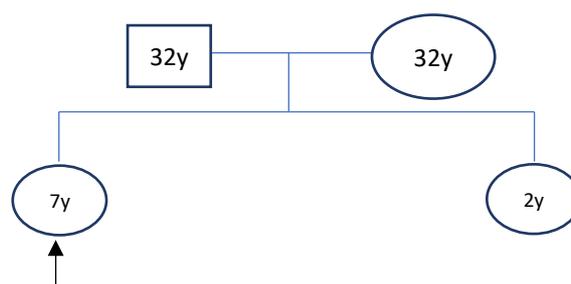
*could occupy the major time of this stable family, and incongruencies can be more easily dealt with under normal conditions of stability and predictability. When a serious illness of a child (such as cancer) imposes significant change to previously stable family circumstances, the incongruent understandings begin a significant deterioration in the QoL of the family system injecting conflict and upheaval that might result in divorce and separation.*

While oncologists are often preoccupied by tumour management, escalating conflicts between parents and the deterioration of the psychosocial domains is considered outside the scope of the practicing physician. Thus, it becomes the duty of the QoL practitioner to determine the priorities in normalizing the QoL of the family with a goal of preemptively diffusing the tension. In the case of conflict between father and mother, the QoL practitioner functions as a family counselor to boost change resilience of the affected family. The routine medical psychological practice, also applied to QoL clinical care, is to document the chief complaints of the patient, take a comprehensive history, run a psychological examination – known as Mental State Examination (MSE) – and administer screening tests and objective clinical interviews to establish a full QoL diagnosis. A QoL practitioner – similar to other medical disciplines – depends on their experience to establish a provisional diagnosis, differential diagnosis and a plan for care.

The Spiral Dynamics® Change State Indicator (CSI) is a useful tool to investigate research resilience. It contains 28 positive and negative style questions that are distributed into ten scales. Five scales evaluate the “states of change” experienced by people as they face challenging life conditions and five scales convey preferences for absorbing and coping with change. The scores for most scales range from 0-30 points – some run from 0-45 - with 0-10 = low, 10-20 = moderate, 20-30 = high, and 30+ very high. This tool has been used in our practice to help couples understand one another, parents to understand their teenage children, and the QoL practitioner to attain an objective and unbiased analysis (G. Bateson 1987, J. Bartunek and M. Moch 1987, C. Graves 2005).

### **Case Presentation:**

A 7-year-old girl diagnosed with Acute Lymphoblastic Leukemia (ALL) on August 2017, started intense chemotherapy for 6 months and is now continuing 18 months of oral maintenance treatment. During the 6-month intense treatment, she experienced the expected fatigue, pain, infection, etc. As a consequence, the child developed maladaptive behaviors to grab increased attention and to “get away with” her desires. For example, as the mother insisted that the child clean and pick up her toys. The child got used to the “good dad” intervening and letting her off her expected duties. The father would openly challenge the mother noting “the child is not well, don’t be so hard on her”; thus, when the child wanted something, she approached the “good dad”, avoided the “bad mum”, and later it became a trend to say ‘mum is evil and dad is good’. This increased the tension between the couple and the relationship between mother and daughter.



*Figure 1: The family tree; Arrow indicates the child with Leukemia. The 2-year-old child is also being considered for a QoL support. The grandmother is currently supporting the parents with their care to both children*

This inconsistency in the parent's approach caused significant tension between them. Given the mother had to quit her job to look after the child's medical care, her stress levels increased. She perceived little to no support coming from her husband. He put all his energy into looking after the child's needs because the mother was unable to cope with the new, demanding attitude of the child. The parents landed in our QoL clinic when the father found it too difficult to cope with the situation. Like his wife, he stopped working and made it his job to look after the child. Not knowing how to evaluate changes in her condition, trivial deterioration of her illness caused panic and he would call the QoL officer after midnight in a markedly distressed state. As the child improved through treatment, the tension between the parents escalated, and family counselling sessions started at the QoL clinic. A clinical interview focusing on family dynamics was conducted, and the subjective impression of the family practitioner was documented. The CSI tool was administered, analysed, and followed by another clinic interview.

### **Results:**

There was a significant discrepancy between the subjective clinical impression and the objective CSI assessment. The main discrepancy was due to the expectations of the practitioner regarding the situation of the suggested intervention. The CSI, on the other hand, identified the similarities and differences between both parents while neutralizing the practitioner's own projection and biases Figure 2.

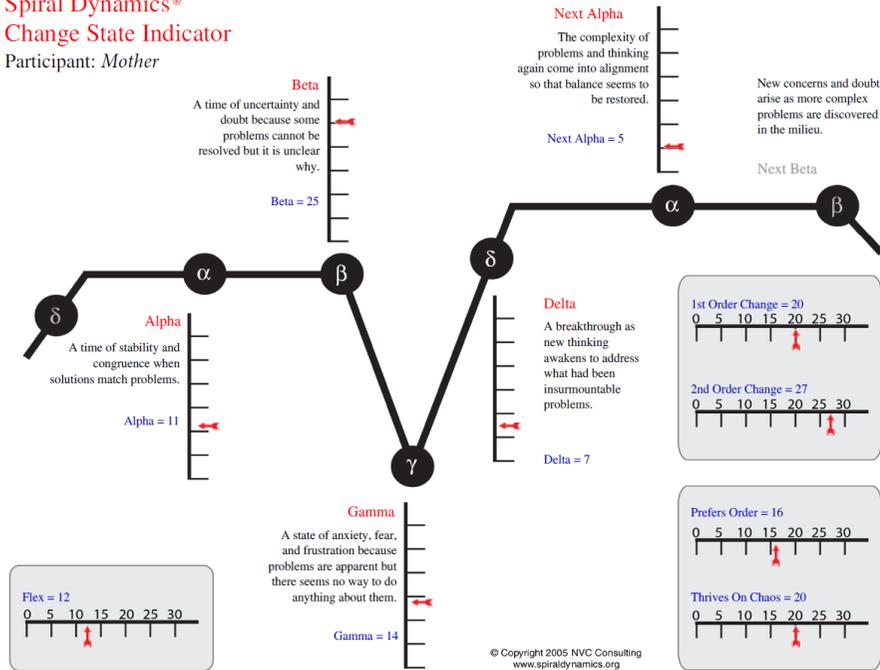
The intervention was constructed based on the CSI results. Education began with the parents exploring their similarities, differences and coping styles. They were guided on how to exploit the similarities to capitalize on common ground. Their differences were used to complement one other, to boost their change resilience, and they were discharged from the clinic with instructions to implement the new suggested communication strategy for a week. Provisional improvements in communication were observed making a couple's sessions the next logical step where they had detailed discussions of their problems and explored the sense of being trapped in a negative cycle. The CSI will be repeated in 6 months to identify changes in different patterns after the intervention.

### **Concluding Summary:**

In patient and family-centred QoL psychosocial care, it is important to put less weight on the subjective projection of QoL practitioners since personal experiences might bias accurate perception of the situation. Seeing the situation through the patients/family own eyes and perspectives is an important step in transforming the health care system towards patient and family-centred care. The CSI tool provides a concise objective overview to counteract the subjective biases, establishing a clearer perspective of the family situation while enabling the QoL practitioner to tailor a personalized QoL approach for both the individuals in the family and to better help families.

Spiral Dynamics®  
Change State Indicator

Participant: *Mother*



Spiral Dynamics®  
Change State Indicator

Participant: *Father*

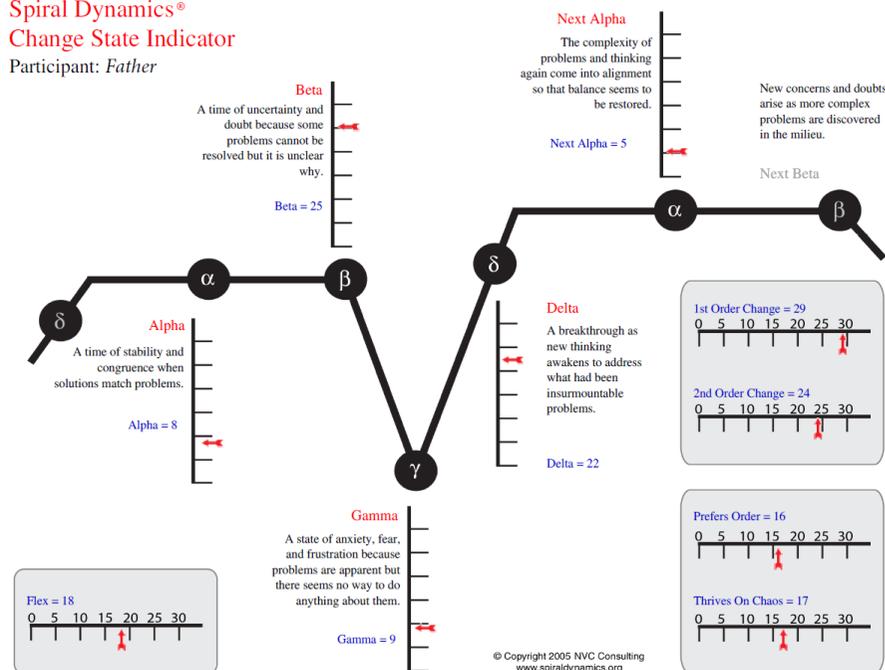


Figure 2: The results of the CSI analysis of parents, where absolute similarity was identified in the lack of clarity around the specific problems (beta), lack of future perspective (next Alpha). Absolute differences were identified in original preferences around the scope of change (Dad is a high 1<sup>st</sup> while mum is a high 2<sup>nd</sup> order change), sense of breakthrough in life (delta). Relative differences were identified in gamma where both parents felt trapped and unable to solve the problems they face with the mother feeling it more acutely than the father and the level of flexibility with the mother in the average range and the father extremely flexible. Relative similarities were observed at the level of preference for order and adaptability to chaotic environment.

The main findings of this analysis was the high degree of dissonance felt between problematic life events and the perception of their ability to effectively solve the problems and the to reform when faced with such problems.

1<sup>st</sup> order change: consists of reformations that occur with no change in the meaning of the context

2<sup>nd</sup> order change: involves the creation or change of a context and presents new images, defines (bounds) new concepts, or intrudes into the space of existing concepts uses one reality to modify representations in another reality interpersonal and societal changes "morphogenesis," "policymaking," "root," "revolutionary," "radical," "transformational" (G. Bateson 1987)

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