



THE SCOPE

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IN THIS ISSUE



PAGE 02

What is Quality of Life and why is it so complicated?

PAGE 05

Measuring Quality of Life: Why and How?

In recent years, quality of life (QoL) has been widely discussed as an indication of health outcomes and well-being in the paediatric field.

In this issue, we explore what QoL means and their various definitions in the current literature. We will also look at the importance of using validated measurement tools to measure QoL.

QUALITY OF LIFE (QOL)

What is Quality of Life?

An individual's 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.

(Source: World Health Organisation)

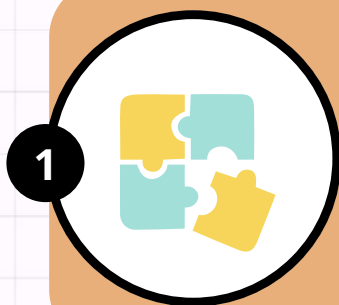
A key reason why QoL is a complex concept is because its **definition is fluid**.

There are numerous variations used across studies, each with their own merits as they strive to best describe the QoL of the target population.

Why is it so complicated?



Even though numerous variations of QoL exist in literature, there are **three underlying concepts** at hand:

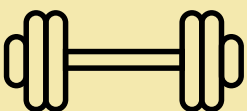


QoL as a **multi-dimensional** concept

QoL comprises of numerous elements that form the individual experience.

Domains of QoL

PHYSICAL



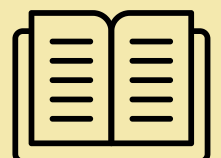
EMOTIONAL

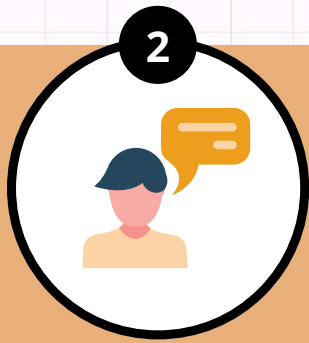


SOCIAL



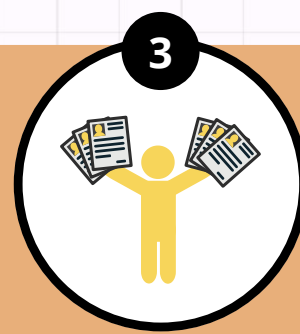
SCHOOL (for children)





QoL is **person-centric**

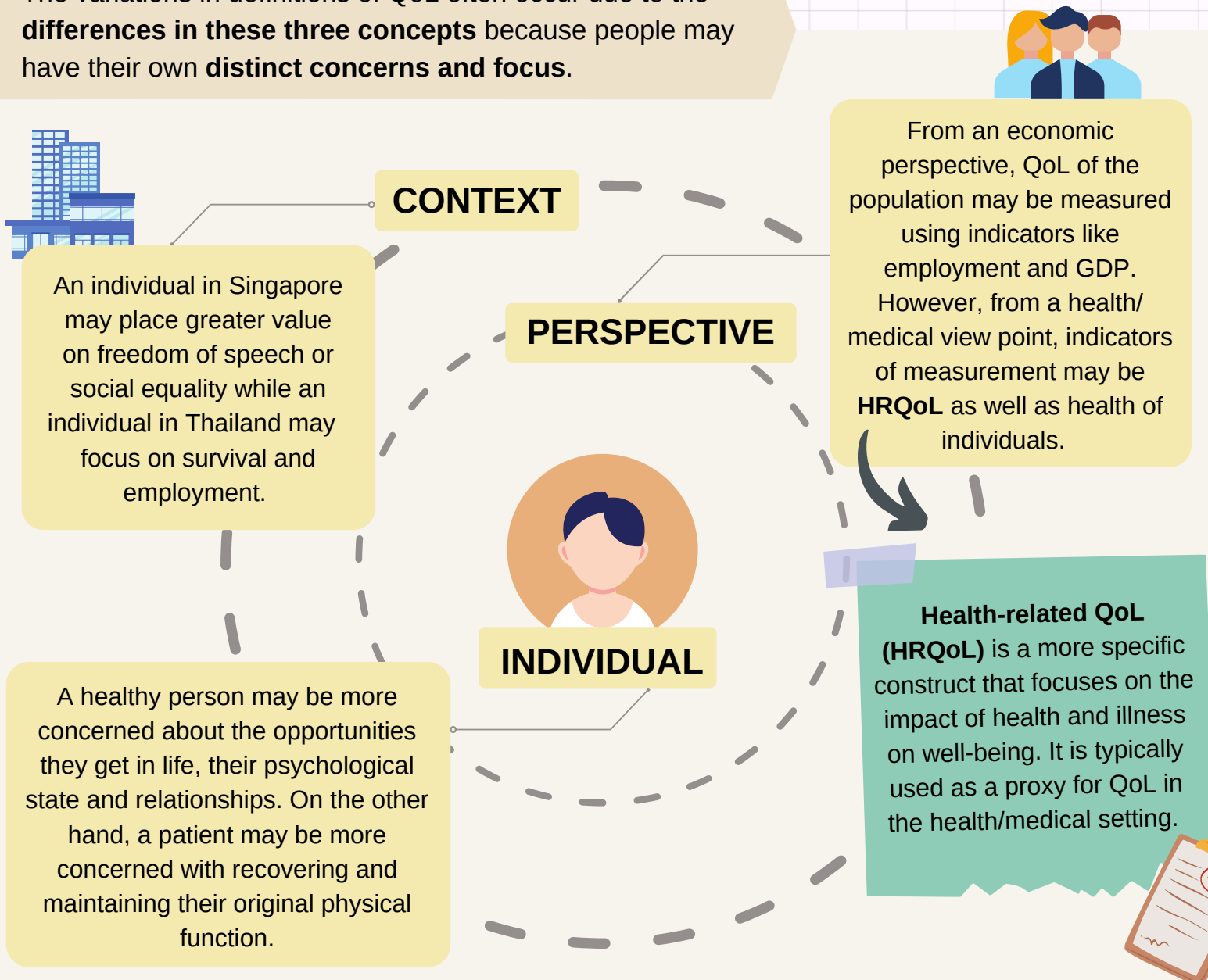
It is important for QoL to consider the opinions and perspectives of the individual.



QoL is described using both **objective** and **subjective** indicators

QoL should account for both objective metrics and subjective experiences of the individual.

The variations in definitions of QoL often occur due to the **differences in these three concepts** because people may have their own **distinct concerns and focus**.

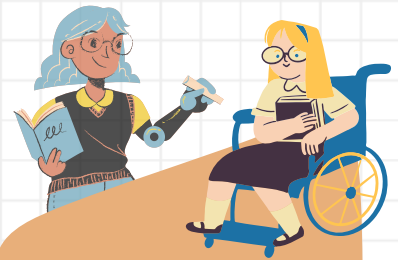




Focus: QoL of Children with Cancer

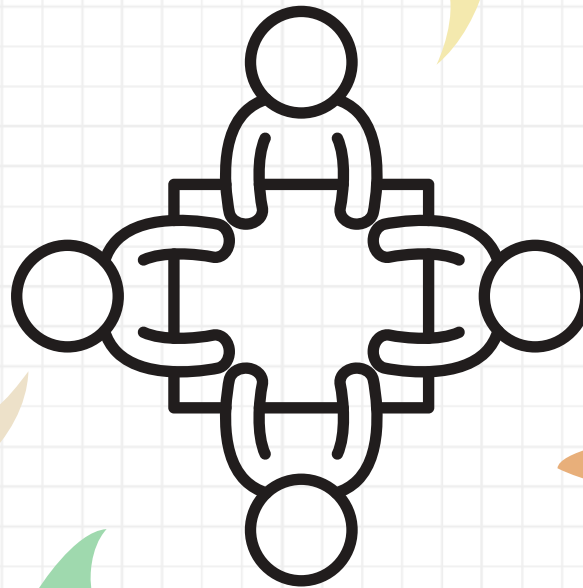
We will now explore the nuances in defining QoL of children with cancer.

Should we focus on how well the child is currently? Or should the focus be on the child's well-being in the future?



Should the QoL of a child with cancer be of the same standards as that of a healthy child?

Does the definition of QoL stay the same along the illness trajectory?



How much say should parents have on their child's QoL?



The truth is that there is **no definitive answer** to what QoL means for children with cancer and that of any other population. There are simply too many ways of how we can look at and understand their lived experiences.

Instead, we should constantly **consider what is important to the population and us** to build a definition of QoL that is meaningful for both our beneficiaries and our work.



Measuring Health-Related Quality of Life (HRQoL)

In this section, we will look at HRQoL measurement tools given that CCF's work is based in a medical setting.



Why do we want to measure HRQoL?

Measuring HRQoL can provide a **meaningful and comprehensive assessment of our beneficiaries' well-being**, aside from their illness or functional abilities.



This will allow us to understand both the needs of our beneficiaries and the outcomes of our work.

Using measurement tools that have been proven to be **reliable** and **valid** would provide us with the desired quantitative data that allows us to draw meaningful conclusions and make comparisons between populations or across time.

Reliability: consistency of a measurement that gives the same results on different occasions

Validity: the property of a measurement that tests what it is supposed to test

What are some considerations when choosing measurement tools?



Length of time needed by respondents to complete the questionnaire/ scale



Methods of administration
e.g. questionnaire, interview



Age or education level of respondents

Examples of HRQoL Measurement Tools

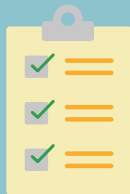
Below are two paediatric HRQoL measurement tools that have demonstrated good reliability and validity. Both measurement tools:



Consist of both self-administered **child reports** and **parent proxy-reports**



Take a **short amount of time** to complete (approx. five mins for each scale)



Consist of **generic** and **illness-specific** measurements



Are available in **several languages**, including a **Singapore English** version

click on the tools for more information!

The Paediatric Quality of Life Inventory (PedsQL)

(Varni et al., 2002)

- One of the **most frequently used** measurement tool for HRQoL, thus **providing data for comparison** among various paediatric populations
- Assessment is based on the **frequency of problems** experienced by the individual over the past month
- Used in our collaborative study - *The Growing QoLaS - QoL Assessments Growing Up in Singapore After Cancer*

KINDL-R

(Bullinger et al., 2008)

- The generic scale measures an additional domain of **self-esteem** as compared to PedsQL
- Assessment covers both **positive and negative aspects of well-being** experienced over the past week
- Availability of an **online** version (CAT-SCREEN) which caters to children

Keep a lookout for more info. in a future volume!

Measurement of QoL in children with cancer is imperative for us to understand the impact of cancer and its related issues more holistically. This can allow us to **monitor our beneficiaries' well-being** and **provide targeted interventions** accordingly.

While there are several instruments that measure the various dimensions of QoL in paediatric literature, it is important to choose those that address our questions.

1. Varni, J. W., Burwinkle, T. M., Katz, E. R., Meeske, K., & Dickinson, P. (2002). The PedsQL™ in Pediatric Cancer. *Cancer*, 94(7), 2090–2106. <https://doi.org/10.1002/cncr.10428>

2. Bullinger, M., Brütt, A. L., Erhart, M., & Ravens-Sieberer, U. (2008). Psychometric Properties of the Kindl-R questionnaire: Results of the bella study. *European Child & Adolescent Psychiatry*, 17(S1), 125–132. <https://doi.org/10.1007/s00787-008-1014-z>



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Thank you!

We hope that you've enjoyed reading this issue of The Scope. The Scope is published bi-annually, providing you with exclusive insights into our latest research studies in a digestible format. Through sharing these bite-sized research findings, we hope that we can make research related to childhood cancer more accessible to everyone.

If you are interested to read about our studies in greater detail, please reach out to us via email.