Operationalizing Family Quality of Life: Occupational therapy outcome measurement for South African forensic psychiatric rehabilitation

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Preface

This study was pursued due to a personal desire to contribute towards a support paradigm of care within mental health service delivery, as well as a desire to understand how to empower families to be functional and healthy units in society. Social determinants of health are prioritized in understanding health outcomes and directing public health care, however, little research has taken place directing family-centred occupational therapy. The families of forensic MHCUs experience an immense burden of disease but are often neglected in being supported to develop their potential of being a protective factor, thus buffering the negative influences of mental illness experienced by the forensic MHCU and other identified family members.

The occupational therapy (OT) researcher was thus confronted with a question of how the OT profession could contribute meaningfully towards enhancing the family unit as an empowered support structure experiencing health and well-being, as well as what health outcomes could be developed to inform family-centred intervention. The researcher queried how the forensic OT department could shift the strategic and operational objectives focus from primary generic client-centred intervention to impactful family-centred care to keep in alignment with psycho-social rehabilitation objects, and thus achievFing optimal rehabilitation gains for community reintegration.

Two quotes affirm the value of focusing on the family in forensic mental health occupational therapy. The one is the isiZulu proverb “Umuntu ngumuntu ngabantu” which means “A person is a person because of other people”. The second was mentioned by the researcher’s spouse, “this is who we are, and this is what we do”, reflecting on his family of origin.

For occupational justice and individual or collective occupational identity to be developed in the family of a forensic MHCU, OTs would do well in incorporating an occupational lens to family-centred practice and thus incorporating foundational aspects of occupation in daily living, namely, “doing, being, becoming, belonging” (Wilcock,1999).

Declaration

I, Ms Margaux Louise d'Hangest d'Yvoy, hereby declare the following:

1. The work described in this thesis is based on my original work, except where acknowledgement indicates otherwise, the American Psychological Association, 6th Edition (2010) system of referencing was used.
2. This work has not previously been submitted to the University of KwaZulu-Natal or any other tertiary institution for purposes of obtaining an academic qualification, by me or any other party.
3. A Turnitin Similarity Report (Appendix T) is provided to confirm prevention of plagiarism in this work.

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Abstract

Background: Families of forensic mental health care users (MHCUs) experience a great burden of disease. Families of forensic MHCUs in KwaZulu-Natal, South Africa, are identified as the primary community based support system. Relevant psycho-social rehabilitation and support services are required to empower the family as the primary community based support structures, for successful community reintegration and role re-acquisition of young adult forensic MHCUs to be achieved. Occupational therapists (OTs) have had a limited role in forensic "family work" in achieving family-centred health outcomes. Health outcomes have not been developed for occupational therapy practice to direct strategic family-centred rehabilitation. Family Quality of Life (FQOL) has been identified as a strengths-based family outcome which could be used in forensic mental health care. Operationalization of a unique occupation-based FQOL construct was required to inform outcome measurement tool development ensuring family-centred effective and efficient service delivery in the future.

Research aim: This study aimed to identify and operationally define FQOL in the development of a FQOL outcome measurement tool that could direct family centred OT services for MHCUs and their families within a forensic psychiatric facility setting in KwaZulu-Natal, South Africa.

Method: A qualitative research strategy was used to establish the meaning of FQOL, particularly, an interpretivist qualitative research design. Focus groups of experts (mental health care professionals, forensic MHCUs, and family members) attributed meaning to the existing FQOL construct. A hybrid of inductive and deductive data analysis was necessary to operationalize this construct for application to forensic mental health outcome measurement tool development.

Results: An operational definition of the occupation-based FQOL construct using an occupational lens for evidence-based forensic mental health OT practice, was developed. FQOL operational definition(s) of the construct, themes, sub-themes, domains, and sub-domains were formulated and presented in a meaning map of meaning attributed by expert participants. This novel construct consists of two (2) themes (family unit factors, and individual member factors), their related sub-themes (e.g. family unit factors' sub-themes: family characteristics, family dynamics, and external family unit support) and domains addressing pertinent areas of family life contributing to a collective FQOL experience of forensic MHCUs and their family members. Findings merged FQOL and OT frameworks for application to forensic mental health as compared to previous disability fields of inquiry. A diagrammatic presentation of the novel FQOL construct using an ecological perspective

displays pertinent areas of family life requiring support by OTs rendering psycho-social rehabilitation.

Conclusion: OTs practicing within the specialist forensic mental health facility in KwaZulu-Natal, South Africa, are hereby presented with an operationalized FQOL health outcome which could direct evidence-based, family-centred, strengths-based, and support-orientated service delivery, strategically positioning the profession in community-based rehabilitation.

Key words: Family Quality of Life, Forensic Psychiatry, Mental Health Care Outcomes, Occupational Therapy Outcomes

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My family of origin and my new family - my husband Wessel Venter - have assisted me in crossing over the finish line in trying times and times of change. Thank you for inspiring a desire for healthy families in me, and for partnering with me through life. This study is attributed to our shared lives. Thank you Wessel for your sacrifice in allowing me to complete and thank you for your encouragement to persevere. I am so glad that I get to do "family life" with you!

Finally, to God of my heart and of my understanding, the Lord Jesus Christ, to Him alone be the glory. He has impressed this desire for whole families within me, and has enabled me to do this work. He has sustained me throughout, and so much more.

SDG.

Table of Contents

List of Tables and Figures

List of Tables

List of Figures

Important Definitions

1. Caregiver is a closely related individual (biologically or socially related) accepting the primary role of rendering emotional and practical support towards a forensic MHCU family member/ friend during various stages of recovery. (Ridley et al., 2014).
2. Construct is an abstract concept/ idea which specifically describes a particular phenomenon/ phenomena and is used to communicate or argue a phenomenon. It can be either be uni-dimensional (i.e. temperature) or multi-dimensional (i.e. quality of life) in nature (Waltz et al., 2010; Uys, 2003).
3. Custodian: is a person allocated with the legal guardianship or custody of a state patient, including protection and guardianship of the state patient's property/ assets and personal records while said state patient is unable to consent due to temporary or permanent incapacity. The primary caregiver and custodian can be the same person.
4. Domains: Clearly defined, precise and accurate concrete underlying conceptual elements of a greater abstract construct of inquiry (Waltz et al., 2010). Domains are the parts of a multi-dimensional construct/ primary outcome of interest (i.e. quality of life) which are measured in an outcome measurement tool. Domains is used synonymously with construct.
5. Forensic psychiatry: is a sub-specialisation of mental health care services specializing in the care, treatment and rehabilitation of forensic state patients, persons awaiting trial, and mentally ill prisoners (MHCA No.17 of 2002).
6. Forensic psychiatric rehabilitation: refers to psycho-social rehabilitation services rendered within a forensic sub-specialisation in mental health care (see definitions for Forensic psychiatry, and Psycho-social rehabilitation)
7. Family Quality of Life: is an abstract construct which "refers to the presence of conditions under which families are satisfied that their needs are met, enjoy their shared life, and have opportunities to do the things they perceive as important (Park et al., 2003)" (Samuel et al., 2018, p.14).
8. Mental health care professional (MHCP) refers to trained/ qualified clinicians providing forensic mental healthcare services (namely care, treatment and rehabilitation in accordance with the Mental Health Care Act (MHCA No.17 of 2002) and include social workers, and psychiatric nursing staff as represented by participants in the study. This term however can further include psychologists, psychiatrist, and occupational therapists practicing in this forensic sub-specialization.

9. Forensic Mental Health Care User predominantly referring to state patients admitted to designated hospitals in terms of the MHCA (Houidi, 2018, p. 545)
10. Occupation: is a concept with linked to health, well-being and justice referring to any meaningful activity participated in individually or collectively as a group. These activities are including but not limited to employment, leisure, self-care, and education. (Samuel et al., 2018, p.14)
11. Occupational therapy: is "the therapeutic use of everyday life activities (occupations)" or occupation-based intervention "with individuals or groups for the purpose of enhancing or enabling participation in roles, habits, and routines in home, school, workplace, community, and other settings." Change is facilitated in client factors and particular skills required for the desired end result of meaningful and successful occupational participation. (AOTA, 2014)
12. Occupational science: is the field of inquiry into humans as occupational beings. "Research into the purpose, meaning and complexities of the interaction between people, what they do, and where and how, is of primary importance to inform, not only occupational therapy practice, but also almost all disciplines, professions, and agencies responsible for sociocultural-political and health planning." (Wilcock, 2005, p.7)
13. Operational definition: an explicated abstract construct into its concrete and observable parts (aspects of meaning, attributes, properties, behaviours, or objects) (Uys, 2003; Waltz et al., 2010).
14. Operationalization: the process of establishing how a construct will be measured. "It involves making a concept explicit in terms of the observable indicators associated with it and /or the operations that must be carried out in order to measure it." (Waltz et al., 2010).
15. Outcome (or sub-scale): the occupation-based or non-occupation based desired end result/consequence of occupational therapy intervention (Kirsh et al., 2019; Casteleijn, 2010). These ought to be the results that primary value to the service users rather than the service providers.
16. Outcome measure/ outcome measurement tool: An evaluation instrument used to assess the efficacy of mental health services rendered, and to track change attributed to therapeutic or rehabilitative intervention in pursuit of desired end results related to occupation-based or non-occupation based outcomes (including, health, wellness, and participation). One or more attributes of an outcome can be measured by means of a particular measurement tool. (Kirsh et al., 2019; Chui et al, 2016; Casteleijn, 2010, p.xvi)
17. Psycho-social rehabilitation consists of interventions and models aimed at the fulfilment of mental health care users' chosen roles or areas of meaningful function (i.e. independence,

autonomy of choice, vocational and community functioning) and assists clients in overcoming areas of challenge caused by chronic mental illness. It is an internationally recognised standard of best practice within mental health care. (Kramers-Olen, 2014)

18. Quality of life: the evaluation of perceived/ subjective life experience versus an ideal expectation regarding important aspects in one's life (Schalock, 2004). Quality of life is defined by the World Health Organization as '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.' (The World Health Organization Quality of Life assessment (WHOQOL): position paper from the World Health Organization, 1995).
19. Theoretical definition: Mature concepts that are well understood, in that they have clear definitions and are well differentiated from other concepts within existing literature and developed conceptual frameworks (Waltz et al., 2010).

Abbreviations and Acronyms

ACT	Assertive community treatment
AMPS	Assessment of Motor and Processing Skills
APOM	Activity Participation Outcome Measure
Beach Center FQOLS	Beach Center of Disability Family Quality of Life Scale
BREC	Biomedical Research Ethics Committee
CBR	Community Based Rehabilitation
CBT	Cognitive-Behavioural Therapy
DoJ	Department of Justice, the Republic of South Africa
DoH	Department of Health, the Republic of South Africa
EE	Emotional Expression
FM	Family Member
ForACT	Forensic Assertive Community Treatment
FQOL	Family Quality of Life
FQOL ForOT	Family Quality of Life Outcome Measure for Forensic Occupational Therapy
FQOLS-2006	Family Quality of Life Survey (2006) – generic or ID/DD versions
HPCSA	Health Professions Council of South Africa
I/DD	Intellectual and developmental disability (IDD or I/DD)
ID/DD	Intellectual disability and developmental delay
ILS	Independent Living Scales (manual)
KZN	KwaZulu-Natal
LOA	Leave of absence

MHC	Mental Health Care
MHCA No. 17 of 2002	Mental Health Care Act (No.17 of 2002) (The Presidency, 2002)
MHCP	Mental Health Care Professional
MHCU	Mental Health Care User
MoCA	Montreal cognitive assessment
OCAIRS	Occupational Circumstances Assessment Interview and Rating Scale
OT	Occupational therapist/ therapy
OTPF	Occupational Therapy Practice Framework
PEOP	Person – environment – occupation – performance model
PRO	Self-administered patient-reported outcome (PRO)
PSR	Psycho-social rehabilitation
QoL	Quality of Life
SA	South Africa
SES	Socio-economic status
WHO	World Health Organisation
GSOS	Global Subjective Outcome Scales

1. Introduction

"Occupational therapy is the art and science of ... enabling a just and inclusive society so that all people may participate to their potential in the daily occupations of life."

(Townsend & Polatajko, 2007)

1.1. Introduction of the Problem

Forensic mental health care is a sub-specialization within mental health care service delivery (Sullivan & Mullen, 2006; Moore, 2005, 2014) rendering care, treatment, and rehabilitation to service users according to the MHCA No.17 of 2002 (The Presidency, 2002). Forensic Mental Health Care Users (MHCUs), consisting of observandi awaiting trial (Criminal Procedure Act No.51 of 1977, 1977), state patients, and mentally ill prisoners (Houidi & Paruk, 2018) receive mental health service delivery addressing pertinent support needs and responding to unique challenges experienced. As a result, occupational therapists within this field have expertise in responding to the unique occupational support needs and challenges experienced by forensic MHCUs, particularly, state patients who are admitted to forensic psychiatric facilities. These forensic MHCUs have been referred by the court for admission based on their having committed serious crimes, being unfit to stand trial and/or found to be not criminally responsible (Houidi et al., 2018; Muller & Flisher, 2006).

Multi-disciplinary teams (MDTs), including OTs with particular forensic expertise, render rehabilitative services to achieve shared outcomes. These include comprehensive client-centred psycho-social rehabilitation, service user empowerment, and recovery (Lund et al., 2010, p. 394, Muller & Flisher, 2006); and at a societal level - social inclusion, sustained community reintegration, meaningful role re-acquisition, and family reunification, as per standards of mental health care in South Africa (Muller & Flisher, 2006). MDTs also hold an ethical responsibility towards ensuring community safety, and the submission of appropriate reports for the judicial system to make a decision regarding unconditional discharge/release (Houidi et al., 2018). As a result, occupational therapists practicing in forensic mental health contexts are required to render strategic intervention to achieve shared MDT outcomes, and provide evidence-based practice. However, occupational therapists seldom render rehabilitation services directed at the social environments of forensic MHCUs (i.e. families) (Fitzgerald et al., 2012). This may be due in part to a paucity in rehabilitation literature, or due to the South African psychiatric services being currently underfunded in

comparison to general hospitals, especially in the KwaZulu-Natal province, where prioritization of human and financial resources do not take place for psychiatric, or specialized psychiatric institutions (Burns, 2010; Lund et al., 2010). As a result, limitations exist in the sustainability of services, preventative mental health care services, effective outreach, and community engagement projects.

Particular societal challenges have hindered sustained mental health rehabilitation outcomes in KwaZulu-Natal, South Africa (Department of Health KwaZulu-Natal, 2013; Lund et al., 2010; Pule, 2016). Accordingly, available structured support systems (at home or in the community) post discharge are lacking (Pule, 2016). Houidi & Paruk (2018) particularly identified the need for capacitated social environments (i.e. "more structured social support systems") within KwaZulu-Natal based forensic services addressing needs of vulnerable forensic MHCUs, especially those with cognitive deficits. Capacitated social support systems accommodate forensic MHCUs, optimize forensic MHCU health and wellness, and facilitate optimal community reintegration once intensive in-patient care, treatment, and rehabilitation has been concluded. This is achieved through preventative mental health practice, and rehabilitative programs focused on the social system (e.g. through family education). Consequently, an overall lack of mental health intervention at a systemic level impacts on forensic MHCUs likely defaulting on medication, experiencing relapse, re-offense, and readmission contributing to revolving door admissions or further institutionalization (Houidi & Paruk, 2018; McKeown et al., 2019). Furthermore, many remain unemployed, live in poverty, and experience severe marginalization by their families and communities due to socially unacceptable criminal offenses (McKeown et al., 2019; Chui et al., 2016). Persons with mental health challenges are often marginalized experiencing stigma and discrimination (McKeown et al., 2019, p.166; World Health Organization, 2003) preventing opportunity for occupational development (Pettican & Bryant, 2007), occupational justice, social inclusion, and quality of life.

Unfortunately, recent examples exist in South Africa of premature deinstitutionalization efforts while ignoring human rights advice given by mental health experts (OTASA & POTS, 2017), and social or occupational justice standards. This has resulted in state representatives prioritising monetary redeployment over human dignity and quality of life. Preparedness for community reintegration (including community survival skills) as well as capacitated social environments are essential in achieving these aims. The National Mental Health Framework (Department of Health, Republic of South Africa, 2013) cautions against the risk of rapid deinstitutionalisation without necessary community based services. It should be noted that the Mental Health Care Act No.17 of 2002 (The Presidency, 2002) as well as the National Core Standards (National Department of Health, 2011) addressing key mental health care legislation and health care evaluation tools, are under

review due to inadequacy in addressing effective and efficient psychiatric services and negating the necessity of community based resources for mental health care users.

Neglect of health prevention programs in forensic mental health care and public health services impact on prevalence of preventable initial or recurrent forensic cases. Essential preparation of forensic service users as well as the establishment of supportive microsystems in the communities is key to successful community reintegration and deinstitutionalization.

It can thus be argued that a client-centred approach to forensic MHCU rehabilitation is inadequate in achieving rehabilitative goals, and requires inclusion of assertive community treatment (ACT) or service delivery at a community-level as per the gold standard established in psycho-social rehabilitation (Kramers-Olen, 2014; Marquant et al., 2016). It is therefore essential that forensic MDTs, including OTs, incorporate rehabilitative services at a societal level as well as preventative public health interventions to ensure sustained rehabilitative gains made and successful community reintegration. This intervention priority is validated by occupational science which asserts that occupational justice is required at individual and environmental levels of practice ensuring social inclusion of at risk communities, prevention of disease, and enhancement of service users' health and well-being (Pettican & Bryant, 2007; Blank et al., 2017; van Niekerk, 2005, 2014; Ramugondo et al., 2015; Ingeborg & Townsend, 2010; Townsend & Polatajko, 2007). Limited focus has been placed on quality improvement of forensic mental health occupational therapy prioritizing essential relevant occupational therapy services at various levels of care (individual-, environmental, or community-levels). Few international therapists participate in family-centred care addressing occupation based support needs (Fitzgerald et al., 2012), and no clear outcomes have been set for this strategic level of public health service delivery.

These gaps in forensic mental health occupational therapy service delivery highlight particular unmet needs. These unmet needs have been validated by researchers in the forensic psychiatric field as pertinent, namely, unmet needs at a societal level of care recognizing the long-term support need of forensic MHCUs, recovery or rehabilitative unmet needs, gaps in early intervention in rendering strategic timely intervention, quality improvement and use of instruments and “metrics” addressing protective factors, and research into routine outcome monitoring (ROM) of forensic MHCUs (Goethals at al., 2012).

The researcher of this study expounds from literature why OTs should be pertinent mental health care providers promoting social and occupational inclusion of forensic MHCUs into their respective communities by addressing unique occupation based family centred outcomes.

1.2. Background of the Study

1.2.1. A social system's family-centred approach

Families of forensic MHCUs form part of the most influential component of MHCUs immediate community (microsystem) (Lehman et al., 2017), and are integral in achieving sustainable psycho-social rehabilitation (PSR) gains (Muller & Flisher, 2006; Lund et al., 2010; Kramers-Olen, 2014). Despite this, occupational therapists have historically fulfilled more of a client centred generic role within forensic institutions, and have not been actively involved in program planning, intervention, and targeting of outcomes within forensic community based public health programs.

Policy frameworks, such as The National Mental Health Policy Framework and Strategic Plan 2013 – 2020 (Department of Health, Republic of South Africa, 2013) have identified a gap in Mental Health Care Policy as well as primary health service delivery by comprehensively detailing the previously un-prioritized vision of "mental health care for all" underpinned by key values and objectives.

Recognition of the essence of supportive social environments can be seen in the international trend of developing disability friendly towns, communities, or participation societies (Boelsma et al., 2018) as social systems which uphold the values of justice, inclusion, and empowerment through support of persons with disabilities (Rimmer & Rowland, 2008; Canadian Association of Occupational Therapists, 2008). These values originate from disability orientated paradigms, frameworks and models acknowledging the importance of the social environment in the planning and implementation of health promoting programs. A person-centred approach, incorporating the Social Model in Disability (GB Disability Training & Consultancy, 2007), views disability in terms of the communities' ability to accommodate persons with disabilities to enable participation in meaningful occupation. The International Classification of Functioning, Disability and Health (ICF) views the occupational performance of an individual as taking place within a context – consisting of their physical, social and attitudinal world (Cerniauskaite et al., 2011). Bronfenbrenner's ecological systems theory (Bronfenbrenner, 1994) differentiates between social environments of varying proximity to a person. Considering the varying social determinants of health (or occupation) (Canadian Association of Occupational Therapists, 2008; Lehman et al., 2017), the immediate community (or Bronfenbrenner's microsystem) consists of the person with a disability's family who is intricately involved in the day to day activities of life. This element of the microsystem has great influence in particularly facilitating or hindering occupational performance and the fulfilment of important life roles of persons with mental illness (Bronfenbrenner, 1994).

Mental illness of a family member, especially when a criminal offense has been committed, places considerable pressure on a family unit (McKeown et al., 2019; World Health Organization, 2003). It can be asserted that the family experiences the immediate burden of disease in comparison with the broader community, due to immediate proximity and responsibilities towards the forensic MHCU, as well as associated stigma and discrimination directed at both forensic MHCU and the family (World Health Organization, 2003, p.12-13). Mental illness has the potential to directly and negatively impact on the day to day family functioning, the quality of family activities, family health and wellness, and Family Quality of Life (FQOL). Families of persons with disabilities have historically been viewed as vulnerable and thus requiring additional support. Van Beurden (2011) highlights the assumption of FQOL that by "effectively supporting the family, one can improve FQOL, and in turn improve the Quality of Life of the individual members". New family strengths, needs and priorities (Chiu, et al., 2013, p. 367) could be ascertained.

Family-centred mental health intervention in occupational therapy practice, however, has focused primarily on health education, and has understandably relinquished key responsibility to social welfare, nursing, and psychological services. Few international forensic occupational therapists have incorporated family work within service delivery towards forensic MHCUs and their families (Fitzgerald, et al., 2012).

In support of these efforts, it can be postulated that occupational therapy has a unique role to play in addressing family support needs.

1.2.2 Occupational Therapy evidence based practice in forensic mental health care

The continuously developing discipline of Occupational Therapy has recently seen an intentional shift to outcomes orientated and evidence-based practice validating the specific role of occupational therapy practice in the mental health context (Casteleijn & Graham, 2012; Andresen, Tang, & Barney, 2006). This has proved critical in equipping occupational therapists with tools directing therapeutic services drawing from occupational science philosophies (Wilcock, 1999; Wilcock, 2005; Pettican & Bryant, 2007; Blank et al., 2017; van Niekerk, 2005, 2014; Ramugondo et al., 2015; Ingeborg & Townsend, 2010; Townsend & Polatajko, 2007) which view persons as occupational beings, and occupation as health giving with relevance to both individuals and groups.

Strategic and operational objectives for forensic mental health occupational therapy directed towards the immediate social environment (i.e. family-centred care) has however been less documented, with a particular focus on other aspects of psycho-social rehabilitation (namely, client-centeredness with a vocational rehabilitation outcome during hospitalization). Little focus has been

placed on after care support, the successful transference of skills into the community, maintenance of rehabilitative gains post discharge, or the ability of immediate support systems (namely, families of forensic MHCUs) to accommodate and support forensic MHCUs when reintegrated.

1.2.3. Family Quality of Life as a forensic mental health occupational therapy outcome

Family Quality of Life (FQOL) is a useful multi-dimensional social construct borrowed from intellectual and developmental disability (I/DD) literature that describes and quantifies the subjective experiences of the family. It combines different dimensions of family life to describe FQOL as a whole. Additionally, FQOL deals with the goodness of or satisfaction with family life (Turnbull, Brown, & Turnbull III, 2004). It is a dynamic sense of well-being of the family defined by individuals and as a collective, where individual and family needs intertwine. FQOL is aligned with quality of life theory as well as positive psychology thus making it a neutral unbiased concept allowing for subjective interpretation of the satisfaction in pertinent areas of family life (Chiu, et al., 2013). It thus makes use of a strengths-based support paradigm (Hu et al., 2011).

Occupational therapists specialize in occupational engagement, meaningful occupational performance leading to "participation in desired life situations" (AOTA, 2014), enhancing occupational justice strategies to empower individuals and communities, and in the development of important occupational identities. As forensic mental health professionals, these occupation-based outcomes can be established for individuals and groups, ensuring individual or shared subjective health and wellness.

An occupation based FQOL measurement tool is required to track change in particular areas of family life.

1.2.4. Operationalization of FQOL for occupational therapy outcome measure

This study, therefore, identifies and operationally defines the neutral, unbiased, strength-based construct of FQOL that is relevant to a forensic mental health context to direct evidence based occupational therapy input at a societal level addressing optimal participation in desired areas of family life. The operationalization process involves the sequential breakdown of measurable indicators (Uys, 2003, p.15) to attribute particular meaning to this abstract construct and presenting the construct as a clear description of concrete behaviour(s) to be evaluated over time.

1.3. Problem Statement

There is a paucity of literature pertaining to family centred occupational therapy services rendered to forensic mental health care users (MHCUs) and their families. The role of occupational therapy in generic mental health services when addressing family support needs in African contexts has predominantly addressed health education of the family pertaining to their family member with mental illness (Alers & Crouch, 2010). Limited research is available directing environmental level practice addressing family support needs through occupational therapy family work (Fitzgerald, et al., 2012), with minimal evidence of collaboration between occupational scientists and occupational therapists in directing family work in this valuable field of OT practice (Van Niekerk, 2014).

The construct of FQOL has been used in the field of intellectual disability to measure the effectiveness of health interventions and the implementation of policies focused on family centred care (Chiu et al., 2013). Family centred occupational therapy improving the FQOL health outcome in a mental health context has not specifically been explored. FQOL as a health outcome has not been deconstructed into theoretical and operational definitions for use by occupational therapists in forensic mental health care. Operationalizing the abstract FQOL construct and its related concrete concepts would assist occupational therapists in setting relevant treatment objectives for effective and efficient family centred OT. Therefore, it is unknown how to operationally define FQOL for a forensic mental health context for occupational therapy practice, and which domains would be perceived as relevant for use to families of mental health care users within a forensic institution in KwaZulu-Natal, South Africa.

The FQOL construct within this forensic psychiatric context is unknown and requires identification of meaning and operational definition thereof. The FQOL construct is thus borrowed from existing literature and required operational definition using an occupational lens.

The primary problem exists that there are currently no outcome measurement tools to identify the unique FQOL support needs to direct relevant family-centred forensic mental health occupational therapy practice. Clearly defined family-centred occupation based outcomes directing occupational therapy practice are necessary. This study identifies and operationally defines the FQOL construct from an occupational lens to direct family centred occupational therapy intervention within forensic mental health services in KwaZulu-Natal, South Africa.

1.4. Research Question

The research question explored by this study was “What are the FQOL constructs to be included in a FQOL outcome measure which could direct occupational therapy practice for MHCUs and their families in a forensic setting?”

1.5. Research Aim and Objectives

1.5.1 Research Aim

This study aimed to identify and operationally define Family Quality of Life (FQOL) in the development of a Family Quality of Life outcome measurement tool that could direct family centred Occupational Therapy services for mental health care users and their families within a forensic psychiatric facility setting in KwaZulu-Natal, South Africa.

1.5.2 Research Objectives

There were two objectives to the study that answered the research question and achieved the aim of the study.

Objective 1: To identify FQOL constructs through focus groups with MHCUs, family members, and health care professionals working in forensic mental health.

Sub-Objective 1.1: To develop interview schedules for the focus groups based on literature of FQOL and OT conceptual frameworks.

Sub-Objective 1.2: To identify FQOL constructs through inductive analysis of the qualitative data generated.

Objective 2: To operationalize the FQOL constructs and their measurable indicators through a process of deductive reasoning towards a synthesized diagram.

1.6. Significance of the Study

This is an original study contributing significantly to the field of occupational therapy within forensic mental health. This novel study highlights and responds to the existing gap of identifying and defining relevant outcomes for family centred occupational therapy practice. The study's primary significance is the successful operationalization of the abstract FQOL construct and its related concrete concepts, assisting occupational therapists in setting relevant treatment objectives for effective and efficient family centred OT.

It has further significance for expanding existing literature and theoretical frameworks (FQOL, and occupational science), to support best practice in forensic OT (evidence based, client centred and systemic interventions). This will contribute to achieve MDT psycho-social rehabilitation outcomes, and has the potential to influence resource allocation to forensic mental health occupational therapy.

1.7. Summary

This thesis documents the process of operationalizing the FQOL construct within a forensic psychiatric setting in KwaZulu-Natal, South Africa, as underpinning for the development of a novel outcome measurement tool for family centred occupational therapy rehabilitative purposes. Clear theoretical frameworks as well as a review of existing literature was however required to justify the purpose of this study and in identifying an evident paucity in existing literature.

Chapter 2 of this study addressed a literature review related to the following concepts: themes of quality improvement; best practice standards in forensic mental health occupational therapy; contextual considerations in forensic mental health occupational therapy practice; existing forensic mental health occupational therapy practice at an individual and family level of care; and the FQOL construct related to social science frameworks and occupational science.

2. Literature Review

2.1. Introduction

Quality improvement is essential for the sub-specialisation of forensic mental health care, treatment, and rehabilitation. Monitoring and evaluation at various institutional levels (national, provincial, institutional, and rehabilitation department) provides evidence of service delivery rendered.

Outcome measurement in occupational therapy for individual- and community- orientated levels of care is essential for validating the unique value adding contribution of rehabilitation services rendered towards mental health care users (MHCUs) (Kirsh et al., 2019; Casteleijn, 2013; Andresen, Tang, & Barney, 2006). Within a forensic setting, the outcome measurement requirement for evidence based occupational therapy practise is invaluable (Fitzgerald et al., 2012; Duncan et al., 2003; and Chui et al., 2016). This has particular relevance to local forensic OT practice due to the KwaZulu-Natal Department of Health's commitment towards the forensic MHCU, the MHCUs community of origin (Houidi et al., 2018; Department of Health KwaZulu-Natal, Vision, Mission and Core Values; Muller & Flisher, 2006; Chui et al., 2016), as well as to the national judicial system (DoJ), thus ensuring safe community reintegration, family reunification, recovery, and role re-acquisition of vulnerable forensic MHCUs.

Within this unique sub-specialization of mental health care, the researcher proposes that occupational therapists are able to effectively and efficiently make use of an occupation-based and family-centred approach to community-level practice to achieve specific forensic psycho-social rehabilitation objectives as key members of forensic assertive community treatment (ForACT) MDT teams (Marquant et al., 2016). This is in alignment with McKeown et al. (2019) calling for forensic mental health care services to facilitate transformative change through individual- and family- level service delivery (p.183).

This chapter presents a review of the literature, in explaining the "cause to action" or the Why? question for this research study. As notable author Simon Sinek postulates in his book Start with Why (Sinek, 2009), others are only included in action if they are inspired through the "Why" of a cause. Herewith, the Why? answer to operationalizing FQOL for forensic MHCUs and their family members for OT practice by addressing the current context of local forensic psychiatric services; best practice standards for forensic mental health care; family work in mental health care and

occupational therapy; the FQOL construct; and the need to operationalize FQOL for forensic MHCUs and their family members.

2.2. Forensic Mental Health Care

Forensic mental health care is a distinct sub-specialization within mental health care service delivery (Sullivan & Mullen, 2006; Houidi & Paruk, 2018; Moore, 2005, 2014; Muller & Flisher, 2006) rendering care, treatment, and rehabilitation to service users according to the MHCA No.17 of 2002 (The Presidency, 2002). Forensic Mental Health Care Users (MHCUs), consisting of "observandi" awaiting trial (Criminal Procedure Act No.51 of 1977), state patients, and mentally ill prisoners (Houidi & Paruk, 2018) receive mental health service delivery addressing pertinent support needs and responding to unique challenges experienced. It is thus evident that optimal intersectoral collaboration between the DoH and DoJ is required (Houidi et al., 2018; Kramers-Olen, 2014, p.509).

This sub-specialization has transformed in priority from assessment of offenders, to achievement of actionable outcomes (Goethals et al., 2012; Houidi et al., 2018), such as the management of behaviour and prevention of deterioration of health and function (Sullivan & Mullen, 2006). Furthermore, forensic mental health care is increasingly following the changed trend by which mental health care in general is being delivered (Pettican & Bryant, 2007), namely, shifting from custodial care within institutionalized environments to community based service delivery (Department of Health, Republic of South Africa, 2013; Lund et al., 2010; Muller & Flisher, 2006; Houidi & Paruk, 2018). Interestingly, quality of life research has also seen a recent paradigm shift from deficit to empowerment support (I/DD field) (Samuel, Rillotta & Brown, 2012; Kyzar et al., 2012); or from fixing the individual, to fixing the system (Turnbull et al., 2004, p.59-60). Forensic mental health care has become a multi-disciplinary approach to addressing the holistic needs of the forensic MHCUs shifting from punitive containment to effective and evidence-based models of treatment and service delivery (Sullivan& Mullen, 2006). The priority of care thus facilitates community reintegration and prioritizes deinstitutionalization (Kramers-Olen, 2014).

Priorities within forensic mental health care in alignment with standards of mental health care in South Africa (Muller & Flisher, 2006) furthermore include recovery, maintained rehabilitation gains, improvement in quality of life, health promotion, and health prevention (Lund et al., 2010, p. 394). Health prevention aims at the prevention of defaulting on medication, experiencing relapse, re-offense/ recidivism, and readmission contributing to "revolving door" admissions or further institutionalization (Houidi & Paruk, 2018; McKeown et al., 2019). Health promotion strategies include facilitating occupational development, occupational justice, social inclusion, and quality of

life of MHCUs and their social environments. Stages of recovery are supported through the graded service provision noted within a forensic psychiatric facility: closed ward, semi-closed, open ward, and independent living facility. MDT objectives are in alignment with the respective level of care and improvement in symptomatology, behaviour, and occupational function noted within clients (Moore, 2005, 2014). Historic use of diversional treatment (which lacks in client-centred meaningfulness) by nursing and occupational therapy disciplines is insufficient in preparing the forensic MHCU for community reintegration. “Occupational therapy is a key discipline in the field of psychiatric rehabilitation and brings to the field a strong theoretical and knowledge base and some unique procedures and practices.” (Krupa et al, 2009). Krupa et al. (2009) indicate how OT can focus their efforts on supporting occupational engagement instead of diversional activity involvement (through improving activity participation, social participation, and creating supportive environments - whether social, physical, or cultural). There is difficulty in implementation for forensic MHCUs due to the restrictive institutional pattern of forensic mental health care (Chui et al., 2016; Duncan et al., 2003). The role of the occupational therapist working in a specialised forensic institution is multi-faceted. It starts with evaluation of persons awaiting trial/ under observation by means of activities, and ends with a preparatory pre-discharge stage prior to community reintegration. Moore (2015) expounds on the pre-discharge stage as involving “intensive life skills training” (p.259), “recreation” and work skills development. She highlights a gap if community members are not empowered to handle or care for forensic mental health care users. Relapse and the hindrance of lasting rehabilitation/treatment gains takes place if occupational therapists do not intervene at a community level. Poor family education is a concern for forensic psychiatry presently.

Certain South African contextual considerations need to be made, particularly to its history of violence, socio-economic challenges or poverty, and the prevalence of mental illness.

South Africa is particularly known for its apartheid history of violence, racial discrimination and dehumanisation (Lund et al., 2010; Kramers-Olen, 2014). KwaZulu-Natal is also known for its civil war history affecting many communities in the 80s and 90s.

KwaZulu-Natal has an estimated 46 – 60% of the population living in poverty (Department of Health, Republic of South Africa, 2013). Most persons with lower socio-economic status reside in the rural areas of this province with extensive areas of remote settlements and communal villages. These rural districts in the province experience difficulty in accessibility to critical resources, such as, healthcare, transport, and employment opportunities. The majority of those residing in rural communities generate income from self-employment, or subsistence farming or agriculture (Mtshali, 2002). Some of the most densely populated areas are the economic hubs of eThekwini and uMgungundlovu. (Department of Health KwaZulu-Natal, 2013, p. 15). Both districts are considered

to be urbanised districts, however, hosting lower socio-economic areas, such as peri-urban communities on the urban hub's peripheries and the presence of informal settlements.

The KwaZulu-Natal province has a specialized forensic psychiatric hospital based in the uMgungundlovu district, as well as two (2) forensic units in general psychiatric facilities in KZN (Houidi & Paruk, 2018) which serves the entire province with an estimate of 11,5 million citizens in 2020 (Statistics South Africa, 2020, July 9) in this expansive province. Figure 2.1 presents a map outlining the various health districts and municipal metropolitans (List of municipalities in KwaZulu-Natal, 2020, March 11)

Figure 2.1. Health districts and municipal metropolitans (List of municipalities in KwaZulu-Natal, 2020, March 10)

There is a high incidence of substance use and addiction disorders increasing population susceptibility to severe mental illness and functional impairment (Lund et al., 2010; Houidi & Paruk, 2018). Underlying mental illnesses, such as depression and PTSD, are particularly prevalent amongst persons infected with HIV in certain South African communities (Myer, et al., 2008). Existing forensic MDTs render in-patient care, treatment, and rehabilitation (The Presidency, 2002; Muller & Flisher, 2006). Burden of non-communicable disease (Mayosi et al., 2009) and social determinants of health such as poverty/socio-economic status (World Health Organization, 2003) impact on individual and collective mental health and require urgent attention by state entities and service providers. The burden of mental disorders is noteworthy with an approximate 14.3% of adults (over 15 years) estimated to battle with a mental illness in the province of KwaZulu-Natal (Department of Health KwaZulu-Natal, 2013, p. 32). Interestingly, a considerable amount of 4 million residents were recorded to be between the ages of 18-35 years old around 2014 (Statistics South Africa, 2020, July 9).

Houidi et al. (2018) has indicated that the majority of state patient admissions have been young adults with severe mental illness, many who have developmental delay in achieving critical milestones due to onset of illness during adolescence or early adulthood (Chui et al., 2016). As a result, many are single and employed due to social skills and vocational skill deficits caused by the severe mental illness onset (Houidi & Paruk, 2018). Healthcare providers establishing shared MDT outcomes include advanced psychiatric nursing, psychologists, psychiatrists, social workers, and occupational therapists. Lund et al. (2010) highlights the severe staff shortages present in South African mental health contexts despite clear national policies and frameworks stipulating resource requirements. The KwaZulu-Natal province health services are particularly underfunded with the neglect of resource allocation to psychiatric facilities, particularly forensic facilities (Burns, 2010).

Researchers (Sullivan& Mullen, 2006; Goethals et al., 2012) have highlighted an urgent need for forensic mental health research which would inform future clinical practice as well as refine outcomes validating policy making and funding. International forensic psychiatry researchers have recommended areas of inquiry, namely, the unmet needs at a societal level of care recognizing the long-term support need of forensic MHCUs, recovery or rehabilitative unmet needs, gaps in early intervention in rendering strategic timely intervention, quality improvement and use of instruments and “metrics” addressing protective factors, and research into routine outcome monitoring (ROM) of forensic MHCUs (Goethals et al., 2012). Furthermore, recommended research priorities within forensic OT research have highlighted three (3) predominant areas, namely, risk assessment, the development of appropriate outcome measures (including, quality of life outcome measurement tools), and intervention effectiveness (Chui et al., 2016; Duncan et al., 2003). Duncan et al. (2003)

has further highlighted other lower prioritized research areas including occupational science themes (such as occupational deprivation), community occupational therapy services, and the value of OT in community teams (i.e. ForACT, Marquant et al., 2016), readjustment post discharge, assessment tools with forensic MDT appeal, and quality of life issues.

2.3. Best Practice in Forensic Mental Health Care

Policy makers, theorists, researchers, and practitioners advocate for best practice in forensic mental health care. Duncan et al. (2003) prioritizes a best practice agenda for forensic occupational therapy by exploring quality improvement opportunities informing future forensic OT research.

The KwaZulu-Natal Department of Health (KZN DoH) (Department of Health KwaZulu-Natal, Vision, Mission and Core Values) and the provincial forensic psychiatric facility (Department of Health KwaZulu-Natal, Fort Napier Hospital) have committed to a standard of service delivery to citizens of KwaZulu-Natal, being held accountable by established national legislation (Lund et al., 2010; The Presidency, 2002). This is clearly extrapolated in the respective vision and mission statements which address the following themes: “optimal health for all”, “optimal psychiatric health for all”, development and implementation of “comprehensive health systems at all levels”, “universal access to health care”, as well as offering the “best possible psychiatric services” to service users. These vision and mission statements express a commitment by government services (inclusive of all associated medical and rehabilitative services) to ensure best practice within mental health care services rendered at individual- levels of care, as well as inclusive of public mental health care. It recognizes the immense burden of disease caused by non-communicable diseases such as mental illness (Mayosi et al., 2009; World Health Organization, 2003)

A review of literature of how best practice could be ascertained and the meaning hereof took place with the following outcomes. Best practice in forensic mental health care includes: an ethical approach; a psycho-social rehabilitation approach to health care service delivery; a systemic approach addressing health needs at all levels of society, including families; an occupation-based approach ensuring occupational justice and inclusion of all; a quality of life approach; and evidence based practice establishing effective and efficient service delivery through the development and use of appropriate and relevant outcome measures.

2.3.1. Ethical practice

Pertinent South African legislation ensures legal and ethical best practice directed at MHCUs with a focus on rehabilitation outcomes. The MHCA No.17 of 2002 (The Presidency, 2002), and the

Criminal Procedure Act No.51 of 1977 are two (2) legislative acts facilitating intervention promoting community health services, deinstitutionalization, and the empowerment of MHCUs through shared decision making to obtain optimal independence (Moore, 2005, 2014; Muller & Flisher, 2006).

Disability and rehabilitation legislation and strategies (National Department of Health, 2015; World Health Organization, 2016; Office of the Deputy President, 1997; The Presidency, 2002) in South Africa furthermore speak to the necessity of community engagement for effective and efficient health care service delivery, including mental health care. Valuable community engagement and rehabilitation services in South Africa are rendered, for example, in light of the community based rehabilitation (CBR) matrix (National Department of Health, 2015, p. 14) focusing on five key components, three (3) of which are of particular interest to a person with a disability's micro-system/ family, namely: -

1) Livelihood (Skills development, self -employment, social protection, etc.),
2) Social (Personal Assistance; Relationships, Marriage and Family; Recreation, Leisure and Sports; etc.), and
3) Empowerment (Advocacy and Communication, Community Mobilization, Self-help groups, etc.).

However, it is noted that the CBR matrix does not speak specifically to family-centred interventions, while only speaking of persons with disabilities being involved in decision making processes (National Department of Health, 2015, p. 14). In comparison, The National Development Plan 2030, specifies family centred intervention as one of the nine health goals, i.e. "Primary Health Care Teams providing care to families and communities" (Department of Health KwaZulu-Natal, 2013).

These intervention priorities asserted by legislation render protection of vulnerable forensic MHCUs and their families' human rights thus countering the institutionalized South African apartheid policies which impacted on citizens accessing mental health care services (Kramers-Olen, 2014, p.505; Lund et al., 2010). Unfortunately, recent examples exist in South Africa of premature deinstitutionalization efforts while ignoring human rights advice given by mental health experts (OTASA & POTS, 2017), and social or occupational justice standards. This has resulted in state representatives prioritising monetary redeployment over human dignity and quality of life. Preparedness for community reintegration (including community survival skills) as well as capacitated social environments are essential in achieving these aims. It is apparent that upholding human rights and human dignity as stipulated by legislation and standards of mental health care in South Africa (Muller & Flisher, 2006) is a shared implementation responsibility applicable to policy makers, state leaders, facility managers, and clinicians.

It should be noted that individual forensic MHCUs and their family members have their own unique needs and rights (McKeown et al., 2019). Particularly, a smooth and timely forensic appellation process (between DoH and DoJ/ the judicial system) with relevant forensic facility admission of state patients (Houidi et al., 2018; McKeown et al., 2019) is essential for accessing mental health services otherwise withheld. Furthermore, family needs or rights are compromised when inclusion of forensic MHCUs into society may consequently result in the exclusion of the family who carry an immense burden of disease without adequate support (Brown, 2017; Boelsma et al., 2016). Neglect of the above compromise the implementation of constitutional rights of vulnerable forensic MHCUs and their family members, as well as the implementation of legislation, mental health frameworks and standards, and policies aimed at the provision of care and protection of rights of South African citizens. Ethical practice requires cognisance of these realities.

Interestingly, ethical forensic OT practice is cognisant of three unique types of justice: criminal justice, occupational justice, and social justice (Muñoz, 2011, as referenced by Chui et al., 2016, p.230). An example of this may include ensuring community safety (Houidi et al., 2018; Muller & Flisher, 2006), while facilitating access to limited typical activities of daily living and personal choice within a restrictive environment (Chui et al., 2016), as well as systemic social inclusion of forensic MHCUs into society in preparation of community reintegration (Duncan et al., 2003; Chui et al., 2016; Fitzgerald et al., 2012; Muller & Flisher, 2006). Incorporation of these justice types are essential to provision of, and the development of service delivery within the novel forensic OT sub-speciality (Duncan et al., 2003).

Family work advocates in forensic mental health (McKeown et al., 2019) challenge forensic MHCPs to consider how to balance service delivery priorities of community protection and ensuring “a right to family life” for forensic MHCUs.

2.2.2. Psycho-social rehabilitation (PSR)

Psycho-social rehabilitation (PSR) is a widely accepted gold standard of practice within mental health care services prioritizing optimal community reintegration and deinstitutionalization of forensic MHCUs. Various national and international policy documents policy (WHO, 1996, and DoH, 2003, as referenced in Crouch & Alers, 2005, p. 437; Department of Health, Republic of South Africa, 2013) and organisational position statements (OTASA, 2017) have been guided by existing psycho-social rehabilitation providing standards of multidisciplinary practice to ensure public mental health care, community reintegration, and deinstitutionalization of service users. The National Framework of Mental Health (NFMH) (Department of Health, Republic of South Africa, 2013) is an

example of a local framework clearly guided by WHO's PSR Policy. The NFMH's focus on empowerment of the community (especially MHCUs and their caregivers) is underpinned by the values of 1) Community Care ("with an emphasis on psychosocial rehabilitation" (p.20) and 2) Social Support and Integration (maximal support provided to families and carers of those with mental illness). Hereby, South African MHCPs are held accountable to these standards of best practice of mental health care (Muller & Flisher, 2006).

Key concerns raised by the PSR policy include 1) client-centeredness, 2) empowerment strategies, 3) a family-centred approach, 4) enabling community integration (work, residential, community survival, social interaction), and 4) provision of community based rehabilitation (public mental health care, and assertive community treatment). All priorities contribute towards systemic- and occupation- based approaches to rehabilitative mental health care.

PSR is highly effective within rehabilitation and recovery work. Interestingly, many authors have shown that recovery is primarily a social process that takes place among the everyday occupations in a person's life (Borg & Kristiansen, 2008; Blank et al, 2017; Gibson et al., 2011), hence, the suitability of consideration of contextual aspects to PSR intervention. Local and international research indicates that there is a high prevalence of forensic MHCUs with chronic mental illness (namely, schizophrenia, intellectual impairment, and mood disorders) (Duncan et al., 2003; Houdini & Paruk, 2018; Kramers-Olen, 2014). Specific skill deficits experienced requiring rehabilitative input include social skills, adaptive skills, and daily living skills (function) (Kramers-Olen, 2014; Gibson et al., 2011; OTASA, 2017). Simulated living and work environments assist in skills development, however, authentic and relevant contexts have are thought to reinforce acquisition of new or relearned skills, yet, findings of its effectiveness in community reintegration processes is inconclusive (Gibson et al., 2011). Particular interpersonal skill development within the context of family relationships has shown reduced family burden of chronic mental illness in the family (Dixon et al., 2010; Kramers-Olen, 2014).

Occupational therapists ensure role re-acquisition especially that of a being a worker (Gibson et al., 2011; OTASA, 2017; Kirsh et al., 2019) associated with financial well-being and quality of life. Prevention of occupational deprivation in terms of employability is essential for community reintegration (Duncan et al., 2003). Occupational therapists have taken on proactive roles in CBR which aim to provide culturally relevant intervention and preventative services to the MHCU as well as to families and their communities (Homer, 2005). Homer (2005, p. 148) further elaborates on how OTs aim to support families to be destigmatizing social environments for MHCUs by "mobile(sing) the community to accept and integrate those with mental health problems" as well as knowledge and skills transference to MHCUs, family members and communities. Homer (2005) further

recommends that therapists capacitate the family members through collaboration for decision making, implementation and monitoring of treatment programs aimed at improvement of healthy lifestyle and independent living skills, as well as by identifying the families' priorities and needs. Intervention involves family and mental health service users involved in self-directed support groups (Homer, 2005, p.164).

In alignment with PSR objectives, occupational therapists are involved in empowerment projects addressing all areas of life so as to equip them to become change agents (p. 166) – a heavy responsibility for those engulfed in poverty and at risk of mental illness (Lund et al., 2010; World Health Organization, 2003). The debilitating nature of mental illness implies the essence in capacitating their support systems. This mobilisation language is supported by Frank & Muriithi (2015) urging occupational therapists to adopt the newly developed theory of "occupational reconstruction" – inquiring into how people (individuals or communities) act to change their situations "for the better". The researchers highlighted innovative occupational therapy intervention being that which addresses social issues, not only the individual level factors (Frank & Muriithi, 2015, p. 11).

PSR intervention is directed by The National Mental Health Policy Framework and Strategic Plan 2013–2020 (Department of Health, Republic of South Africa, 2013) which "represents the first move towards an officially sanctioned national mental health policy in South Africa" (p.506). It thus complies with an empowerment paradigm enhancing consumer participation, and personal choice (Muller & Flisher, 2006).

A collaborative approach to family-centred and community-centred mental health care service delivery is a core characteristic of PSR practice (Kramers-Olen, 2014; McKeown, 2019) with particular application to forensic secure settings. This can be rendered through public mental health services or assertive community treatment making mental health care accessible to out-patients in communities located a distance from the forensic facility.

A family-centred approach to forensic intervention has been established as a PSR best practice standard (Kramers-Olen, 2014; Muller & Flisher, 2006; Evans, 2019). It is used along with pharmacotherapy for impactful therapeutic gains (McKeown et al., 2019; Kramers-Olen, 2014). In order to render family orientated outcomes for quality care, a clear understanding of the family is essential. It is necessary for clinicians to understand what constitutes a family unit prior to rendering family-centred mental health care (MHC) as contemporary family structures (for example, blended non-biological families) differ significantly from traditional family units (biologically related). It is necessary to ensure that MHCUs define who they consider family in terms of belonging, attachment

and social connection (Davies & Hannigan, 2019). Furthermore, families are viewed as the fundamental unit of society (Samuel, Rillotta, & Brown, 2012; Samuel et al., 2018) thus requiring particular protection (African Charter on Human and Peoples' Rights, 1987). The Public Service Regulations views a family member as having a relationship by birth, marriage or adoption; including those who reside permanently with the family, or is a dependent (Department of Public Service and Administration, 2016, pp. 10-11). The value of the family ought to be affirmed, namely, "the family forms the primary structure for the functioning and ongoing stability of all human societies" (Brown & Brown, 2003, referenced in Samuel, Hobden, LeRoy, & Lacey, 2012, p.111).

Family-centred care in adult mental health care is synonymous with "family involvement" which is usually referred to when responding to the support needs of an adult MHCUs family (McNeil, 2013; Davies & Hannigan, 2019), with the value of supportive family involvement being affirmed (McKeown et al., 2019, p.179). Authors (McNeil, 2013; McKeown et al., 2019) particularly endorses unique family-centred service delivery directed at families and caregivers of forensic MHCUs in meeting their unique support needs, as per PSR standards. For this to take place, family members and caregivers of forensic MHCUs need to be viewed as being "a significant resource" (Coffey, 2012, as referenced by McKeown et al., 2019, p.178.) and to be capacitated to shift care from therapist-led to family-led care (Davies & Hannigan, 2019) complying with an empowerment paradigm.

Benefits of family-centred care (for approximately 6-9 months) include reduced relapse rates and hospital readmission, thus having a meaningful fiscal impact on service delivery (Dixon et al., 2010; Kramers-Olen, 2014; Davies & Hannigan, 2019). Kyzar et al. (2012) furthermore highlighted a significant relationship between family supports and family outcomes. Family support needs have been prioritized as an essential family outcome identified. Samuel, Hobden, LeRoy, & Lacey (2012, p.112) further expands on the rationale behind family-centred support, namely, "families that function well support societies, and families with effective quality of life are a social resource (Isaacs et al. 2007,p. 178)".

Quality of life is a recommended health outcome in PSR (Van Niewenhuizen et al., 2002; Boumana et al., 2008; Vorstenbosch et al., 2007; Muller & Flisher, 2006). It addresses individual QoL directed at forensic MHCUs. The WHO Global Action Programme for mental health (mhGAP) stipulate that interventions enhance QoL of both the MHCU and the whole family by means of family involvement in the care of chronic MHCUs (World Health Organization, 2003, p.43). No literature expanded further on the particular FQOL outcome for families of MHCUs.

OTs practicing in forensic mental health care have indicated use of PSR techniques to ensure occupation-based recovery and rehabilitation goals are met. Chui et al. (2016) indicated that theories used to inform OT practice included: Cognitive Behavioural Theory, Motivational Interviewing/Transtheoretical Model, Psychosocial Rehabilitation, Dialectical Behaviour Therapy and Recovery Philosophy (p. 233). Use of associated strategies have been supported by PSR advocates (Kramers-Olen, 2014; Muller & Flisher, 2006), and forensic OT researchers and/or clinicians (Fitzgerald et al., 2012). Forensic OT clinicians (d'Hangest d'Yvoy, Kharva, & Shongwe, 2018; and d'Hangest d'Yvoy, 2018) practicing in KwaZulu-Natal have indicated incorporation of unique PSR strategies to achieve recovery and rehabilitation goals, namely, vocational rehabilitation strategies (pre-vocational rehabilitation, and transitional employment opportunities), life skills training, and clubhouse models of PSR. Further exploration is required to ensure that PSR is optimally incorporated as a best practice standard for forensic occupational therapy, namely, in the areas of peer support groups, assertive community treatment (Krupa et al., 2009), and family-based interventions. These community orientated interventions can be facilitated by forensic occupational therapy in recovery-orientated intervention for forensic MHCUs and their families (Chui et al., 2016; Fitzgerald et al., 2012; Duncan et al., 2003; and Kramers-Olen, 2014; McNeil, 2013).

2.2.3. An ecological or systemic approach

Recent developments in forensic mental health care dismiss punitive long term incarceration of MHCUs, but rather focuses on preparation for re-entry into society as important life roles are assumed in name and practice.

Various sources (legislation mentioned earlier directing MHC and CBR, and differing fields of inquiry) highlight the importance of family and community as important resources impacting on individual health and wellness outcomes, thus using a systemic approach to well-being.

Theorists adopting a support-orientated paradigm to rehabilitation recognise that "fixing" an individual's deficits is disabling, while "fixing" the environment through rendering support of the social environment enables participation in important and satisfying areas of life (Turnbull et al., 2004; Kyzar et al., 2012). Disability theorists focusing on experiences of individual- or family-orientated quality of life have adopted a systemic approach to research and clinical practice incorporating terminology developed by social scientists, such as differentiating between microsystems, mesosystems, and macrosystems of their service users).

Social scientists, such as Bronfenbrenner (1994), are known to have developed a systemic approach to service delivery within education. This approach has been applied furthermore to

various fields of inquiry, such as healthcare (Lehman et al., 2017; Eriksson et al., 2018). It has relevance to individuals, families, and social groups, with an interdependence existing between them, as individuals create their own meaning within their unique environments. The ecological systems theory further recognizes the environment as certain social and cultural structures; and measurement using this model focuses on the social structures and climate within the relevant groups (Bronfenbrenner, 1994).

Bronfenbrenner (1994) recognized the immediate social environment (microsystem) as an environment consisting of activities, social roles, and interpersonal relationships which facilitate or hinder participation and allows for development and sustainability of gains made. He stated that family centred care has been prioritized in terms of psychological intervention. Bronfenbrenner's ecological systems theory is thus an example of a theoretical theory which would provide a clear frame of reference for the community reintegration of forensic MHCUs as it recognizes the social development of a MHCU over their lifespan existing within different dynamic interdependent social systems (Law et al., 1996; Lehman et al., 2017). Successful inclusion of forensic MHCUs into their immediate social systems (i.e. family) is a goal of forensic mental health care (Fitzgerald et al., 2012). This immediate social system has the greatest impact on the individual's health outcome and vice versa (Lehman et al., 2017), and therefore holds centrality.

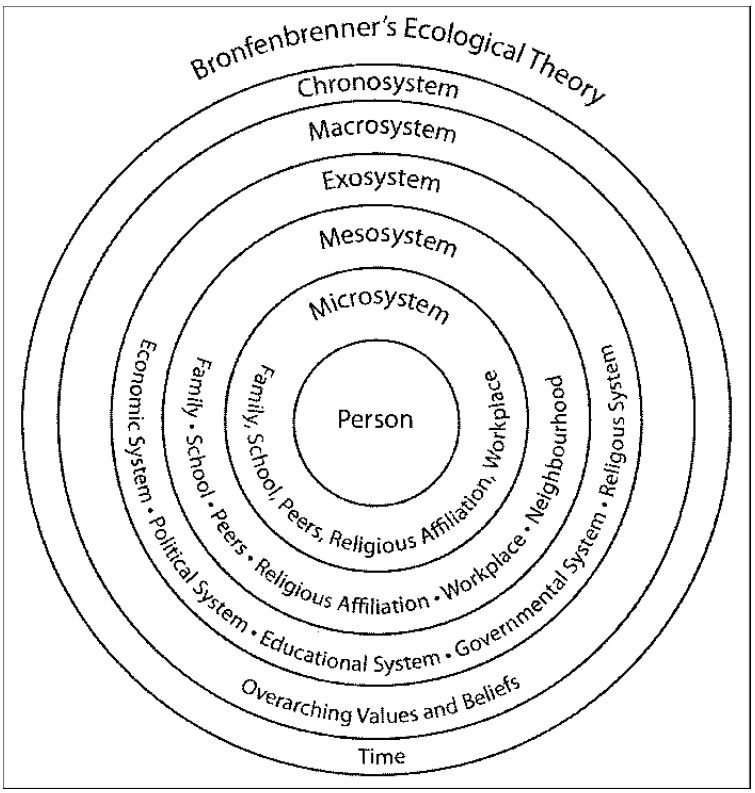

Figure 2.2. Diagrammatic representation of Bronfenbrenner's Ecological Theory (Stanger, 2011; adapted from Berger, 2007)

Bronfenbrenner's ecological systems theory (See Figure 2.2.) identifies this immediate social environment as the *micro-system* consisting of social entities who the forensic MHCU would have direct and regular contact with. This would include the most influential centralized social factors, namely, family, friends, work environment, local health resources, and the immediate community (Lehman et al, 2017, p. 3-4). Furthermore, Lehman et al (2017) recognize health care addressing these dynamic immediate interpersonal relationships. *Mesosystem* factors include the direct and dynamic relationships that would take place between different entities within the microsystem, such as between the family and health care personnel. The nature of these interactions influence the health outcomes of the individual. (Lehman et al., 2017). Microsystem factors influencing one another indirectly (*Exosystem*), and contextual dynamics (*Macrosystem*), all have influence on the individual.

However, the immediate context has greatest influence and impact, such as the family of forensic MHCUs.

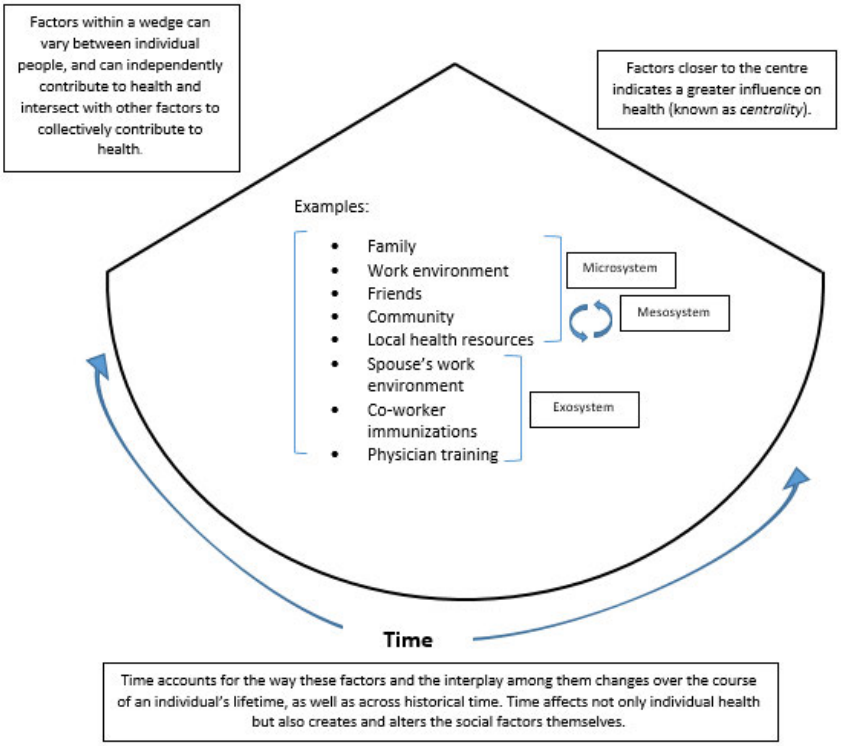

Figure 2.3. The centrality of the microsystem (adapted from Lehman et al., 2017, Figure 2)

Lehman et al (2017) postulates that the use of this systemic or contextual frame of reference helps organize health dynamics and informs health research, intervention, and policy development

(p. 12). Figure 2.3 provides an illustration presented by Lehman et al. (2017) of an existing interpersonal dynamic within a health context. Herewith, Bronfenbrenner's terminology is applied to a health context elaborating on the interpersonal factors and their interaction with the bio-psycho-social model of health. Factors may change over time, and mutually influence one another over one's lifespan.

This systemic perspective is furthermore advocated by public mental health experts and those researching and rendering PSR interventions. Public mental health experts (Muller & Flisher, 2006; Lund et al., 2010; Davies & Hannigan, 2019; Kramers-Olen, 2014; and McKeown et al., 2019) have promoted application of intervention using an eco-systemic approach.

Occupational science theorists, researchers, and clinicians have adopted this social support paradigm to service delivery ensuring consideration of facilitators of function within an individual's environment. For example, Wilcock (1999) identified an ecological model of health, '… (the) promotion of healthy relationships between humans, other living organisms, their environments, habits, and modes of life' (p.8), as being essential for sustainable "health for all". It is noteworthy that occupational science advocates for occupational and social inclusion in society thus adopting a systemic approach to healthcare. Merging of an occupation-based systemic approach is of interest.

2.2.4. Occupation-based practice

Through a review of relevant occupational science and occupational therapy related literature, it was established that occupation-based practice facilitating the development of pertinent life skills and life roles for community independence and empowerment is considered best practice within forensic mental health care (Kramers-Olen, 2014; Duncan et al., 2003; Chui et al., 2016; Fitzgerald et al., 2012; Muller & Flisher, 2006). Occupation-based family-centred OT practice requires further exploration considering valuable occupational science theories, frameworks, and models.

Herewith, a review of key constructs which validate this position, namely, the occupational therapy practice framework (OTPF) (AOTA, 2014) and person-environment-occupation model (PEOP model) (Krupa et al., 2009; Law et al., 1996; Crouch& Alers, 2005, p.436) informing OT practice, the dimensions of occupation characterising occupation (Wilcock, 1999; Wilcock, 2005; Hitch & Pepin, 2021), and a review of occupational justice risk factors and the ethical professional responsibility held by forensic OTs to prevent occupational injustice in at risk individuals and communities (Ingeborg & Townsend, 2010).

2.2.4.1. The occupational therapy practice framework (OTPF)

The OTPF describes the interrelated constructs that define OT practice. The American Occupational Therapy Association (AOTA, 2014) defined OT as "the therapeutic use of everyday life activities (occupations) with individuals or groups for the purpose of enhancing or enabling participation" (p. S1) hereby promoting intervention at individual, group and population levels. Application to the family unit is relevant as this unique group engages in particular everyday life activities, routines, habits and tasks. The main purpose of the OTPF is to achieve "health, well-being and participation in life through engagement in occupation." (p.S2). The framework is divided into two sections, namely, the *domain*, and the *process*. *Domain* refers to the areas in which the profession has knowledge and expertise, and includes the occupations, client factors, performance skills, performance patterns, and context/ environment; whilst *Process* describes the actions taken by therapists, and includes the *Evaluation Process* (Occupational Profiling and the Analysis of Occupational Performance), the *Intervention* (Intervention Plan, Implementation and Review), concluded by the *Targeting of Outcomes*. *Outcomes* are viewed as the "determinants of success in reaching the desired end result of the occupational therapy process." (p.S10). The framework differentiates between different terms: *Health* is the complete state of well-being, not only the lack of disease; *Well-being* is a general term covering all domains of human life; *Participation* is the "involvement in a life situation (WHO, 2001, p.10)" (p. S4); *Engagement in Occupation* is the performance of occupations that are meaningful to the individual and the context (including subjective and objective aspects of experiences) and which lead to "participation in desired life situations." (p.S4). The social environment is also emphasized and described as the "presence of, relationships with, and expectations of persons, groups, and populations with whom clients have contact." (p. S9).

The OTPF (AOTA, 2014) promotes the priority of OT health prevention in acquiring and preserving the occupational identity of forensic MHCUs and their family members, who are considered as a vulnerable population group due to the burden of disease experienced by the family or immediate context (Mayosi et al., 2009; World Health Organization, 2003).

2.2.4.2. The person-environment-occupation-performance model (PEOP)

In line with a systemic approach to forensic mental health care, the Person-Environment-Occupation Model (Law et al., 1996; Crouch & Alers, 2005, p.436; Krupa et al., 2009) shifts to a community focus while describing the transactional and dynamic interaction that takes place between three (3) entities - a person; their occupations and life roles; as well as the environments in which they function. Similarly to Bronfenbrenner's Ecological Systems Theory, the PEO model recognizes the interdependence between these three (3) concepts. However, when compared to

Bronfenbrenner's model, the PEO does not only concern itself with the relationship between individuals and their environments, but measures growth in terms of participation and occupational performance.

The family of a forensic MHCU can be understood by means of this model as the entity ("person"), which participates in meaningful everyday family life activities ("occupations"), and functions within a broader supportive community ("environment"). The PEOP model offers a unique perspective in assessment and treatment of the family unit group requiring further exploration.

2.2.4.3. Occupational science

Occupational scientists and theorists have provided pertinent insight informing OT practice. Wilcock (1999) for example stated that:

"An occupational view of health can encompass the relationship between doing well, well-being and becoming healthy at cellular to global, biological to socio-cultural and microscopic to macroscopic levels. This is so because doing, being and becoming affects health on an individual basis through the integrative systems of the organism, on a social level through shared activity, the continuous growth of occupational technology and socio-political activity and on a global level through occupational development affecting the natural resources and ecosystems" (p.8).

Occupational behaviours of a group, such as a family, is an acceptable outcome to be evaluated. Fogelberg & Frauwirth (2010, p.136) argued that 'like individuals, collective entities such as groups, communities and populations also engage in occupational behaviours, and that occupation produced at each of these levels represents a legitimate unit of analysis for occupational science'. Hence, further enquiry into the occupational behaviours of forensic MHCU families is permissible.

Occupational scientists have studied the interaction between environment (micro-, meso-, exo-, or macro-systems) and people's occupational behaviour, thereby gaining particular insight on individual's and social groups' health and wellness. Krupa et al (2009, p.158) furthermore highlights occupational therapy practice within mental health settings as enabling occupation at various levels of intervention - person level, environmental level, and community level. This indicates that the support needs of the individual and the collective can be addressed through "environment-level interventions focused on the program/ service and the community", with the ultimate outcome of optimal occupational engagement.

Andresen, Tang & Barney (2006) also highlighted occupational therapy's strength in achieving health outcomes – namely, use of the person, environment and occupation model (also

see Law, et al., 1996), and the contextual factors impacting on "engagement in activities and participation in society." Family life being an aspect of community participation with its associated activities affirms a family-centred approach to OT service delivery.

Van Niekerk (2005, 2014) further states that occupational science would most ideally inform occupational therapy practice. Occupational Science, "the site for theorising and interdisciplinary research aimed at understanding the form, function and meaning of human occupation" (Ramugondo et al., 2015), provides a basis from which to validate occupational therapy intervention in the social environment. The authors promote the participation of OTs in various levels of society to remove any barriers of participation (p. 71) and asserts the necessity of broadening the OT role to address the adverse environmental influences impacting on at risk individuals' occupational opportunities and behaviour (p.72). Pettican & Bryant (2007) further advocate for occupation-focused practice within community settings through the incorporation of occupational justice considerations and strategies, minimizing occupational risk factors.

2.2.4.4. Occupational justice priority within occupational science

Authors (Pettican & Bryant, 2007; Ingeborg & Townsend, 2010; Chui et al., 2016) advocate for occupational therapists practicing within mental health care to ensure occupational justice within service delivery. Occupational Justice or "doing things fairly" is defined as "recognising and providing for the occupational needs of individuals and communities as part of a fair and empowering society" Wilcock & Townsend, 2000, p.84; Pettican & Bryant, 2007). The concept was developed from an ethical vision for "occupationally-just world supported by public health and societal initiatives" and for OT practice that was ethically committed to empower and socially include vulnerable persons or groups through everyday occupations of their communities (Ingeborg & Townsend, 2010). It is unknown which everyday occupations are participated in by families of forensic MHCUs.

Authors Pettican & Bryant (2007) view occupational therapy as being strategic in inclusion of marginalized individuals and communities (such as forensic MHCUs and their families). By not prioritizing an occupational justice outcome within one's strategy to reintegrate forensic MHCUs into the community, an OT does not address the occupational support needs of various levels of society (microsystem to macrosystem), and does not prevent occupational injustice associated risk factors, namely, occupational deprivation, occupational imbalance, occupational alienation, occupational marginalization, and disease at individual and society level (Blank et al., 2017; Ingeborg & Townsend, 2010; Townsend & Polatajko, 2007). Occupational therapists ought to uphold occupational justice in both direct service delivery and public health care (Pettican & Bryant, 2007, p.143). Consideration of these risk factors "justify occupation-focused practice in the contemporary community mental

health setting" (p.145). It can thus be concluded that forensic mental health OTs have an obligation to prevent harm by prioritizing occupational justice at an individual and systemic level of practice. Hence, forensic OTs are responsible to provide rehabilitation services that are accessible, balanced, and meaningful to individuals or groups. Authors Ingeborg & Townsend (2010) advocate for relevant OT practice upholding occupational justice by combining population and individualized intervention approaches. Existing OT practice within forensic mental health settings appear to promote individualized client centred approaches predominantly with limited community directed service delivery (Moore, 2015).

The family of forensic MHCUs, as a group, has not been evaluated according to their occupational injustice associated risk factors. This is essential in ensuring an occupationally just environment within which the forensic MHCU will reintegrate post discharge.

Occupational justice or occupational rights (inclusion into participation in occupations) is complementary to the dimensions of occupation (Ingeborg & Townsend, 2010). Occupation has been further described in terms of dimensions "doing, being, becoming, and belonging (Wilcock, 1999; Wilcock, 2005; Hitch & Pepin, 2021).

2.2.4.5. Dimensions of occupation

Defining features of any meaningful occupation-based mental health theoretical framework or program are the core concepts as defined by Wilcocks' dimensions of occupation, namely, "doing", "being", "becoming", and "belonging" (Wilcock, 1999; Wilcock, 2005; Hitch & Pepin, 2021)

Blank et al (2017) supports the relevance of MHCUs experiencing a sense of self and a sense of belonging through two overarching themes identified in their study, namely, 1) building and maintaining an occupational identity, and 2) work and other ways of belonging. Their findings reinforced that activity is not only valuable through participation (the act of "doing"), but rather gains in self-fulfilment ("becoming"), thus providing a "sense of belonging". Other phrases used to describe this sense of "belonging" included: being validated by others, being part of a social network. Blank et al (2017) further referred to Christiansen (2004) who suggested that people develop their personal identity through what they do, introducing the concept of "occupational identity". This occupational identity is who one is "becoming" as one engages in occupations/ activities in creation of this new valued sense of self. Participants identified valued life roles as providing identity, namely, family roles, parenting activities, volunteer roles, and service roles in the community. Occupation is therefore immensely influential in creating and maintaining a personal identity and a social identity, which appears to be of more value than the occupation (i.e. work/

leisure, etc.) itself. A mental health occupational therapist is thus required to ensure that irrespective of whether service delivery is directed at an individual-, environmental-, or community-level, that it holds true to these characteristics or dimensions of occupation. However, insufficient research has been done by occupational experts to truly understand the influence that the environment has on occupation, and vice versa, within a mental health context. This is a recommended area of research as stipulated by Van Niekerk (2014, p.38).

Hitch & Pepin (2021) identified through research that the core concepts of Wilcock's dimensions of occupation could be considered as a defining characteristic of occupational therapy conceptual practice models. Therefore, existing or novel theoretical frameworks or definitions can reasonably be considered as being occupation-based if including terminology related to concepts of doing, being, becoming, and belonging (Hitch & Pepin, 2021; Wilcock, 1999, 2005).

2.2.5. Evidence based practice

Evidence-base practice is a standard of best practice in mental health care service delivery as it ensures effective and efficient service delivery and allows for ongoing quality improvement in service delivery. It allows mental health professionals, i.e. occupational therapists, to make decisions regarding practice based on the most recent evidence of best practice, incorporates clinical expertise, and client autonomy. OTs are able to set outcomes for practice ensuring that desired end results of intervention are clearly formulated and targeted (Kirsh et al., 2019; AOTA, 2014; Casteleijn, 2010; Uys, 2003). These outcomes are primarily required to have particular value to service users rather than service providers. Outcome measures (evaluation instruments) are developed and used to assess the efficacy of mental health services rendered, and to track change attributed to therapeutic or rehabilitative intervention in pursuit of desired end results related to occupation-based or non-occupation based outcomes (including, health, wellness, and participation). One or more attributes of an outcome can be measured by means of a particular measurement tool (Kirsh et al., 2019; Chui et al, 2016; Casteleijn, 2010, p.xvi). Outcome measurement is essential for evidence based practice, and where outcome measures are lacking, operationalization of constructs need to take place. Data generated by these measures then clearly provide evidence or "observable facts" when evaluating the effectiveness or efficiency of health care (Uys, 2003, Waltz et al, 2010).

There is a paucity of occupational therapy specific outcome research in mental health care which is specifically notable in the forensic psychiatric sub-specialization (Chui et al., 2016).

Occupational therapy within mental health care has been viewed as having subjective outcomes, and being poorly validated (Casteleijn, 2013). Various authors within mental health (Casteleijn, 2010, 2013; Kirsh et al., 2019) and forensic mental health (Chui et al., 2016; Duncan et al., 2003), have been concerned with validating professional occupational therapy practice both at individual- and an environment- levels. These authors advocate for evidence based program development which evaluates "occupational changes" affected by rehabilitative services. Furthermore, there is an increasing demand internationally for criminal justice and health care systems to demonstrate outcomes (Chui et al., 2016, p.230) speaking to the relevance of outcomes research within forensic occupational therapy in South Africa. Chiu et al. (2016) advocate for forensic occupational therapists to strategically exhibit the value of their role to stakeholders, as governments and funding agencies necessitate outcome delivery above mere service delivery. These ethical procedures ensure that evidence can be provided to service users, employers, and funders ensuring accountability and transparency of effective and efficient service delivery.

It is clear that evidence based practice is synonymous with outcome measurement. Outcome measurement is a known standard of best practice. According to the OTPF (AOTA, 2014), targeting and achieving outcomes are essential in determining success (achievement of the desired end result post intervention), which is critical for positioning the profession as a value adding critical discipline in mental health care (Casteleijn, 2010, 2013; Chui et al., 2016; Duncan et al., 2003). As previously stated, it enhances the credibility of the OT profession within the mental health MDT (Casteleijn, 2013, p. 4; Chui et al., 2016; p.237). Outcomes are required to be specific enough to ensure one is able to prove change as it is defined as the "impact of the service on the status of individuals or a group" (Quilliam & Wilson, 2011, p. 4). There is an ethical responsibility by OT practitioners to ensure measurability of services delivered within mental health as they practically apply grounded theory into OT practice. Uys (2003) has emphasized the marked difference between theory and practice, in that "theories are organized systems of interrelated abstract constructs" that can only be applicable to practice as measurable "clearly defined and observable behaviours", thus defining practice in nature as being evidence based. This has been further expounded by other authors (Waltz et al, 2010). For evidence based practice, Uys (2003) further highlights the following professional research related practices as essential, namely, documenting practice, validating standards of practice, and testing of outcomes. These practices clearly describe the OTPFs Process of OT practice (AOTA, 2014). Authors Kirsh et al. (2019) conducted an overview of researched OT interventions and their related non-occupation- and occupation- based outcomes within mental health, and discovered that even though outcome measurement is implemented at an increasingly

exponential rate that there is a clear gap in terms of mental health OT practice targeting well defined outcomes.

Concern has been raised by Kirsh et al. (2019) that a wide variety of different outcomes and measures are used within OT practice, making comparisons and further study cumbersome, and that studies establishing an evidence base for practice are limited and include small sample populations limiting generalizability of results. They report that there is presently an extensive evidence base for outcomes research pertaining to supported employment interventions, and a developing evidence base for a) skills and habits development and, b) interventions based on time use and occupational balance (p. 152). Despite most outcomes being occupation-based, the following categories of outcomes were identified through this study (Kirsh et al., 2019) - namely, 1) supported employment, individual placement and support, or supported education; 2) psychoeducation; 3) creative occupations or activity-based intervention; 4) time use or occupational balance; 5) skills or habit development; 6) group or family approaches; and 7) animal-assisted therapy. Skills or habit development was further described as "skill development, lifestyle modification, or occupational engagement" (p.111) All of these outcome categories exist within expected mental health OT practice. Where most outcomes were directed at an individual-level of practice, some outcomes could be directed at an environmental-level, namely psycho-education, and group or family approaches.

Standardised outcome measures aimed at individual levels of intervention have been developed to provide relevant outcomes based treatment (Casteleijn & Graham, 2012; Chui et al., 2016). Historically, outcome measurement, such as the Canadian Occupational Performance Measure (COPM), has focused on the individual client as the critical component of clinical intervention in both generic and specialist mental health contexts (Casteleijn, 2011; Chui et al., 2016). Further outcome measures with established psychometrics available mostly used by forensic OTs include three (3) identified generic tools (Chui et al. (2013, p.237), namely, the Independent Living Scales – manual (ILS), the Montreal cognitive assessment (MoCA), and the Assessment of Motor and Processing Skills (AMPS); as well as the less reported Occupational Circumstances Assessment Interview and Rating Scale (OCAIRS). OCAIRS is the first reported occupational therapy outcome measure to include a forensic component.

More recently, an outcome measure accurately tracking change in MHCUs activity participation or occupational engagement has been developed by South African researcher Prof. Daleen Casteleijn (Casteleijn, 2010, 2013; Casteleijn & Graham, 2012), namely, the Activity Participation Outcome Measure (APOM). During the qualitative phase of tool development, a sample of participants included those working within diverse settings, including forensic psychiatric

facilities (Casteleijn, 2010). Furthermore, use of this tool has been incorporated in validating OT practice within forensic psychiatric settings across South Africa (Moore, 2014, p. 108) and is a recognized outcome measure used within KwaZulu-Natal forensic occupational therapy practice.

It is noteworthy that during the systemic review of mental health OT outcomes (Kirsh et al, 2019), that there is limited evidence of client centred intervention within "natural setting(s)" as compared to facility based settings (often a simulated environment used in the development of community survival skills and life skills). This raises repeated concern for mental health OT practice (irrespective of whether client centred or family centred) to focus increasingly on an environmental level of practice.

In circumstances where established and particular outcomes and outcome measures addressing the domains of occupation (AOTA, 2014) are lacking, authors (Casteleijn, 2013, p. 4; Uys, 2003; Waltz et al, 2010) explain how health care workers, namely occupational therapists, are able to formulate outcomes and their measurable indicators to develop outcome measures enhancing the credibility of the profession. In the article "Operationalizing theoretical constructs: a research basis for effective therapy", Uys (2003) emphasizes that without careful and precise operationalization of abstract constructs indicated in discipline specific theoretical frameworks or theories, that therapists are unable to provide meaningful or worthwhile evidence of therapeutic input. This need for the development of reliable and appropriate outcome measures as a research priority in forensic occupational therapy is validated by Duncan et al. (2003, p.59). Of particular interest was top priority placed on the development of outcome measures related to QoL outcomes within forensic rehabilitation (Duncan et al., 2003, p.57).

Prior to the use of outcome measurement tools, their careful development is required. This development process requires researcher insight into different classifications of outcome measurement tools. Waltz et al. (2010, p.19) stipulates that "the measurement framework employed in a given situation will have important implications for instrument development and for what can be done with and on the basis of the resulting information." Outcome measurement tools were categorized as either being criterion-referenced measures or norm-referenced measures with both holding value in evidence based health care practice. Both have been described as having unique stages in development contributing to the reliability and validity of norm- or criterion-referenced measures (Waltz et al., 2010).

Outcome measurement tool development is further extrapolated in Waltz et al. (2010, p.37) operational definitions of health care constructs are formulated in the development of measurement tools for use in evidence-based practice. Abstract concepts, such as quality of life, can

be operationalized for use in health care but requires particular attention and conceptualization ensuring observable and measurable aspects are clearly identified and defined. Operational definitions are developed with Waltz et al (2010) recommending that the principal investigator incorporate the subjective lived experience of service users or research participants alongside principal investigator clinical observation and experience.

The exploration process of establishing meaning requires an initial review of pertinent literature to map the meaning of constructs of interest. This "mapping of meaning process" enables researchers to compare similarities and differences between varying construct definitions and their particular dimensions/domains. This is advised as an essential step in conceptualization of quality of life constructs in particular as it includes both "objective (perceivable to others) and subjective (perceivable only by the person experiencing it) aspects" (Dijkers, 1999 as referenced by Waltz et al, 2010, p. 37). It is expected that through the process of operationalization, that the meaning map would become increasingly precise or specific further informing the theoretical definition of a health care related construct of interest.

It is essential that the particular purpose of an outcome measurement tool be specified prior to the development process allowing key objectives for service delivery to be identified, and change to be tracked through pre- and post-test evaluations.

As established in literature, the benefits of evidence-based practice, the pursuit of well-developed outcomes, and use of outcome measurement tools, are wide ranging. Progression towards desired end results are tracked, change is quantified, occupational therapy strategic and operational objectives are informed, occupational therapy professional input is validated, policy development can thus be informed, funding for valuable occupation-based service delivery can be motivated for, and the gold standard of PSR rehabilitative practice can be directed and achieved.

2.2.6. Best practice gaps in forensic mental health care in KwaZulu-Natal

Through this literature review, it is apparent that gaps exist in occupational therapy practice. These gaps include service delivery which is focused on the family (systemic treatment approach) for optimal family reunification and family reintegration, service delivery which is evidence-based through use of outcome measures addressing family outcomes, and strengths-based service delivery addressing quality of life needs of forensic MHCUs and their families. If these gaps were addressed best practice standards of occupational therapy mental health care delivery would be ascertained ensuring ethical practice and optimal PSR intervention.

The “unmet need” of the forensic MHCUs and their families (Goethals et al., 2012) of family-centred outcomes directing occupational therapy practice, is thus a relevant topic of inquiry for occupational therapists in forensic mental health care.

2.3. Family work in forensic mental health care

Family work in forensic mental health care is a growing field of practice and inquiry. Implementation at a local or international level depends on the implementation of PSR intervention. According to Marquant et al. (2016) forensic multidisciplinary assertive community treatment teams (ForACT teams) render community based care to achieve particular health outcomes, including both non forensic and forensic outcomes. Relevant forensic family outcomes are herewith addressed.

2.3.1 MDT family work

Historically, family work within a forensic setting has primarily been directed by social workers, advanced psychiatric nurses, and psychologists (Pule, 2016; McKeown et al., 2019; Davies & Hannigan, 2019; Evans, 2019). Mental health family directed services has involved psycho-education and collaborative problem solving which recently included CBT strategies (providing psychological, emotional, and practical support) to improve emotional expression (EE) of family members and caregivers (Pule, 2016; McKeown et al., 2019; Kramers-Olen, 2014). Davies & Hannigan (2019, p. 26) also advise use of trauma-informed treatment procedures. It is clearly posited that psycho-education is inadequate without a more systemic approach including facilitation of family-orientated therapy (McKeown et al., 2019).

Successful family work outcomes to date (predominantly international services) directed by the forensic mental health care MDT has been documented (McKeown et al., 2019; Fitzgerald et al., 2012). Some of these outcomes have included decreased revolving door pattern, “general improvements in well-being (social, emotional, practical support outcomes, and family connection) (McKeown et al., 2019), reduced illicit substance use or relapse rates, “associated criminality” (or recidivism), a reduced burden of disease, residual trauma experience, or psycho-social stress within the family, and decreased stigma from extended family members, neighbours/community members, and the media. Furthermore, maintained family involvement, problem solving, and coping with crisis situations was also identified as pertinent outcomes (Absalom-Hornby, 2012; p.51-52)

Recommended family work within a forensic setting include supportive interventions such as information sharing, ongoing feedback on forensic MHCU progress, open dialogue with family

members giving and receiving relevant information, having regular events (content not specified) or welcome meetings, support groups for caregivers/ custodians and family members (Pule, 2016; McKeown et al., 2019; Muller & Flisher, 2006), practical support overcoming transportation challenges, and facilitating maintained communication between the forensic MHCU and family members.

Systemic considerations for family intervention within a forensic setting were identified as necessary institutional family intervention outcomes which included training of personnel, and obtaining financial and human resource support from facility management (Absalom-Hornby, 2012; p.51-52). Pertinent research (Absalom-Hornby, Gooding, & Tarrier, 2011; Absalom-Hornby, 2012, p.148) highlighted particular barriers to family intervention in forensic services, namely, "insufficient time, poor support, lack of training, deficient information sharing, and geographic limitations" with recommended solutions of this qualitative inquiry highlighting a means to implement forensic family intervention, namely, "a clear pathway, protected staff time, revised policy and structure specific to family intervention, improved supervision, increased managerial support, shared education, and modernisation." (p.148). Achieving family outcomes within family-centred forensic mental health care is impossible without consideration of these barriers and facilitators to family work.

Particular outcomes recommended by South African forensic advanced psychiatric nursing literature (Pule, 2016, pp. 58 -65) affirms family outcomes of forensic MHCUs, namely, psycho-education, peer support groups in the community, provision of emotional support, family therapy (e.g. CBT), and involvement in discharge planning and obtaining finance-related skills (i.e. money management). Furthermore, referrals to community based organizations are also recommended.

International forensic studies have indicated the creation and successful implementation of *ForACT* MDT teams in the provision of multi-disciplinary service delivery within the community with the forensic sub-speciality focus (Marquant et al., 2016). Limited evidence exists of application of forensic assertive community treatment strategies within South Africa, despite health education taking place by nursing staff and social work staff in community clinics.

2.3.2. Family work in forensic occupational therapy

There is a paucity within occupational science and occupational therapy literature which assists clinicians in understanding the transactional relationship between environment and occupation within forensic mental health care, and a clear call exists for public mental health strategies and indicators ensuring "mental health care for all", such as forensic at-risk groups (Department of Health, Republic of South Africa, 2013). Forensic occupational therapy has a role to

play in addressing the support needs of an “at risk” group (Mayosi et al., 2009), particularly the families of forensic MHCUs.

International studies refer to OTs including the novel family-centred intervention approach to forensic mental health care approach using outcomes such as emotional expression (EE) to measure success (Fitzgerald et al., 2012). Other family outcomes reported related to forensic MHCU occupational performance; improved social interaction, communication, and interaction; improved community engagement; and improved goal setting (Fitzgerald et al., 2012; Kirsh et al., 2019). This was achieved through psycho-education (i.e. diagnosis, relapse signs, etc.), and through a discussion process with the OT pertaining to fears and anxieties and coping strategies (Kirsh et al., 2019). Other family-centred mental health related outcomes were reported by Kirsh et al. (2019). Intervention rendered included a nondescript TIME approach referring to an occupational balance program. MHCUs and their family members were hereby supported and empowered. Kirsh et al. (2019) concluded that family work within OT mental health care could be beneficial in supporting young adults with mental illness stating that “interventions incorporated into community living may help facilitate the attainment of goals and enhancement of life circumstances” (p. 151). However, studies regarding this category of intervention was limited. (p. 147)

South African literature however predominantly focuses on individual support needs and individualized treatment plans within forensic mental health care, while primarily engaging with families through family or caregiver directed psycho-education (Moore, 2014; Alers, & Crouch, 2010). However, Moore (2015, p.108) particularly referred to a systemic approach by stating that “it is important to remember that the environment, namely, the physical, social, cultural, economic and political aspects, has a huge impact on the motivation, organisation and occupational performance of the patient or forensic MHCU). Occupational performance, the actual doing, the skill, participation, competence and adaptation, is influenced and shaped by the external environment that is continually changing.” There is, however, no recommended implementation of this practice standard other than inclusion of close relatives in the MDTs individual care plans (p. 107).

OTs provide relevant support on family days (i.e. in KwaZulu-Natal). However, this support is not evidence-based, formalized, or clearly directed. Family life has not been formulated as a domain/ family outcome for forensic mental health occupational therapy intervention.

Further international forensic occupational therapy literature indicates a need for non-family specific community-orientated evidence-based practice indicating a potential requirement for occupation-based family work.

2.4. Family Quality of Life outcome measurement

2.4.1. Existing family centred constructs (outcomes)

Family outcomes are actioned through services, supports and practices to ensure change is realised. Family outcomes have been defined by Summers, Poston & Turnbull (2005, p. 778) as the "impacts (either positive or negative) experienced by families as a result of supports and services". Family outcomes have historically included negative constructs, i.e. evaluating family related stress (Kyzar et al., 2012), depression, or burden of care (Zuna et al., 2009). Examples of positive constructs include social support and family satisfaction (Kyzar et al., 2012). They have usually been uni-dimensional assessing a particular aspect of family life, with numerous being used together as need arises. These family outcomes have seldom been used to provide overall composite scores of family well-being (p. 113).

Interesting, family outcomes within the intellectual and developmental disabilities field have been studied and implemented in practice, namely, burden of care, family functioning, eco-cultural adaption (the accommodation to family life required by a person's disability), family well-being, and family resilience (Chiu, et al., 2013). Furthermore, Brown et al. (2015, p.3) refer to "whole life quality of life" used by social workers in the evaluation of individual and family support factors. Other family outcomes from I/DD studies (Hu et al., 2011), social science studies, healthcare studies and general family studies have also been identified.

It should be noted that family outcomes ought to be defined and determined by family members as they independently access family unit support. It is uncertain the extent to which action participation research methodologies have taken place in the development of family outcomes to date.

In response to a required multi-dimensional family outcome related to quality of life theory, the FQOL construct and outcome has been developed over the past few decades by QoL and FQOL theorists (Schalock, 2004; Brown & Brown, 2004). FQOL deals with the *goodness of or satisfaction with* family life (Turnbull, Brown, & Turnbull III, 2004). It is a "dynamic sense of well-being of the family" (Chiu, et al., 2013) defined by individuals and as a collective, where individual and family needs intertwine. Thus, FQOL outcome measurement tools (i.e. Beach Center FQOLS, and the FQOLS-2006) assess "a family's perception of the *importance and satisfaction* in different domains of family quality of life" (Van Beurden, 2011).

2.4.2. Family Quality of Life theoretical framework

FQOL theory has developed from Quality of Life theory (Van Beurden, 2011; Brown & Schippers, 2018; Schalock, 2004) which addresses the subjective experience of the areas of life that are common to all humans (Bertelli et al., 2011). Critical components of individual quality of life include attainment, satisfaction, and empowerment of service users (Brown & Brown, 2004, p.32-33). Schalock (2004) explicates the eight (8) core concepts of QoL (p. 14-15). According to Brown & Brown (2004, p. 39) some but not all individual quality of life well-being related domains core to human life may be applicable to FQOL. Individual quality of life core domains and indicators (e.g. physical well-being, emotional well-being, interpersonal relations, self-determination, etc.) can be categorised into 1) personal health, or 2) behaviour (p.39). It appears that these categories relate to health and well-being, and individual behaviour or interaction with others or their environment.

FQOL is viewed as a "unifying construct…encompassing disability impacts on families" (Summers, Poston, & Turnbull, 2005, p. 781). This unifying concept, including the burden of care placed on the family, family functioning, and adaptability strategies (Zuna et al. 2009), appears to be predominantly used in literature as a long-term outcome influencing systems and policies (Summers, Poston, & Turnbull, 2005). However, recognition is given to the value of programs in addressing short-term family-unit support needs (Chiu, et al., 2013), ultimately improving a family's capacity to care, and for purposes of program accountability (p. 383). This unifying family outcome is able to address both generic and unique aspects of family life while pursuing family-centred service delivery (Van Beurden, 2011). Van Beurden (2011) refers to Wang & Brown (2009) who presents the assumption that through offering family-centred support, FQOL as well as individual QoL can be simultaneously improved. Authors (Brown et al., 2015; Samuel, Hobden, LeRoy, & Lacey, 2012) assert the value of enhanced support factors in achieving FQOL, thus, affirming the significant relationship observed in literature between family-directed support and family outcomes (Kyzar et al., 2012). This highlights the particular shift within the disability field from fixing pathology or deficits to rendering pertinent client or family-centred support. Rehabilitative practice ought to be "more person-centred" leading to "higher levels of self-determination" (Samuel, Rillotta & Brown, 2012, p.4).

Therefore, family-centred practice affirming FQOL leads to "typically undeserved", low-income, or marginalized family's self-determination and self-sufficiency (Samuel, Rilotta & Brown, 2012) in accordance with QoL theory (Brown et al., 2015; Schalock, 2004). Thus, FQOL and Psycho-social rehabilitation (Kramers-Olen, 2014; Muller & Flisher, 2006) are two (2) fields of inquiry that focus on the empowerment of service users and their families.

This theory (Figure 2.4; seen diagrammatically in Zuna et al., 2009, p.27; Chiu, et al., 2013, p. 367) recognises how FQOL is an outcome of an ecological system of factors within which a person with a disability functions. In the microsystem, certain individual member factors, family-unit factors, individual-level support factors, and family-level support factors interact within broader meso- and macro-system, which consists of programs, systems, policies, and societal values. The development of new family strengths, support needs and priorities are inputted into this complex system, thus causing the changed output expressed through changed Family Quality of Life. Therefore, the FQOL framework particularly prioritizes focus on identifying support needs, and strengths of service users and their families (Samuel, Hobden, LeRoy, & Lacey, 2012) and is the most well developed family strengths-based family outcome in existence (Samuel et al., 2018).

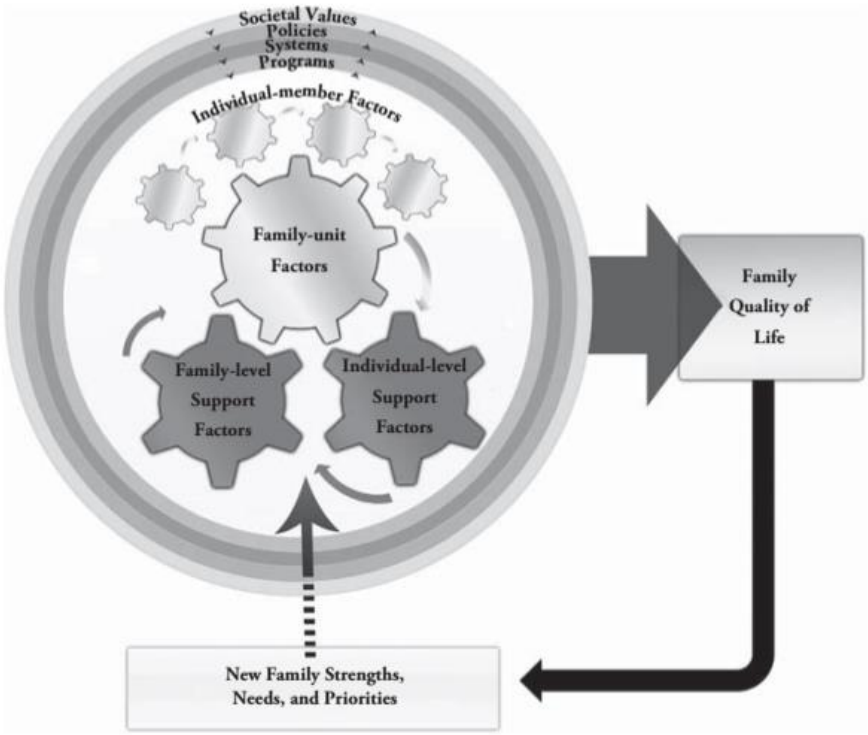

Figure 23.1 Overview of family quality of life (FQOL) theory. Adapted with permission from Zuna et al., 2010.

Figure 2.4: Overview of family quality of life (FQOL) theory (Chiu et al., 2013, adapted with permission from Zuna et al., 2010)

The FQOL framework concepts can be summarised into 4 major themes as stated by Zuna et al. (2009) - 1) *System*, the environment in which the family and individual functions with indirect effect on individual- and family-level support factors; 2) *Performance*, the health care services rendered; 3) *Individual family member*, the descriptive aspects of members in the family in terms of specific demographics, behaviours and beliefs; and 4) *Family Unit* – a description of the family as a

whole in terms of characteristics and dynamics states. FQOL theorists (Zuna et al., 2009) have acknowledged the complexity of the family unit noting that a family includes those who have a sense of belonging to each other, and who support and care for each other regularly. The family unit is viewed as a whole. Two family-unit concepts that have relevance to the understanding of the family are a) family-level characteristics (traits or descriptors of the family as a whole) and b) family-level dynamics (the quality of the interactions). Assessment of family dynamics is complex and usually requires formalised psychological tools.

The authors (Zuna et al., 2009) further elaborate that the "FQOL theoretical model can serve to enable practitioners to examine which family, ecological, and programmatic variables are amenable to change to positively impact FQOL" (p.25). As a result, researchers in the field of intellectual and developmental disabilities have validated FQOL as a valuable outcome for policy development and service delivery (Summers, Poston, & Turnbull, 2005; Hu et al., 2011). It is aligned with quality of life theory as well as positive psychology thus making it a neutral unbiased concept allowing for subjective interpretation of the satisfaction in pertinent areas of family life (Chiu, et al., 2013). It thus makes use of a strengths-based support paradigm (Hu et al., 2011; Samuel, 2018) while providing a means of objectively measuring overall family well-being (Zuna et al., 2009) through family-centred programs and service delivery (Van Beurden, 2011; Samuel, 2018).

2.4.3. FQOL Outcome Measurement

FQOL outcome measures have been identified as one of the primarily quantitative measures, where analysis focused on the theoretical basis, domains, response possibilities, scoring strategies and psychometrics (Hu et al., 2011; Kyzar et al., 2012). Compared with uni-dimensional family outcomes, FQOL is an example of a neutral concept as it not only ameliorates negative impacts but reinforces the positive strengths/ assets of the family.

Chiu, et al. (2013) describe the particular value of FQOL outcome measurement tools as determining the overall satisfaction with their family lives, identifying strengths and needs in family domains, and partnering with families in service delivery and accountability. Van Beurden (2011) highlights FQOL scales (namely, the Beach Center FQOLS) as potentially being used as an outcome measure presenting pre-and post-test data indicating the effectiveness of service delivery. Samuel, Hobden, LeRoy, & Lacey (2012) recommends use of FQOL outcome measurement tools (such as FQOLS-2006) to "longitudinally track families to compare the efficacy of the quality of supports that they receive over a period of time" (p.124). These authors, furthermore, highlight usefulness of

these tools in “systematically explor(ing) a family’s engagement in ...different life domains” in the development of individualized family-centered intervention plans.

Further value of FQOL outcome measures in establishing the collective health and well-being of the family is the incorporation of more than one (1) respondent in rating FQOL. This is validated by Hu et al. (2011) who highlighted the inaccurate use of FQOL tools when only the caregiver of the person with a disability is interviewed. They indicate that QoL assesses the individual quality of life, and advise that incorporating more than two (2) family member respondents allows for generalizability of findings when considering the family as a whole. This is further supported by Uys (2003, p.17) in recommending the inclusion of another rater to ensure inter-rater reliability.

The conceptualization, operationalization, and validation of these FQOL outcome measurement tools have predominantly been developed for families of children or persons with multiple disabilities, predominantly developmental delay and intellectual impairment (Samuel et al., 2018) within an educational or early childhood intervention context. Other disabilities incorporated in critical evaluation studies of the Beach Center’s FQOLS (Van Beurden, 2011) included autism spectrum disorders, ADD/ADHD, emotional disorders, learning disabilities, and other physical disabilities. Evaluation of this construct has further been applied to different contexts, namely, children without disabilities within early childhood intervention programs (Zuna at al., 2009), children on the autism spectrum within speech therapy pathology programs (Van Beurden, 2011), and adults with dementia within mental health programs (Brown & Schippers, 2018, p.2-3; Brown, 2017). Further research appears to have been predominantly developed by educational specialists (Brown, 2017), African speech and language pathologists (Schlebusch et al., 2017), and occupational therapists (Samuel et al., 2018) within early childhood intervention, with recent application to other fields or contexts (i.e. health and rehabilitation sciences, or mental health care). There has been a call for FQOL theory to be applied to practice within numerous fields of expertise, namely, social work (Brown et al., 2015). It has been posited that the FQOL construct and its application to rehabilitation services provides excellent opportunity for development within clinical practice and research (Van Beurden, 2011). However, there appears to be no direct call to apply FQOL theory to occupational therapy practice specifically.

As presented below, three (3) FQOL theorist groups have conceptualized FQOL within their independent studies (Zuna et al., 2009, p. 113). Two (2) of these initiatives have led to the development of psychometrically validated FQOL measurement tools have been developed, namely, the International FQOL Project (Brown et al., 2006; Brown, Isaacs & Werner, 2015) and the FQOL initiative by the Beach Centre on Disability in Kansas (Van Beurden, 2011). A third group focusing on

families in Latin America (Aznar and Castanon, 2005, as referenced by Zuna et al., 2009, p. 113) also proposed a theoretical definition of FQOL, however, further research has focused primarily on the two (2) previously mentioned qualitative inquiries into FQOL.

1) **International FQOL Project *(Family Quality of Life Survey (FQOLS-2006)*** (Zuna et al., 2009; Brown et al., 2006; Brown, Isaacs & Werner, 2015) - FQOL was organized into nine (9) domains. These included, for example, the research of the International Family Quality of Life Project (e.g., Brown, Anand, Fung, Isaacs, & Baum, 2003; Brown, MacAdam-Crisp, Wang, & Iarocci, 2006; Isaacs et al., 2007), which organized FQOL into nine domains: (a) health, (b) financial well-being, (c) family relationships, (d) support from other people, (e) disability-related services, (f) influence of values, (g) careers and preparing for careers, (h) leisure and recreation, and (i) community interaction." The ***Family Quality of Life Survey (FQOLS-2006)*** is a FQOL outcome measure which was developed for use in multiple international countries (Bertelli et al, 2011).
2) **Beach Centre on Disability in Kansas *(Beach Center Family Quality of Life Scale (Beach Center FQOLS)*** (Poston et al., 2003; Summers et al., 2005) - A team of researchers operationalized FQOL for tool development and concluded the process through field testing so that the measure consisted of five domains of FQOL: (a) family interaction, (b) parenting, (c) emotional well-being, (d) physical/material well-being, and (e) disability-related supports. During the initial stage of FQOL outcome measurement tool development using a qualitative inquiry, six domains related to individual family member characteristics Individual orientation), and four domains related to family characteristics (family orientation) were identified (Poston et al., 2003). These were viewed as more comprehensive in content (domains and sub-domains) than the Internal FQOL Project's nine (9) domains for the FQOL construct. The domains with an individual orientation were expounded as 1) advocacy, 2) emotional well-being, 3) health, 4) physical environment, 5) productivity, and 6) social well-being. Family orientated domains included 1) daily family life, 2) family interaction, 3) financial well-being, and 4) parenting. As a result, it was apparent that certain domains impacting collective family life were however relevant at different levels of experience, namely, individual- and family-levels. This was informed by the meaning attributed to concepts during the qualitative inquiry stage of FQOL conceptualization.

Notable similarities and differences exist between the existing two FQOL outcome measurement tools. There are similarities in terms of shared QoL characteristics, validity and reliability, some shared domains and sub-domains, and use of an action participatory study design

during tool development. There are however clear differences in terms of conceptualized domains and sub-domains, use of tools in terms of generating subjective and/or objective data, and differences in the tools' rating scales.

Both leading FQOL initiatives (FQOLS-2006; and the Beach Centre FQOLS) and their respective tools are characterised by the following defining features when measuring QoL (Verdugo et al.(2005b,p.707) referenced in Schalock (2004, p.14); Zuna et al., 2009, p. 113):

1) FQOL is multidimensional involving key domains and measurable indicators (Zuna et al., 2009, p. 113), where domains represent key "areas of family life". Overall, the domains represent FQOL.

2) FQOL uses "methodological pluralism" in collecting both objective and subjective data by means of surveys or scales.

3) FQOL uses a multivariate research design to "evaluate the ways personal characteristics and environmental variables relate to the person's assessed QOL"

4) FQOL uses a systems perspective evaluating how micro-, macro-, and meso- environments influence the people

5) FQOL involves the persons with disabilities in the design and implementation of the assessment, research and evaluation (Samuel, Rillotta, & Brown, 2012)

Both FQOL measurement tools have been shown to be psychometrically sound (valid, authentic and efficient) and generalizable to various population groups (Summers, Poston, & Turnbull, 2005; Samuel, Rillotta, & Brown, 2012). Further studies are required to establish cross-domain relationships, factor analysis to decrease the overall amount of domains, and application to different contexts (Perry & Isaacs, 2015).

Both tools made use of a degree of action participation with research participants ensuring that the FQOL conceptualization and operationalization was defined and determined by family members thus reinforcing self-determination or empowerment of participants at the early stage of FQOL conceptualization.

Both existing FQOL outcome measurement tools have contributed significantly towards conceptualizing the FQOL construct with similarities in sharing key QoL characteristics and overlap with some domains, yet with content differences. A comparison of final domains included in both measures was done by Perry & Isaacs (2015, p.585) where parenting and family interaction domains (of the Beach Center FQOLS) is similarly correlated with family relationships of the FQOLS-2006. For example, it is apparent that both include an occupation related outcome, namely productivity

(Beach Center FQOLS) and careers and preparing for careers, and leisure and recreation (FQOLS-2006). However, these tools have significantly different intentions for respective domains, in terms of application to individual or the collective family. The productivity domain is an individual-orientated domain, where it appears that the careers and leisure related domains of the FQOLS-2006 appeared to be predominantly family-orientated.

Further similarities and differences are noted in terms of the subjective and objective data generated from the two existing/available FQOL outcome measures. According to Samuel, Rillotta & Brown, (2012, p. 8), it is evident that the Beach Center FQOLS acts predominantly as a quantitative measure where none of the domains generated subjective descriptive content. This is in comparison with the FQOLS-2006 which generates both descriptive data from open ended questions, as well as quantitative data from a separate section of the survey. As a result the Beach Center FQOLS works well as a succinct and efficient to use outcome measure tracking change, where the FQOLS-2006 assists greatly in program planning and setting individualized intervention plans. Critical evaluation of the Beach Center's FQOLS indicated that service adequacy, disability support, and material well-being were most likely to indicate FQOL amongst service users and their families (Van Beurden, 2011).

Finally, existing/available outcome measures can be compared in terms rating scales. Both tools are psychometrically sound. The Beach Center FQOLS (Perry & Isaacs, 2015) is described as a questionnaire with 25-items measuring the degree of satisfaction experienced in certain areas of family life. These are rated using a 5-point Likert scale by respondents. The five domains have been empirically derived.

Brown et al. (2006) indicated that the FQOLS-2006 makes use of various data generation means, namely, Section A of each domain including open-ended questions and generating descriptive data (descriptive answers to particular questions), Section B of each domain generated quantitative data. In conclusion, the tool included an overall FQOL rating to be completed by respondents where they rated their overall experience of FQOL. Section B of each domain included six key concepts/quality of life dimensions while generating quantitative data, namely, Importance, Opportunities, Initiative, Attainment, Stability and Satisfaction (Bertelli et al, 2011). In reference to disability-related support, these key concepts can be expounded as follows: "Importance of support from disability- related services to overall FQOL; Opportunities available for disability-related support; Initiative taken to obtaining support; Attainment achieved in service support; Stability of the achieved level of service support in the near future; and Satisfaction with the present level of support" (Samuel, Hobden, LeRoy, & Lacey, 2012, p.114). Rating of these objective measures takes

place using a 5-point rating scale. Respondents were reminded throughout the process to consider the connection between individual and the family as a whole (Samuel, Hobden, LeRoy, & Lacey, 2012, p.114, referencing Brown et al., 2006, p.19). Samuel, Hobden, LeRoy, & Lacey (2012) further evaluates the quantitative six key concepts, and indicates strengths, namely, the importance ratings providing a stable characteristic on an aggregate level, as well as importance and opportunities ratings indicating and facilitating self-determination and self-sufficiency of family units. The opportunity rating appears to indicate a direct impact on both attainment and satisfaction ratings, with both correlating positively with overall satisfaction with FQOL (Brown et al., 2015).

2.5. Family Quality of Life directing forensic occupational therapy

2.5.1. Comparison between relevant FQOL, non OT and OT frameworks

Kirsh et al. (2019, p. 150) posits that "as the (OT) profession continues to define and evaluate its domain and aims of practice clearly, it must also clarify how the occupational lens is applied." It is hence necessary to identify key occupation based terminology, and opportunity for application of non OT terminology within OT definitions.

In a comparison of occupation based terminology within various OT related and non OT related frameworks and models, such as the FQOL framework, the following similarities were highlighted as shared meaningful concepts or areas of interests as seen in Table 2.1. Similarities are clearly noted throughout the assessed frameworks, models, and concepts in terms of adopting an ecological approach to service delivery where dynamic transactional relationships existed between various aspects of society (individuals, contexts, organizations, etc.). Overall the promotion of healthy interactions and social environments across lifespans was affirmed. The types of social environments ranged from centralised microsystemic groups within which occupation and direct interpersonal relationships took place to broader ecosystems (i.e. macrosystem) where indirect interactions with the individual took place. Other types of environments to be considered included cultural and institutional environments. Participation in life roles, interpersonal relationships, and activities were particularly affirmed by Bronfenbrenner (1994) and occupational frameworks, models, and concepts (AOTA, 2014; Krupa et al., 2009; Law et al., 1996; Crouch& Alers, 2005; Pettican & Bryant, 2007; Blank et al., 2017; van Niekerk, 2005, 2014; Ramugondo et al., 2015; Ingeborg & Townsend, 2010; Townsend & Polatajko, 2007; Wilcock, 1999; Wilcock, 2005; Hitch & Pepin, 2021). The FQOL framework and occupational science regard occupation as collective referring to shared activity or collective family functioning. Health, wellness, and quality of life were

deemed as valuable outcomes. Occupational science uniquely framed the outcomes in terms of human occupation (Pettican & Bryant, 2007). Ideal outcomes for service delivery (whether relevant to education, health care related, or other contexts) included optimal occupational performance for all within the ecosystem which consisted of facilitating/empowering environments. Furthermore, groups would present with improved strength, support needs, and priorities directed constantly towards the ideal. A strong emphasis was placed on subjective experience of desired outcomes, namely, an experience of satisfaction. Domains of intervention included various levels of existence, namely, individual client factors (abilities and skills in line with bio-psychosocial model) (Lehman et al., 2017), inclusion in occupational engagement, for an ultimate sense of belonging to various levels of the ecosystem. OT practice was clarified as facilitating occupational performance at individual or environmental levels of care in an attempt to achieve relevant outcomes.

These pertinent frameworks, constructs, and dimensions (of occupation) (Wilcock, 1999) have established the boundaries within which the construct of FQOL could be deconstructed/ operationally defined for different contexts, such as forensic mental health care.

All theories, frameworks, models or concepts could be applied to all age groups experiencing various types and extents of disability, including mental illness.

2.5.2. FQOL conceptualisation for forensic mental health rehabilitation

There is limited evidence of application of the FQOL construct to psychiatry. Historically, FQOL was developed for use for I/DD, but had recently been applied to various other contexts of interest, such as mental health or families without persons with I/DD (Samuel, Rillotta, & Brown, 2012).

Authors (Van Niewenhuizen et al., 2002; Boumana et al., 2008; Vorstenbosch et al., 2007; Muller & Flisher, 2006) have reported on and investigated the pursuit of quality of life as a health outcome in forensic mental health care. The Forensic inpatient Quality of Life Questionnaire (short version) is an example of a measurement tool developed to track change of inpatient chronic forensic MHCUs individual QoL at this unique stage of recovery (Vorstenbosch et al., 2007).

No FQOL studies have been conducted in forensic mental health care to identify and address the pertinent support needs of forensic MHCUs and their families at the unique pre-discharge stage of recovery.

Table 2.1: Comparison of OT and non-OT theories/frameworks/models

	Bronfenbrenner's ecological systems theory/ model (Bronfenbrenner, 1994, Lehman et al., 2017)	**PEOP Model** (Krupa et al., 2009; Law et al., 1996; Crouch& Alers, 2005, p.436)	**Occupational science** (Pettican & Bryant, 2007; Blank et al., 2017; van Niekerk, 2005, 2014; Ramugondo et al., 2015; Ingeborg & Townsend, 2010; Townsend & Polatajko, 2007)	**Dimensions of Occupation** (Wilcock, 1999; Wilcock, 2005; Hitch & Pepin, 2021)	**OTPF** (AOTA, 2014)	**FQOL** (Chiu et al., 2013; Zuna et al., 2010; Bertelli et al., 2011; Summers et al., 2005; Beach Center on Disability, 2012; Beach Center on Disability, 2015; Poston et al., 2003; Brown et al., 2006; Brown et al. 2015, p.10)
Type of Theory/ Framework/ Model	An ecological model	A conceptual model regarding occupational performance	A field of inquiry directing occupational therapy practice	An ecological model of health	Not serving as a taxonomy, theory, or model of OT, but as a framework describing OT practice.	A theoretical model
Uses	Predominantly used in education to offer educational support	Directs assessment and intervention in OT	Theorise individual- and community-level occupational justice, theory, and scientific inquiry	Characterise occupation at various levels of society	Habilitation, rehabilitation, and promotion of health and wellness for clients with disability- and non–disability-related needs in OT.	Establish satisfaction, attainment, and empowerment of at risk individuals and their families to experience individual and collective quality of life with application to ID/D.
Population	Children	Children, adolescents, adults, elderly	All populations predominantly those at risk of occupational	Applicable to all humans	Directing OT practitioners rendering services to	Children and adults

			injustice		those with acute/chronic illness/disability.	
Types of disabilities	Unspecified	Unspecified (Any and all impacting on occupational performance)	Any and all impacting on occupational performance	Any and all impacting on occupational performance	Any and all impacting on occupational performance	Children with intellectual disability and developmental delay, those with no disabilities; adults with dementia
Relationship or interaction	Describe relationship between persons and their interdependent social systems, over life span	Describes the transactional, dependent, and dynamic relationship between: person, occupations and life roles, and environment in which they function, shaping occupational performance. Life span perspective (changing occupational performance)	Describe interaction between environmental (social structures) and a person or group's occupational behaviour.	Describing '... (the) promotion of healthy relationships between humans, other living organisms, their environments, habits, and modes of life'	Presents a summary of interrelated constructs that describe occupational therapy practice	To examine which family, ecological, and programmatic variables are amenable to change to positively impact FQOL
Types of social environment	*Microsystem:* most influential centralized social factors allows for development/ sustainability of gains made *Mesosystem:* direct and dynamic relationships that would take place between different entities within the microsystem. *Exosystem:* Microsystem factors influencing one another indirectly	Environment described ito: *physical, *cultural, *institutional, *social, and *socio-economic environments	Any and all contexts within which occupations takes place. Inclusive social environment in terms of social inclusion and occupational inclusion.	Occupational performance at all levels of society, i.e. shared engagement in activity, and socio-political involvement, etc.	Presence of, relationships with, and expectations of persons, groups, and populations with whom clients have contact	In the microsystem, certain Individual member factors, Family-unit factors, Individual-level Support Factors, and Family-level Support Factors interact within broader meso- and macro-system Broader meso- and macro-system including Programs, Systems, Policies, and Societal Values System, the environment

	Macrosystem: contextual dynamics					in which the family and individual functions
Participation/ engagement in occupation	*Microsystem:* an environment consisting of activities, social roles, and interpersonal relationships which facilitate or hinder participation	Enable occupation at all levels (individual, environment, and community) Occupation defined as the "groups of tasks that a person engages in and meets his/her self-maintenance, expression and fulfilment" Occupations and life roles	Understand the form, function and meaning of human occupation. Group's engagement in occupational behaviours at different levels (persons, groups, communities, populations).	Doing Becoming	Enhance and enable participation through everyday life activities Performance of occupations that are meaningful to the individual and the context leading to "participation in desired life situations.""	Family functioning and family adaptability strategies Family's capacity to care for person with a disability.
Health and wellness outcomes	*Mesosystem* (e.g. relationship between family and health professionals): The nature of these interactions influence the health outcomes of the individual.	Optimal occupational performance within supportive and facilitating environment	Gaining particular insight on individual's and social groups' health and wellness; purposeful and meaningful everyday life. A definition of mental health and well-being in terms of human occupation (Pettican & Bryant, 2007	Being (identity/ essence) Becoming (self-development) Belonging (social inclusion/shared identity)	Health (the complete state of well-being, not only the lack of disease), well-being (a general term covering all domains of human life) and participation in life (involvement in a life situation) achieved through engagement in occupation	Decreased experience of burden of care; individual QoL, and overall FQOL
Ideal outcome	Optimal educational output by individual within the social environment/ ecosystem.	Optimal congruence between PEO influences optimal quality of occupational performance. As a result: occupational	Occupational justice: individuals and communities being part of a fair and empowering society (Wilcock and Townsend, p84).	Sustainable "health for all"" (Ann Wilcock, 1999)	Achieving health, wellbeing, and participation in life through engagement in occupation	Inputted new: * Family Strengths, *Needs and *Priorities As a result: changed output as changed Family

		performance	Legitimate unit of analysis for occupational science for each level			Quality of Life
Type of experience	Non-specified (predominantly subjective experience, with educational or developmental objective output).	Non-specified (predominantly subjective experience, however, with observable functional change).	Occupational and social inclusion in social environment	Subjective experience of affirmed sense of self, growth, and sense of belonging/ connection to broader social environment.	Includes subjective and objective aspects of experiences related to areas of human life.	Includes the subjective experience of the areas of life that are common to all humans (Bertelli, et al., 2011); FQOL uses "methodological pluralism" in collecting objective and subjective data
Domains	* Individual, *microsystem, *mesosystem, *exosystem, *macrosystem, *chronosystem.	Person domain: * role, *self-concept, *cultural background, *personality, *health, *cognition, *physical performance, and *sensory capabilities Environmental domain: see above Occupation: see above	Occupational justice versus Occupational deprivation, occupational alienation, Occupational marginalization, and Occupational imbalance.	Doing Being Becoming Belonging	The areas in which the profession has knowledge and expertise, and includes the: •occupations, •client factors, •performance skills, •performance patterns, and •context/ environment	4 core microsystem related concepts from which domains have been developed (individual member factors, individual support factors, family unit factors, family support factor) Unique domains for different FQOL tools (See chapter 4.2.3.)
OT Process/ service delivery	Interpersonal dynamics to be understood and considered in community health and well-being by health care providers (OT not specified, yet application relevant) (Lehman et al., 2017)	Environment- level interventions focused on the program/ service and the community (Krupa et al., 2009)	Strategies to remove barriers to participation in and access to occupation (work, education, and community life) (Pettican & Bryant, 2007)	Incorporation of core characteristics in service delivery at individual and environmental levels of care.	The actions taken by therapists: •Evaluation Process •Intervention •Targeting of Outcomes	*Performance*, the health care services rendered

2.5.3. FQOL operationalization for family-centred, occupation-based, evidence-based forensic OT practice

The following quote by Andresen et al. (2006, p. 115) validates the application and operationalization of the FQOL construct for family-centred, occupation-based, and evidence-based forensic OT practice "the occupational therapy profession's historical emphasis on the person, environment, and occupation interface provides a potential for intradisciplinary and transdisciplinary outcomes research that capitalizes on our holistic perspectives. We need to perform more research that focuses on the contribution that occupational therapy makes to improved quality of life throughout the lifespan. The field's emphasis on patient- or client-centered practice that includes family members and other support systems is historically and uniquely inclusive compared to many other health care disciplines. Therefore, the profession needs to capitalize on this trait, partner with other supportive disciplines, and make scholarly contributions to provide the qualitative support and quantitative evidence to support these contributions."

It can be assumed that an occupation-based FQOL construct for the forensic mental health setting could be framed by the OTPF (AOTA, 2014), which is based on the assumption that "health, well-being and participation in life through engagement in occupation." FQOL could rather be based on the assumption, from an occupational lens, that *family health, family well-being, and shared participation in family life* is achieved through *engagement in shared occupation*. Within this occupational perspective, it is clear that FQOL could refer to the desired end result (subjective experience) of family health, family well-being, and shared participation in family related activities. The engagement in occupation outcome of individual level intervention is clarified by the OTPF (AOTA, 2014, S4) as "the performance of occupations" due to personal choice and meaningfulness within a supportive context. Occupational engagement (including subjective and objective aspects of experiences) leads to "participation in desired life situations" (AOTA, 2014, S4). Family engagement in family occupation is a novel concept suggested by the researcher as the performance of occupations that are meaningful to the individual family members, and family unit, which leads to participation in desired family life situations. Furthermore, subjective and objective experience of participation in desired family life situations can be synonymous to the FQOL definition of a family experiencing satisfaction in pertinent areas of family life (Chiu, et al., 2013). The outcome for family life could be described as "meaningful" (OTPF), "pertinent" (FQOL framework), "desired" (OTPF), or "satisfying" (OTPF/ FQOL framework) amongst other descriptors, such as "ideal". It can reasonably be expected that the FQOL could assist in framing occupation-based domains of interest.

Incorporating an occupational lens, FQOL could be perceived thus as the “satisfying participation in desired or meaningful areas of family life”.

2.6. Summary

Through a review of literature, the FQOL construct was identified as a multi-dimensional health outcome with potential of directing mental health care, particularly with relevance to forensic OT. Family work by forensic OTs was validated as a means to achieve best practice in rendering forensic psychiatric rehabilitation services.

The researcher was left with the following research question: What are the FQOL constructs to be included in a FQOL outcome measure which could direct occupational therapy practice for MHCUs and their families in a forensic setting?

How this was achieved is presented in Chapter 3.

3. Methodology

3.1. Introduction

This study aimed to identify and operationally define Family Quality of Life (FQOL) towards the development of a FQOL outcome measurement tool that could direct family centred OT services for MHCUs and their families within a forensic psychiatric facility setting in KwaZulu-Natal, South Africa.

To achieve this aim the following objectives were developed:

1. *Objective 1*: To identify FQOL constructs through focus groups with MHCUs, family members, and health care professionals working in forensic mental health.
    a. *Sub-Objective 1.1:* To develop interview schedules for the focus groups based on literature of FQOL and OT conceptual frameworks.
    b. *Sub-Objective 1.2:* To identify FQOL constructs through inductive analysis of the qualitative data generated.
2. *Objective 2:* To operationalize the FQOL constructs and their measurable indicators through a process of deductive reasoning towards a synthesized diagram.

Objective 1 (Sub-Objectives 1.1 and 1.2) will be discussed within this chapter. However, Objectives 2 which focuses on the operationalization of the FQOL construct into domains, sub-domains, and measurable indicators will be discussed in Chapter 4. This chapter will discuss the study paradigm and design, unique setting, particular methodology for each study objective and sub-objective, trustworthiness of data, ethical considerations, and concluding remarks.

3.2. Study Design

3.2.1. Study Paradigm

The philosophical assumptions of two paradigms namely pragmatism (Dudovskiy, 2018; Goldkuhl, 2012) and interpretivism (Goldkuhl, 2012) were used in this study in an effort to conceptualize and operationalize a FQOL construct relevant to an unique population and context,

namely, forensic MHCUs and their family members. Historically, the construct of FQOL originates from an intellectual disability and developmental delay rehabilitative context (Samuel et al., 2018; Poston et al., 2003; Turnbull et al, 2004, p.81 – 83; Park et al., 2003; Beach Center on Disability, 2015; Summers et al., 2005; Beach Center on Disability, 2012; Brown et al., 2006; Chiu et al., 2013). Therefore it was anticipated that using this construct in a forensic mental health setting would likely result in similar as well as novel aspects arising from the existing FQOL theoretical framework.

The researcher identified the pragmatic value of FQOL as a noteworthy theoretical and operational concept which could inform indirect occupational therapy practice addressing the support needs of the families of forensic MHCUs (see Chapter 2.5). The purpose of the study was not only to add to the body of family-centred occupational therapy literature, but to inform practice as OTs address environmental and systemic familial support needs within the forensic MHCUs immediate micro-system. As discussed in Chapter 2, the researcher identified family centred rehabilitative practice as essential for role re-acquisition and community reintegration of forensic MHCUs. Thus, a pragmatic approach was employed in the development of an outcome measurement tool (beyond the parameters of this study) which could be used to direct family centred occupational therapy intervention, and track the change in recipients of forensic facility's rehabilitation input.

As this study is the initial phase in the development of a FQOL outcome measure, the researcher deemed it as essential to draw from various sources in interpreting the FQOL construct for the unique forensic psychiatric setting. These included existing literature (e.g. occupational therapy, and FQOL theoretical/ conceptual frameworks), the lived experiences of persons with particular insight into family centred practice and pertinent family support needs (namely, particular mental health care professionals or disciplines, family members of forensic MHCUs, and forensic MHCUs), as well as the professional insight of the researcher through inductive and deductive data analysis. It was essential that participants' voice be the primary source of data collection, but necessary to incorporate researcher rationalization using conceptual frameworks. This first stage research project applied a predominant interpretivist paradigm prioritizing the understanding of participants' subjective meaning of a construct (Goldkuhl, 2012) through interpretation of data generated to achieve the outcome of an operational definition for FQOL which would inform OT assessment and practice within this unique context.

3.2.2. Interpretative Phenomenological Qualitative Study Design

This study used an interpretivist qualitative research design. Despite an Interpretative Phenomenological Approach (IPA) having an idiographic emphasis (Clark, 2009; Finlay, 2009), it has

been used to study particular communities which share particular features (Finlay, 2009). Generally, participants (individuals or groups) are homogenous in nature. Therefore, this approach in this particular forensic setting is appropriate.

A phenomenological philosophical base of interpretive research was applied where the abstract construct of FQOL was operationally defined using the meaning attributed by research participants to the phenomenon of FQOL (Chiu et al., 2013; Zuna et al., 2010; Bertelli et al., 2011; Summers et al., 2005; Beach Center on Disability, 2012; Beach Center on Disability, 2015; Poston et al., 2003; Brown et al., 2006; Brown et al. 2015, p.10). FQOL authors support this methodology whereby "family support should … be defined and determined by family members" (Samuel, Hobden, LeRoy, & Lacey, 2012, p.112). Therefore, the researcher particularly characterized the FQOL construct as involving the persons with disabilities, clients, or family members in the design and implementation of the assessment, research and evaluation, further validating this essential study design. The end result of this qualitative stage would provide a "representation of theoretical constructs as objectively measurable indicators through operationalization" (Uys, 2003, p.16).

It was essential for the researcher to establish how this study fits into the extended research process of developing an occupation-based FQOL outcome measure to ensure pragmatic results. This study is the first phase of a broader research study in the development of this FQOL outcome measure. In order to operationalize FQOL for a forensic psychiatric setting, the design of this study was qualitative. A qualitative design was chosen as it aligns well with instrument development protocols (Waltz et al., 2010, p.129; Laver Fawcett, 2007; Casteleijn, 2010, p.27; Creswell, 2015) and evaluation of tool adequacy (Francis et al., 2017, p.65). Creswell (2015) suggested qualitative item generation to take place at the onset of the tool development process. This emphasis on the qualitative phase of the tool development was considered as essential in incorporating the unique voices and lived experiences of participant groups into the development of the tool. This phase focused on the phenomenon of FQOL by exploring how different people view the same construct (Samuel, Rillotta, & Brown, 2012).

Further research will allow qualitative themes, items, scales or variables, to be captured as quantitative measures (McMillan & Schumacher, 2010) for occupational therapy practice. Creswell (2015) highlighted the anticipated next research judgement-quantification phase by stating that the "quantitative portion of the study is used to confirm, determine or expand on qualitative findings", thus ensuring that "objective and reliable measurement of validly operationalized observable behaviours (can take place) before, during, and after treatment" (Uys, 2003).

For occupational therapists to have an operational definition for the phenomenon of FQOL in a forensic psychiatric context, the researcher was required to use a hybrid of inductive and deductive data collection and data analysis to operationalize this construct. The FQOL construct required insight from a unique population with their own unique culture, lived experience, and attributed meaning.

This hybrid analysis process is presented in Figure 3.1 where deductive and inductive processes were used in a cyclical manner (Xu & Zammit, 2020). Firstly, deductive analysis was applied to assess the existing meaning attributed to the FQOL construct in literature in preparation for data collection processes. This was followed by an inductive analysis process of identifying meaning of FQOL attributed by research participants. Deductive analysis concluded the operationalization of FQOL using existing theoretical or conceptual frameworks and inductive analysis outcomes. This allowed an etic perspective (interpretative analysis by an outsider, namely, the researcher) (Clark, 2009). Chapter 3.4.4 and 3.5 expand on these processes.

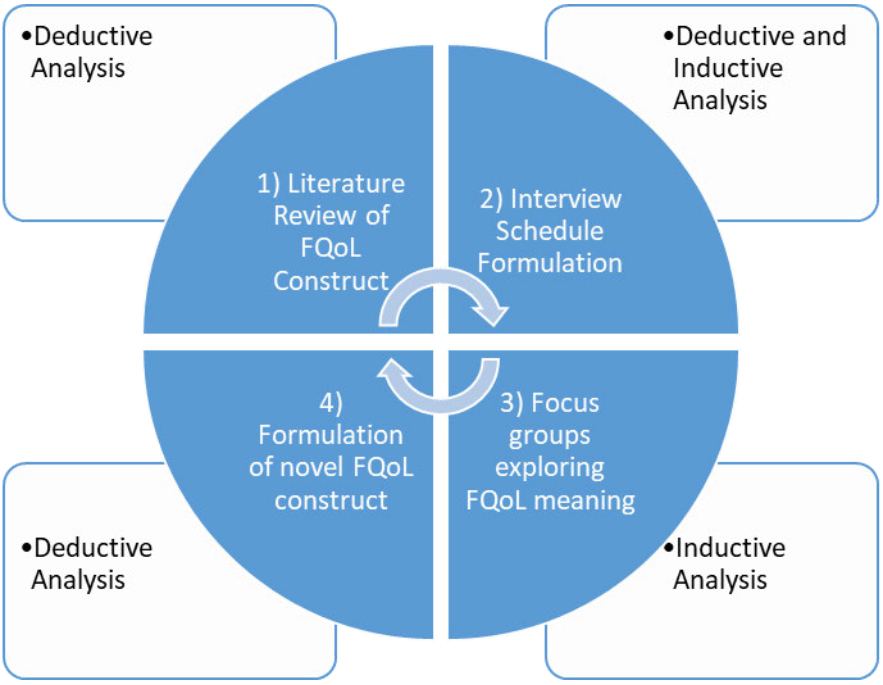

Figure 3.1: Cyclical hybrid inductive and deductive analysis processes

This is in alignment with the aforementioned research paradigms and research design chosen. The researcher was required to analyse findings in a cyclical manner using predominantly participants' lived experience, as well as existing theoretical or conceptual frameworks, such as, FQOL theory or framework (Chiu et al., 2013; Zuna et al., 2010), OTPF (AOTA, 2014), and professional

insight. This ensured that FQOL would be defined in light of occupational science or human occupation using relevant terminology so that findings could be interpreted into observable, useable, and testable indicators for an OT specific FQOL outcome measure. Operationalization of this complex abstract construct through qualitative phenomenology would assist the construct in being defined from an abstract to a concrete construct.

3.3. Setting: Location and Socio-demographic information

The study took place at a specialized forensic psychiatric hospital based in KwaZulu-Natal (KZN), South Africa. This hospital as well as two (2) forensic units in general psychiatric facilities in KZN (Houidi & Paruk, 2018)) serves the entire province with an estimate of 11,5 million citizens in 2020 (Statistics South Africa, 2020, July 9) and is primarily responsible for forensic mental health cases in KZN requiring care, treatment, and rehabilitation (CTR) as outlined by the MHCA No.17 of 2002 (The Presidency, 2003). MHCUs receiving CTR include those with chronic mental health conditions, and state patients (60% of the facility). Furthermore, this specialist facility also collaborates with the DoJ (Houidi et al., 2018) in the provision of specialist assessment of persons awaiting trial (Observation cases/ observandi) (Criminal Procedure Act No.51 of 1977, 1977; Houidi & Paruk, 2018).

Due to the immensity of the KZN province, this study focused particularly on those forensic MHCUs and families residing in the uMgungundlovu and eThekwini districts. Both districts are considered to be urbanised districts, however, hosting lower socio-economic areas, such as peri-urban communities on the urban hub's peripheries and the presence of informal settlements. Other districts in the province are categorized predominantly as rural, where difficulty is experienced in accessibility to healthcare, transport, and employment opportunities. The majority of those residing in rural communities generate income from self-employment, or subsistence farming or agriculture.

Further contextual information is available in Chapter 2.

3.4. Objective 1: To identify FQOL constructs through focus groups with MHCUs, family members, and health care professionals working in forensic mental health.

As previously mentioned, Objective 1 focused on the identification of the proposed FQOL constructs and was achieved through two (2) sub-objectives 1.1 – 1.2.

Waltz et al. (2010) termed a construct as "a highly abstract concept that is not directly observable … sometimes termed constructs because they are constructed of less abstract concepts that are observed directly or indirectly" (p.31). Thus, the complex FQOL construct required operationalization through the generation of observable and measurable items (indicators) at the initial stage of tool development making. This would contribute towards developing an operational definition of FQOL which included less abstract concepts.

This process would include the following activities: 1) reviewing literature of FQOL and OT theoretical or conceptual frameworks, 2) creating a preliminary meaning map of conceptual frameworks, 3) developing an interview schedule to identify entities that exemplify the construct using the existing conceptual frameworks, 4) piloting of the tool, and 5) identifying observable indicators through focus groups prior to operationalization of the FQOL construct. The planned identification of observable indicators was in line with Waltz et al. (2010) critical stages of operationalizing criterion constructs.

3.4.1. Sub-Objective 1.1. Development of Interview Schedules

Sub-Objective 1.1 aimed to develop interview schedules for the focus groups based on literature of FQOL and OT conceptual frameworks.

3.4.1.1. Theoretical/ conceptual frameworks

Due to the ultimate goal of operationalizing a novel FQOL construct, it was established that rich meaningful concepts could be obtained through "real-world observation and the literature" (Waltz et al., 2010, p.32). As a result, valuable literature related to FQOL and OT theoretical or conceptual frameworks assisted the researcher in creating a preliminary meaning map to formulate the interview schedules. Hereby, the researcher developed an understanding of the existing FQOL and OT conceptual frameworks and critical models which would assist in developing questions to explore the meaning attributed to FQOL in this forensic psychiatric setting (the "real-world"). This was essential for the onset of this construct-centred approach which asks "what complex of knowledge, skills, or other attributes should be assessed" and "what behaviors or performances should reveal those constructs, and what tasks or situations should elicit those behaviors." (Messick, 1994, p.17 as quoted by Nemoto & Beglar, 2014, p.2). See Chapter 2 for aspects of the literature review contributing to the preliminary meaning map.

3.4.1.2. Formulation of interview schedules

Three interview schedules were formulated for each of the participant groups. Semantic needs (professional language use versus layperson language use), awareness of medical

terminology, first or second English language, and education level were considered. The researcher drew from existing literature, consulted with supervisors, and navigated various family related terminology (i.e. family well-being, family resilience) and considered incorporation of other researcher directed terminology (i.e. meaningful family life, family participation in meaningful everyday life activities, and meaningful shared family occupation) in order to ensure clarity in conceptualizing FQOL. The researcher incorporated occupation-based terminology drawn from Wilcock's Dimensions of Occupation (Hitch & Pepin, 2021; Wilcock, 1999; Wilcock, 2005) as "doing, being, becoming, and belonging" as they are core concepts of occupational therapy conceptual frameworks, and defining individual or family related occupation was likely to be framed by these concepts. The structure of the interview schedule had a Section A (participant biographical information) and Section B (open ended semi-structured interview questions). Probes were also included.

3.4.1.3. Piloting use of interview schedule

The aim of the pilot was to evaluate whether the interview schedule would generate appropriate and sufficient information desired for items for FQOL theoretical and operational construction.

3.4.1.3.1 Pilot Study participants

A purposive non-probability sampling method was used to select participants who had partial insight into the research topic. Three interview schedules were evaluated by specifically selected participants. Table 3.1 indicates the sampling method and inclusion and exclusion criteria for the pilot study.

Table 3.1 presents the inclusion/exclusion criteria of participants for the pilot study.

Table 3.1: Sampling method for pilot study

Population	Sample	Description of Population	Rationale for Inclusion	Inclusion Criteria	Exclusion Criteria	Process used to recruit
Health Care Professionals to evaluate the interview schedule.	3 – 4	1-2 of the following MHCPs practicing in psychiatry: Occupational Therapist/ Psychologist/ Social Worker, and/or other Health Care	Inclusive of OTs with mental health experience who are invested in evidence based practice. Thus, they would accurately evaluate the interview schedule according to	2 years' experience in mental health in South Africa	Participation in Sub-objective 1.2 focus groups.	Potential participants will be selected from professional connections, and will be initially called, and then emailed with the invitation letter and

		Professional.	clarity, semantics, and its ability to achieve the outcome of the study.			supportive documentation
Forensic MHCUs to evaluate the interview schedule.		1-2	Forensic MHCU able to reflect on suitability and relevance of interview schedule for this unique group (Sub-obj. 1.2)	Young adult (18-35 years old) Pre-discharge program English comprehension.	Participation in Sub-objective 1.2 focus groups. Poor English comprehension. Moderate to severe cognitive impairment.	Participant(s) identified as possible recruits for Sub-objective 1.2, and excluded due to primary diagnosis of a personality disorder or no LOA experience.
Family members of MHCU in a forensic facility to evaluate the interview schedule		1-2	Family members able to assist researcher in reflecting on the suitability of the interview schedule for this unique group (Sub-obj. 1.2).	English comprehension. Family member admitted as forensic inpatient.	Participation in Sub-objective 1.2 focus groups.	Family member(s) approached of forensic MHCU(s) included in pilot study.

3.4.1.3.2 Pilot study data collection

Semi-structured interviews (with individual participants) and focus groups (with collective participants) were used to generate evaluation data while piloting the initial interview schedule. A Dictaphone was used to record the evaluation process and key data was transcribed by the researcher. Evaluation feedback was given through the completion of evaluation forms, and informal discussion. This process ensured that comprehensive feedback was obtained, for the finalization of the interview schedules to be used in Sub-objective 1.2.

The introduction of the pilot study included: 1) completion of pertinent documentation, 2) expounding on the purpose of the pilot interview/ focus group (i.e. critique the process/ interview schedule in terms of clarity, semantics, purpose met, and relevant prompting questions), 3) purpose of the research study, 4) clarifying core terminology (i.e. occupational therapy, FQOL, outcome, domain, indicator), 5) rationale for this family centred study, 6) presentation of main question to be answered, and 6) how to progress (i.e. exploration through use of the interview schedule). The researcher forwarded the initially formulated interview schedules to participants electronically for review. Consent forms, invitations to participate, and biographical questionnaires were sent to most participants for completion prior to review of interview schedules. Participants were instructed to

return the review document, and completed documents to the researcher within the given timeframe.

The initial interview schedule included the following areas of inquiry with relevant prompts - contextual questions; questions related to doing, being, becoming, and belonging as related to the family; as well as inquiry into how the OT discipline could contribute to a better family life. A strong focus was placed on shared family activity which was meaningful and ideal.

Written feedback was given, followed by discussion feedback (as recorded by the Dictaphone) to saturate data generated, and researcher and research assistant notes were taken.

3.4.1.3.3. Pilot study data analysis

Descriptive data analysis took place, with narrative data generated through transcribed audio-recordings, completed evaluation forms, and researcher/research assistant evaluation was collated informing final interview schedules.

3.4.1.3.4. Finalization of interview schedules

Interview schedules for the three (3) participant groups were finalized through incorporation of evaluation feedback given and receiving constructive feedback from supervisors. It became evident that the interview schedule should focus predominantly on the meaning that participants attributed to the FQOL construct without pre-empting the dimensions of occupation (Wilcock, 1999; Wilcock, 2005; Hitch & Pepin, 2021). Furthermore, cognisance took place of the research questions asked during the Beach Center FQOLS qualitative inquiry, namely, for participants to describe the things that were “important for families to have a good life together” (Beach Center on Disability, 2015). The final structure, inclusive of simplified questions, and prompts were formalized for each participant group (See Table 4.2).

3.4.2. Sub-Objective 1.2. Identification of FQOL constructs and indicators

Sub-Objective 1.2 aimed to identify FQOL constructs through inductive analysis of the qualitative data generated. These FQOL constructs and indicators were generated through three (3) particular participant focus groups and thematic analysis.

3.4.2.1 Study participants

3.4.2.1.1 Sampling method

A purposive non-probability sampling method was used to select participants for the three focus groups.

3.4.2.1.2 Inclusion and exclusion criteria

Three (3) different participant groups were recruited for the separate focus groups (Table 3.2), namely, particular MHCPs involved in frequent family work (predominantly, psychiatric nurses, and social workers), in-patient forensic MHCUs, as well as their respective family members. Inclusion and exclusion criteria were applied ensuring that there was homogeneity in participants' insight into identifying family support needs and conceptualizing the FQOL construct prior to its operationalization. General inclusion and exclusion criteria required all participants to be compliant in sharing an interest in and valuing the research topic, and that they have acceptable proficiency in the English language. Occupational therapists were excluded from inclusion as study participants due to limited historical family work conducted with forensic MHCUs and their family members, especially in KwaZulu-Natal. Furthermore, OTs had not been included to date within this forensic setting in Assertive Community Treatment (ACT) despite the PSR gold standard of family-centred care (Kramers-Olen, 2014; Marquant et al., 2016).

Focus group sample size was aimed at between 6 – 12 participants as recommended by Klein, Tellefsen, & Herskovitz (2007) and Fewster (2016). Other researchers have recommended group sizes of 6 - 8 (Stewart & Williams, 2005) or 8 - 12 participants (McMillan & Schumacher, 2010). In light of the limited population from which participants were recruited, the researcher of this study concluded on the range of 6 - 12.

Forensic MHCUs were included/excluded from participation based on their levels of motivation (Vona du Toit Model of Creative Ability (VdTMoCA), de Witt, 2014). Potential participants were excluded if their motivation and action levels were assessed as being in Group 1 ("Preparation for Constructive Action"), namely, tone, self-differentiation, and self-presentation. Forensic MHCUs placed within this grouping were in the process of developing functional body use as a prerequisite for engagement in activities (de Witt, 2014, p.12), and were not yet ready for the following stages where norm compliance behaviour and skill development would take place. Participants who were developing norm compliance were included. They were in the process of developing the necessary occupational behaviours to "live and be productive in the community and comply with the prescribed norms of the society and group within which he lives" (de Witt, p.12). This stage of development in occupational performance/activity participation was in alignment with the study's purpose of facilitating community reintegration only possible once participants were ready for societal norm compliance.

Occupational therapists were co-opted to confirm capacity to consent of their respective clients by means of the recognized Levels of Creative Ability (de Witt, 2014).

Table 3.2: Sampling method of Sub-objective 1.2 participants

Population	Description of Population	Rationale for Inclusion	Inclusion Criteria	Exclusion Criteria	Process used to recruit
FOCUS GROUP 1: **Mental Health Care Professionals** Sample size: 6-12	Mixed group containing a combination of psychiatrists, psychologists, social workers, psychiatric nurses practicing in mental health context.	Unique experience/ expertise in family centred treatment approaches that may be beneficial to incorporate into OT practice	Practicing in mental health in KZN 2 years' experience in the public sector in mental health Forensic experience	Excluding OTs	Collect a contact list of relevant disciplines at Fort Napier Hospital, and correspond via email with invitation to participate to determine interest.
FOCUS GROUP 2: **Mental Health Care Users (MHCUs)** Sample size: 6-12	MHCUs in the Pre-discharge phase of psycho-social rehabilitation and community reintegration	The primary client ought to be involved in the process of identifying support needs in the social environment. MHCUs have unique personal experiences.	Aged 18 – 35 years old Has been on or currently on a 3 – 6 months conditional discharge (Leave of Absence) Therapeutic goal of community reintegration is relevant Varying psychiatric conditions (as per medical file) Varying cultural groups (i.e. African, White, Indian) Resides in the uMgungundlovu or eThekwini Districts	MHCU with primary diagnosis of personality disorder MHCUs with reduced capacity to consent (i.e. moderate to severe cognitive impairment, or present acute or psychotic episode). Exclusion of tone, self-differentiation, and self-presentation levels of creative ability (VdTMoCA) (de Witt, 2014)	Liaise with OT, Nursing, Social Work and Psychology Departments to identify suitable MHCUs from Pre-Discharge Wards.
FOCUS GROUP 3: **Family members** Sample size:	Inclusive of custodian/ any family member residing with MHCU in same house/ on	Family members have unique personal experience in terms of living with a MHCU and the	Family member/ caregiver/ custodian Living with MHCU in same house/ homestead		Contact family members of selected MHCUs via initial telephonic

6-12	same property	functioning of the immediate family. It is essential to hear the "voice" of family members.	Carries some degree of responsibility towards the MHCU Involved in shared daily activities with the MHCU Resides in the uMgungundlovu or eThekwini Districts		conversation.

Biographical data collected is presented in Chapter 4.2.2.1 in narrative and tabulated formats as recommended by Mabuza et al. (2014).

3.4.2.2 Research Assistants

Three (3) research assistants were employed who assisted with data collection while piloting the interview schedule and during focus groups (See 3.4.2.2.2. for task breakdown).

Particular effort was placed on enlisting RAs who would be relational, insightful, and critical thinking individuals. Availability of research assistants were of primary concern, and so some were more experienced in research assistant knowledge and skills than others. Where gaps were identified by the researcher in knowledge or skill, an additional research assistant was incorporated, especially when dealing with larger groups. A total of three (3) research assistants were included in data collection and member checking stages of research inquiry.

3.4.2.2.1 Inclusion and exclusion criteria

Research assistants were recruited as per recruitment plan presented in Table 3.3.

Table 3.3: Recruitment method of research assistant

Population	Description of Population	Rationale for Inclusion	Inclusion Criteria	Exclusion Criteria	Process used to recruit
Research Assistant Sample size: 1	Involved in or concluded pertinent tertiary education.	Critical thinking research assistant for co-facilitation of focus groups, recording of critical observation, and assistance with the group preparation and process.	Bilingual (isiZulu and English proficiency) Excellent interpersonal insight and skills		Head hunting within the Pietermaritzburg based research community. Telephonic or in person invitation to participate, and explanation of the purpose of the study.

3.4.2.2.2. Preparation for data collection

The three (3) research assistants used throughout the course of the study's data generation (Sub-Objective 1.1 and 1.2) and member checking, were prepared prior to contact with research participants. These contact sessions happened at critical moments prior to focus groups. Content of the contact session included the contractual agreement, compensation for time, overview of the research (in terms of topic, process, and methodology), particular responsibilities and expectations (taking "field notes", recording change in speaker, recording noteworthy verbal or non-verbal observations, recording key words or emphasized topics discussed by participants, and assisting research participants in the completion of documentation), as well as providing an opportunity to request clarity or pose questions to the researcher.

3.4.2.2.3. Feedback processes after data collection sessions

Intentional feedback sessions (approximately 20 minutes per session) were held after focus groups, and individual member checking sessions as per their ongoing support needs (Weeks et al., 2015). Limitations were noted in research assistant ongoing availability. However, when available, the research assistants were engaging and provided meaningful feedback, validating the researcher's observations and providing novel or fresh perspectives from observations made.

Note taking took place by the research assistants as per their contractual responsibilities which were insightful and contributed meaningfully to the findings. Valuable content from these "field notes" were used during the data analysis (coding) to confirm codes identified.

3.4.3. Data Collection

Three (3) traditional focus groups were conducted with the three (3) unique participant groups. The researcher acted as facilitator and was accompanied by a research assistant with primary responsibility for documentation of field notes and key observations; assistance with set-up and logistics; and interpretation if necessary.

One- to two- hour in depth focus groups took place. Literature has highlighted the length of time as useful in understanding a phenomenon from the unique subjective viewpoint of participants (Klein, Tellefsen, & Herskovitz, 2007).

On each of these occasions the following procedure was followed:

1) Informal welcoming of focus group participants, directing to the tea station and to the information desk for provision of numbered labels, reimbursement of transport costs, and completion of necessary documentation prior to focus groups. Documentation included consent

forms (Appendix J - K), Assent forms (Appendix L), Invitation to participate document (Appendix I), Biographical Questionnaires (Generic and Population Specific Sections) (Appendices M - P), Indemnity form (Appendix Q), Study feedback request form (Appendix R), and Transportation reimbursement register (Appendix S).

2) All seated participants were formally welcomed and introduced to the researcher and research assistant (and explanation of their particular roles). The participants were orientated to the purpose of the study, to the ethical considerations (ability to withdraw at any point in the focus group, and to refer to one another's allocated numbers on labels to preserve anonymity), to the process of the focus group (researcher use of interview schedule and Dictaphone for audio-recording) and group norms (how participants were to respond - one at a time, to speak audibly, to share all of their thoughts due to the qualitative nature of the study, how to indicate when they are finished answering questions, etc.).

3) Implementation of the one-to two-hour long focus groups took place.

4) Closure and thanks (a commitment to share findings of study with interested participants was reiterated).

The research days were structured as either a workshop (including a guest speaker addressing ethics) or including a leisure time incentive (a motivational video). These were included as appreciation for participation as well as for personal/professional development.

Dictaphone audio-recordings were transcribed verbatim, field notes were generated, and key field notes were included in a tabulated format in preparation of qualitative data analysis (i.e. coding). Aggregate biographical information is presented in Chapter 4.2.2.1.

3.4.4 Data analysis

The first three steps of thematic data analysis recommended by Braun & Clark (2006; 2013) were applied for inductive analysis of the focus group data to identify FQOL constructs and related indicators.

The first step of familiarisation of the qualitative data (Braun & Clark, 2006, 2013; Mabuza et al., 2014) took place through transcription of audio-recordings, repeated immersion in data sets (audio-recordings, transcriptions, observations/ field notes), and highlighting initial codes, or key ideas and themes emerging.

Secondly, initial codes of meaning units were generated through a manual coding process. This process allowed the researcher to determine FQOL related items (from quotes) while organizing

codes into meaningful groups/ initial categories. The researcher ensured emic (insider) data (Clark, 2009) was collected through inductive IPA. Thus, coding was primarily data-driven (Braun et al., 2006). This process of developing a thematic index (Mabuza et al., 2014, p. 2), or a list of codes and initial categories, provided three (3) separate data sets of the different focus groups in Word documents. Indexing (Mabuza et al., 2014, p. 2), which usually entails application of annotated codes to all the qualitative data, took place within separate focus groups' data sets.

The third step of thematic data analysis, namely, searching for themes, entailed an initial charting process of sorting codes and initial categories into initial themes, and formulation of thematic maps (Word documents and visual representations of inductive data generated). Searching for themes within separate focus groups data took place.

Ongoing data reduction took place during this analysis process generating FQOL constructs and items prior to operational definition formulation (Objective 2). The manual charting process as well as data reduction in a Word document format took place ensuring that core data remained after duplicates, synonyms, and repetitions were removed. Herewith, an excerpt of a Word document (Table 3.4) demonstrating the reduction process from codes to refined items:

Table 3.4: Data reduction during thematic analysis (Sub-objective 1.2)

Initial category: Presence of Family Support Structure		
Initial grouping	**Codes (Items)**	**Annotations (Line No.)**
Identified	Support structure or family relationships identified Identify support source (access extra-familial support) Supportive family like relationships Prioritize accessing of available support structures Identify/prioritize/ invest in supportive relationships Access help – create reliable (willing/available) support structures Existence of Family Relationship Biological/ non-biological (contemporary/ biological)	31 46 19 36 19 19 27 31
Data Reduction Outcome: Identified family relationships	Defined family • Identified • Existing • Prioritized Diverse family • Biological/ non-biological • Intra/ extra-familial	

Reduction of data concluded with identified themes, domains, and sub-domains as reflected in Tables 4.6 – 4.8.

Aspects of Objective 1 findings in this research process were presented in Chapter 4 using narrative, tables, and figures. Findings included a summary of FQOL and OT conceptual frameworks reviewed (by means of a preliminary meaning maps, and tables) explored for interview schedule development (See Table 4.2 Final interview schedule - forensic MHCU example). Furthermore, biographical data, excerpts of initial categories or themes, and key quotes related to FQOL.

3.5. Objective 2: To operationalize the FQOL constructs and their measurable indicators through a process of deductive reasoning towards a synthesized diagram.

Objective 2 aimed to operationalize the FQOL constructs and their measurable indicators through a process of deductive reasoning towards a synthesized diagram. Through this process of synthesizing data, indicators/generated items from Objective 1 were further sorted, categorized, and defined. A novel operationalized definition of FQOL was thus established.

This study collectively used a hybrid of inductive and deductive data analysis. Objective 2 used deductive data analysis for the synthesis of data generated in Objective 1. The researcher used existing theoretical frameworks, such as, existing FQOL frameworks (Appendix C referring Beach Center FQOLS, and FQOLS-2006) and the OTPF (AOTA, 2014), for further sorting, categorization, and defining of items generated into domains, sub-domains, sub-themes, and themes. In support of this, Braun and Clark (2006) reports on the value of engaging with literature prior to deductive analysis as it sensitizes one to subtle aspects of data generated. An ongoing process of synthesis and reduction of rich data generated took place. New themes pertinent to this forensic psychiatric setting (not included in existing/available FQOL outcome measures and definitions) were included.

Steps 4 to 6 of thematic data analysis recommended by Braun & Clark (2006; 2013) were applied for deductive analysis of the focus group data to identify FQOL constructs and related indicators. Reviewing of themes (Step 4) took place by merging the indicators, initial categories, and themes generated in the three (3) focus groups. Organizing, synthesize, and consolidation of all this data took place (See Chapter 4.3.1) by means of a manual charting process (Mabuza et al. 2014) or an affinity mapping process (American Society for Quality; Tague, 2005). Affinity diagrams, charts with large amounts of organized information into similar groupings, included all indicators from all data sources organized in one place (Mabuza et al., 2014). This was then transferred to a Word

document with the final themes for inclusion in the novel FQOL construct. Hereafter, themes were named and defined (Step 5) through further interpretation of the phenomena, and findings were documented in written and visual representations.

Through this deductive analysis and synthesis process, it was established which domains, related sub-domains, and behavioural and measurable indicators would be included in a novel FQOL construct and thus could be included in a proposed measurement tool. Indicators relevant to the demands of human occupation and occupational performance were included. Indicators' semantics were phrased in a criterion-referenced appropriate manner (Waltz et al., 2010) defining clear family and individual observations. For example, observable behaviour was described as "The family…" or "The caregiver…". Indicators were similarly phrased to those adopted by the Beach Center of Disability's FQOL Scale (Beach Center on Disability, 2015). Further considerations of item design included principles of each item 1) measuring one idea, and 2) items being written in direct, understandable language so that the item's meaning is explicit/unambiguous to respondents (Nemoto & Beglar, 2014, p.3). Future respondents ought to immediately and accurately perceive the meaning of phrased items/ indicators (p.3). To ensure uni-dimensionality for the measurement of specific constructs or concretized concepts, indicators were all phrased positively (Nemoto & Beglar, 2014, p.3) and not phrased positively and negatively. This also aligned itself with a positive psychology framework (Chiu et al., 2013) making use of a strengths based approach.

The use of respondents' home language (i.e. isiZulu) as recommended by Nemoto & Belglar (2014) was excluded from this study due to study limitations of study time frame, scope, and financial resources (Further discussed in Chapter 6.3.3), but is recommended for future studies (See Chapter 6.4).

Qualitative data was presented by means of descriptive statistics. Furthermore, data was presented using narrative/ thematic prose, tables, and figures/ diagrams. The operationalized definition of the novel FQOL construct (including clear descriptions of concepts pertaining to FQOL themes, sub-themes, domains, and sub-domains) was formulated by the researcher into precise and understandable definitions in a Word document. Furthermore, the novel FQOL construct would be further interpreted and presented visually as a diagram. A tabulated final meaning map comparing novel and existing FQOL constructs, and an ecological diagram for discussion of the constructs meaning and their relationships were formulated. The presentation of summarised key findings or synthesized qualitative data in a visual representation is a recommended step concluding the reporting process (Mabuza et al., 2014, p. 5). Due to the immense amount of data it would be essential to analyse, synthesize, and present data in this manner.

Due to a focus on developing the operational definition of the FQOL construct for forensic psychiatric rehabilitation, the researcher has presented developed themes, domains, and related indicators included in the construct which could be included in a novel FQOL outcome measure for occupational therapy. This study did not address further tool development activities related to factor analysis and comprehensive data reduction for an occupation-based construct due to the research study bounds.

3.7. Trustworthiness of Data

Authors of qualitative research methodology (Mabuza et al., 2014; Waltz et al., 2010; Braun & Clark, 2006, 2013; Fewster, 2016; Klein et al., 2007; Creswell, 2005; Lincoln & Guba, 1985) have highlighted the threats to validity and reliability of research at various stages of a study. It was the researcher's responsibility to ensure that threats were minimized.

Creswell (2015) highlights the following threat: "when developing an instrument, for example, you need to translate the qualitative findings into items or scales and then use good psychometric procedures, such as examining the reliability and validity evidence" (p.33). Experts in outcome measurement tool development have identified threats to the validity and reliability of qualitative data generated through various stages of qualitative enquiry - namely, sampling, data collection, and data analysis (Waltz et al, 2010).

The researcher implemented unique considerations or steps to minimize risks to trustworthiness of data generated during qualitative enquiry, conceptual model development, and tool development.

A literature review on research validity and reliability (Mabuza et al., 2014; Baxter & Jack, 2008; Casteleijn, 2010; Francis et al., 2017; Lincoln & Guba, 1985) identified four (4) strategies/ Lincoln & Guba's evaluation criteria to establish trustworthiness/rigour in qualitative enquiries: 1) credibility (internal validity, triangulation and member checking), 2) transferability (external validity), 3) dependability (reliability), and 4) confirmability (objectivity).

3.7.1. Credibility (internal validity)

Validity refers to the truth value, soundness, or the trustworthiness of data generated, data analysed, data interpreted, and how closely outcomes represent reality (Mabuza et al., 2014; Waltz et al, 2010; Uys, 2003). This "truth value" was ascertained by the researcher of this study by primarily implementing member checking and triangulation in particular. Furthermore, techniques

used for establishing credibility included prolonged engagement, persistent observation, peer debriefing, referential adequacy, and the analysis of deviant cases/patterns in data (Lincoln & Guba, 1985).

As stipulated by Francis et al. (2017), incorporation of participants who represented the target respondent group of the outcome measure in tool development (particularly, operationalization of FQOL construct) was essential to ensure future content validity of an occupation-based FQOL outcome measure.

For the subjective lived experience of participants to be clearly understood (in terms of phenomenological meaning, culture, or social setting) and represented by this study, certain considerations were required including *prolonged engagement* (spending sufficient time in the context/ content), and continuous "*member checking*" or respondent validation was essential. This entailed the researcher reflecting interpretation of narrative shared throughout focus groups, and individual post group member checking interviews where the researcher gained clarity from representatives of particular studies in order to confirm meanings and items generated (during and after the manual coding, and inductive analysis process). *Peer debriefing* with research assistant(s) after focus groups also assisted in achieving credibility of data generated. Thus validity was enhanced primarily through the data collection and data analysis stages of the research study. Member checking during data analysis (development of themes, domains, and indicators) made this qualitative research study rigorous in nature. Member checking thus ensured that research findings were authentic, credible, had valid description, and held internal validity and interpretive validity (truthfulness of the emic meaning or interpretation of the data (Waltz et al., 2010, p.228).

Furthermore, *saturation* of qualitative data was thus ensured, as required for studies incorporating purposive (nonprobability) sampling (Hennink & Kaiser, 2019), for the FQOL construct to be adequate, comprehensive, robust, and valid. Saturation of data was achieved by using multiple relevant population groups and more than one traditional focus groups as accepted in public health (Brown, 03.03.2017). Fewster (2016) recommended that 3 – 6 focus groups are required for saturation of data with one focus group per population group being adequate. Therefore, saturation of data was achieved through this study by initiating three (3) focus groups with three (3) different populations regarding the same topic.

The researcher organized stages of *triangulation* to corroborate evidence to ensure a comprehensive understanding of the FQOL phenomenon as experienced by forensic MHCUs and their families through incorporating various relevant participant groups (forensic MHCUs, family members, and MHCPs) describing the same phenomenon, using various means of analysis (cyclical

inductive and deductive data analysis), planning for varying forms of methods (focus groups, observations, and field notes), and incorporating various theoretical frameworks through recent literature (FQOL and OT conceptual frameworks and models). This process of triangulation ensured that the FQOL construct was true, comprehensive/ holistic in its representation, and held internal validity (Mabuza et al., 2014; Lincoln & Guba, 1985).

3.7.2. Transferability (external validity)

Ensuring the "truthfulness" of data in that it can be generalized or transferred to different contexts, the researcher made consideration of the study's "external validity". It should however be noted that due to the nature of this qualitative phenomenological study being primarily based on the subjective/lived experience of the sample group based in KwaZulu-Natal, South Africa, transferability of findings to other settings is irrelevant. Therefore, comprehensive external validity or generalizability cannot be fully claimed for this study, and would require further study to ensure content validity for different provincial forensic psychiatric settings in South Africa.

External validity was however enhanced for the internal population of the facility and future possible research project possibilities by the researcher through the following considerations:

1) Through a process of thick description describing phenomenon with sufficient detail. (Lincoln & Guba, 1985)
2) Having an adequate sample to expound on the FQOL phenomenon (in terms of purposive sampling, representative participants from within the facility, and varying relevant participant group from within the facility and KZN province)
3) Provision of biographical results of this study (Chapter 4.2.2.1) for replication or comparative purposes.

3.7.3. Dependability (reliability)

"Dependability" or "auditability" refers to the internal reliability of research findings (Waltz et al., p.229; Uys, 2003). This refers to "the degree to which other researchers, given a set of previously generated constructs, would match them with the data in the same way as did the original researcher" (LeCompte and Goetz (1982), p. 32, as referenced by Waltz et al, 2010, p.229).

Internal reliability, or the accuracy of measurable indicators (Uys, 2003), was thus enhanced through the clearly defined and outlined study methodology as stipulated within this Chapter, allowing future researchers to match FQOL themes, domains, and indicators with the original data.

The researcher and supervisors particularly reviewed the hybrid analysis process enhancing the study's internal reliability. A circular analysis and synthesis process (coding-recoding process) took place where the researcher engaged persistently with meaning units, codes, and their interpretations, ensuring that the generated constructs were indeed truthful. This was a lengthy and intensive process. Questions were asked by the researcher and supervisors pertaining to the clarity of the research question, how it fitted with the aims and objectives, and the suitability of data collection methods, and analysis processes. This ensured quality control took place.

3.7.4. Confirmability (objectivity)

Consideration of the study's "confirmability" or "external reliability" contributed towards the truthfulness of the study findings. "External reliability" refers to whether external researchers would be able to confirm study findings and formulate the same construct while exploring the same phenomenon, under the same or similar settings (Waltz, 2010). Thus, confirmability was essential due to the short term and future study purposes, respectively, the qualitative operationalization of FQOL, and the quantitative development of a FQOL outcome measure.

While formulating a FQOL construct for use for occupational therapy practice, it was essential to consider the degree of "objectivity" or "neutrality" of study findings. It required a clear understanding of the different stages of the study with required differing degrees of subjective or objective interpretation of findings (Waltz 2010).

Sub-objective 1.2 used an *emic* (insider) approach where the researcher prioritized hearing and understanding the participant's lived experience, and findings were centred around his/her experience (Clark, 2009). Hereby, newly discovered ideas and themes emerged which were not yet considered in literature (Xu and Zammit, 2020). The researcher ensured optimal objectivity and minimal subjective bias through the ongoing process of reflexivity. Essential to the IPA was this personal reflection or self-awareness ensuring vigilance of how researcher subjective experience or preconceptions influenced the data analysis process (Clark, 2009). This was done through regular consultation with supervisors, by journaling through written or audio-recordings to self, and by engaging with existing literature. Thus, the researcher was able to ensure confirmability (objectivity).

Objective 2 adopted an etic (interpretative outsider) approach in which the researcher tried to "to make sense of the data by bringing in his or her own interpretations and theoretical ideas, but using verbatim quotes to ground these interpretations in the participant's actual experience." (Clark, 2009). Hereby, the researcher did not lose the voice of participants and their lived experience from Sub-objective 1.2. The researcher attempted to minimize subjectivity in this stage by drawing from

occupation-based practice models, as well as established theoretical frameworks. The theoretical frameworks assisted the researcher in considering whether codes and their interpretations were primarily researcher-driven (introducing bias), or in accordance with the occupational therapy profession (theory-driven, or profession-driven).

Subjective interpretation during data analysis is expected within the Interpretative Phenomenological Approach (IPA). It should be noted that a researcher did not attempt to completely bracket themself in IPA qualitative research (Clark, 2009). However, as stipulated above ongoing reflexivity was implemented. Supervisors provided the confirmability audits required to ascertain confirmability of data. Confirmability can be problematic when using an interpretative paradigm. Yet, supervisors were able to audit and offer advice on the process and outcomes of the study ensuring accuracy of findings, interpretations, and outcomes of the study (Lincoln & Guba, 1985).

Furthermore, an audit trail was kept by the researcher (including, raw data, data reduction and analysis findings, data reconstruction and synthesis findings, process notes, and the inquiry proposal). This ensured that categories and patterns identified in data could be confirmed (Lincoln & Guba, 1985).

Other means of increasing researcher objectivity or study confirmability in anticipating tool development included triangulation, and member checking as discussed above.

3.8. Ethical Considerations

ARTICLE 18 (Protection of the Family) of the *African Charter on the Rights and Welfare of the Child Protection of the Family* (African Charter on Human and Peoples' Rights, 1987) highlights the need for family centred care as championed by this research study in stating that “The family shall be the natural unit and basis of society. It shall enjoy the protection and support of the State for its establishment and development.”

Protection of participants was prioritized throughout the stages of this research project. Ethical considerations were prioritized during planning of the study. For example, the Helsinki Declaration had been reviewed by the principal investigator/ researcher of this study to ensure compliance with ethical guidelines when involving human participants in medical research (World Medical Association, 2001). Other resources informing engagement with participants included POPIA (Accessible Law, 2019, September 10; The Presidency, 2013), HPCSA Ethical guidelines and regulatory norms and standards (Health Professions Council of South Africa, 2016, pp. 103-118);

Batho Pele Principles (Department of Public Service and Administration, 1997; KwaZulu-Natal Department of Health, 2014), and Ethics in Health Research Principles, Processes and Structures (Department of Health, 2015) as referred to by the National Health Research Ethics Council of which the Biomedical Research Ethics Council forms part.

The scientific integrity of the study (comprehensive and well-planned study design and methodology) ensured validity and reliability of the study, as well as the prevention of harm towards participants. (Department of Health, 2015)

3.8.1. Ethical procedures followed

The National Institute of Health (NIH) online certification training 'Protecting human research participants' was completed by the researcher in 2015.

Furthermore, the best ethical practices involving human participants (Department of Health, 2015) included gaining permission from gatekeepers for inclusion of vulnerable human participants (namely, forensic MHCUs, their family members, and MHCPs). Ethics approval steps were followed which involved submitting requests for ethical clearance to perform the study through the hospital manager, the hospital Policy, Protocol and Ethics Committee, as well as from Provincial Government, namely, the office for Health Research and Knowledge Management at Head Office, Department of Health, Pietermaritzburg. (Appendices E - H: Gatekeeper Requests and Permissions Granted). Furthermore, the study was endorsed by the Deputy Manager of KZN DoH Disability and Rehabilitation Division (Appendix G), recommending permission to be granted. Ethical Clearance for the study (BE297/17) was approved by the University of KwaZulu-Natal's Biomedical Research Ethics Council (BREC) (Appendix E).

All pertinent permissions were granted prior to commencement of participant recruitment, and data collection activities.

The research study was self-funded and thus excluded any ethical conflicts of interest amongst potential funders.

3.8.2. Respect of persons (dignity and autonomy)

Core ethical principles of dignity and autonomy (Department of Health, 2015) were ensured through the course of the study. This principle ensuring self-determination through empowered personal choices was upheld through the different steps of the study. During recruitment, autonomy was upheld by respecting the disinterest to participate by some without badgering, by providing

opportunity to ask questions prior to participation, by excluding those from the study with a limited ability for self-determination, and only including those who have provided express informed consent. Further consideration of respect to persons was made of how to protect vulnerable persons through the various stages of the study.

3.8.2.1. Informed consent

Gaining informed consent from service users or research participants is an essential ethical practice for both recruitment within research as well as in professional mental health practice (Department of Public Service and Administration, 1997; KwaZulu-Natal Department of Health, 2014).

Participants autonomously provided consent to participate in the study through signing of a written agreement. Informed consent was established only after verbal disclosure of the risks, discomforts or inconveniences, and benefits affiliated to participation in the study, as well as the process of withdrawal from the study if risks were to outweigh the benefits. "Voluntariness and informed choices" (Department of Health, 2015) was reinforced throughout the course of the study with participants being informed of no negative consequences to be expected if desiring to opt out of participation or withdraw from the study at any point.

Illiterate participants had consent forms verbally explained by the isiZulu speaking research assistant prior to conducting the study. Furthermore, Assent Forms, consisting of low tech alternate and augmentative communication through pictorial representations of content, were made available allowing for comprehensive understanding, inclusion of the illiterate, and informed consent to be given.

3.8.2.2. Vulnerable groups and individuals

Respect for persons includes 'the dual moral obligations to respect autonomy and to protect those with developing, impaired or diminished autonomy' (Department of Health, 2015). Forensic MHCUs and their family members were deemed as particularly vulnerable to risk. The researcher ensure protection of this vulnerable population group by following a rigorous ethical approval process making application with key gatekeepers, by excluding forensic MHCUs who were unable to refuse providing consent (according to their levels of creative ability), by excluding certain participant profiles (moderate to severe intellectual impairment and personality disorders with complex needs), and by ensuring that the research was responsive as a whole to the health needs and priorities of this vulnerable population group.

Implementation of the conditions for commencement of research by the FNH Research Ethics Committee (Appendix H) took place relating to: obtaining informed consent from all, capacity to consent being carefully monitored and only including MHCUs and family members who have capacity to consent, ensuring participants have insight into the research being separate from treatment program and not having any impact on intervention or LOA approval whatsoever, ensuring that all were aware of safety and confidentiality concerns, and the indemnification of external participants on entry of the hospital premises.

Occupational therapists were co-opted to confirm capacity to consent of their respective clients by means of the recognized Levels of Creative Ability (de Witt, P., 2014).

3.8.3. Beneficence and non-maleficence

The researcher upheld the ethical principles of beneficence and non-maleficence ensuring that the study offered benefit to participants, and caused no harm (intentional or unintentional) (Department of Health, 2015). This principle ensured that the best interests of all participants were upheld, and that the researcher was committed to protection of participants' health and human rights. Furthermore, the relevance and value of the study was to benefit not only participants but with a broader view of informing beneficial practice to pertinent South African citizens.

Participants benefited through participation in the research study. They held insight that their unique "voice" would inform future rehabilitation and assertive community treatment. They also received indirect support from group members through focus group participation, and reflected on the great socio-emotional benefit gained.

No harm was caused to participants during the research study - whether social, psychological, legal or economic. The data collection method used (focus groups) posed minimal to no major psychosocial or physical harm threat. The therapist recruited psychologically stable individuals who were compliant to group norms, and should have no erratic behaviour. The therapist used group process skills to ensure conducive group dynamics and open communication. Harm was hereby also prevented. Group norms were reinforced ensuring respect of one another took place. It was communicated prior to participation in focus groups that the researcher maintained authority to remove any participants from the group if their behaviour was deemed as harmful towards one another. This would have been done in a manner that was not punitive, maintained respect for all participants, and would promote the well-being of all parties. Fortunately, this action was not required. Written and verbal communication ensured that participants knew to communicate if experiencing any psychological distress, and would be referred to a facility based social worker or

psychotherapist for immediate support. The researcher used emotional regulation and containment skills to ensure that emotional de-escalation took place if required. It was acknowledged though that recalling certain family related experiences may have elicited an adverse emotional response due to the burden of care and other social determinants of health. Communication of distress and need for immediate support was reinforced, but not required in the research process. Furthermore, no financial harm was caused through making travel allowances available so that participation in study would have no cost for unemployed or underemployed individuals (predominantly family members). Incentives (complying with the DoH guidelines for reimbursement) included financing of transportation costs for mental health care users and family members with most requiring transportation from peri-urban or rural communities. Participants signed acknowledgement of receipt of transport monies to ensure transparency and accountability.

3.8.4. Privacy and confidentiality (POPI)

South Africa's Protection of Personal Information Act (Accessible Law, 2019, September 10; The Presidency, 2013) informed the manner in which participants' constitutional right to privacy was applied in this research study. The researcher ensured safeguarding of identifiable personal information being processed through the research exercise. Every effort was made by the researcher to comply with Health Professions Council of South Africa guidelines pertaining to the protection of personal information (confidentiality) (Health Professions Council of South Africa, 2016)

Practically, confidentiality and anonymity were ensured by the researcher through:

a) Data collection having taken place in private venues, thus protecting participants' identities.
b) Obtaining participants' agreement to respect all information shared by other participants and not to disclose one another's personal information beyond the bounds of the focus groups.
c) Allocating each group participant with a labelled number with instruction that participants were to refer to one another via their numbers during Dictaphone audio-recordings.
d) Transcriptions, consent forms, and biographical information were completed ensuring identities were protected (as per autonomous indication of participants), and allocated participant numbers were included.
e) Aggregate data used in demographics feedback ensured that individuals were unidentifiable from research findings.

Furthermore, safe-guarding of personal information was ensured through protective steps. A minimality principle was followed in formulation and collection of biographical information. Accessible Law (2019, September 10) stated that "personal information may only be processed if, given the purpose for which it is processed, it is adequate, relevant and not excessive". Ethical data management was ensured through, namely:

1) All Word documents were saved in MS Word and duplicated by converting to PDF format to ensure no unauthorized changes were made to the data. A group folder was created including: field notes; audio-recording; transcription of the three (3) focus groups; and pdf documents of scanned copies of consent forms and biographical forms.

2) Information was saved on the researcher's laptop with password access control (password only known by researcher), and a duplicate was saved in "Dropbox" to prevent loss of data.

3) Only the researcher and supervisors of this research study had access to study data prior to thesis submission and journal publication.

4) Participants were assigned with pseudonyms/ numbers, and were recorded as such on the transcribed documents and the biographical forms to exclude personal identifiers.

5) Consent forms and biographical form hard copies (raw data) were stored in a lockable cupboard in the researcher's office. The researcher was in sole possession of the key.

6) Documents are to be destroyed five (5) years after research study is completed.

3.8.5 Justice and equality

Core ethical principles of justice and equality ensure that no discrimination takes place through the course of the research study. Distributive justice ensures that all participants access equal and fair measure of risk and benefit through study participation, whether benefits are immediate or experienced in the future (Department of Health, 2015). This was ensured by the researcher through particular attention paid to socio-economic status of participants (transport reimbursement for those from lower socio-economic background), equal and accessible communication of risks and benefits prior to participation, and equal opportunity provided for participants to request feedback from the study.

3.9. Summary

The methodology of this research study was expounded in this chapter in terms of research design, data collection, data analysis and synthesis, trustworthiness of data, and ethical considerations made in this study. This was to ensure that operationalizing of the FQOL construct took place for a South African forensic psychiatric rehabilitation context informing occupational therapy outcome measurement. The outcome of implementation of the methodology was the formulation of an operational definition of the FQOL construct concretising the desired end result for forensic MHCUs and their families.

The findings of Objective 1 and 2 will be provided in Chapter 4, with further discussion of Objective 2 taking place in Chapter 5.

4. Findings

4.1. Introduction

FQOL as a health outcome has not been deconstructed into an operational definition for use by occupational therapists in forensic mental health care. Operationalizing the abstract FQOL construct into concrete concepts will assist occupational therapists in setting relevant treatment objectives for effective and efficient family centred OT. There are currently no measurement tools related to pertinent areas of family support which track change in the quality of family life. The operationalized definition(s) of FQOL constructs that will be presented in this chapter will inform further development of a FQOL outcome measure for occupational therapy practice within a South African forensic mental health setting.

Prior to this study, it was unknown how to identify and operationally define FQOL for a forensic mental health context for occupational therapy practice, and which domains would be perceived as relevant for use to families of mental health care users within a forensic institution in KwaZulu-Natal, South Africa.

Chapter 3 addressed the methodology on how the researcher pursued the aim of operationalizing FQOL for forensic mental health occupational therapy practice. Chapter 4 will provide the findings of this qualitative study by presenting an operational definition of the novel FQOL construct, with its themes, sub-themes, domains, sub-domains, and measurable behavioural indicators. As stipulated in Chapter 3, qualitative data will be presented by means of descriptive statistics including narrative or thematic prose (quotes), tables, and figures. Codes will be included where relevant, and the themes revealed in the study presented (Creswell, 2015).

A valuable process of merging occupational therapy frameworks/ terminology and FQOL theory, as well as gaining invaluable participant insight into the subjective lived experience and phenomenon of FQOL assisted the researcher to concretise a relevant FQOL construct for future occupational therapy outcome measurement.

4.2. Objective 1: To identify FQOL constructs through focus groups with MHCUs, family members, and health care professionals working in forensic mental health.

The following section presents Objective 1 findings, namely, the synthesized FQOL and OT conceptual frameworks (initial meaning map) and the final interview schedule developed (Chapter 4.2.1), as well as biographical information of focus group participants, and the identified FQOL constructs from inductive data analysis (Chapter 4.2.2) presented as initial FQOL descriptive statistics (proposed themes, concepts, and items).

4.2.1. Sub-objective 1.1 – Developed interview schedules to identify FQOL meaning

Pertinent findings from Sub-objective 1.1 included 1) meaning maps of the existing FQOL construct and relevant OT conceptual frameworks (See Table 2.1, Table 4.1, and Addendum C), and 2) the developed interview schedules (See Table 4.2) in light of the conceptual frameworks.

4.2.1.1 FQOL conceptual framework (meaning map)

Existing literature related to FQOL outcome measure domains and sub-domains (developed for children with disabilities and their families, such as the FQOLS-2006, and Beach Center FQOLS), existing constructs were presented in a meaning map in a tabulated form (Appendix C).

The Beach Centre of Disability's FQOL Scale (Poston et al, 2003; Park et al., 2003; Summers et al., 2005; Beach Center on Disability, 2012, 2015), the FQOL Survey (2006) ID/DD (Brown, I., et al, 2006; Brown, I., et al., 2015; Poston et al., 2003), and the FQOL framework in diagrammatic format (Chiu, et al., 2013; Zuna et al., 2009; Zuna et al., 2010) were compared with one another (Appendix C) while identifying similarities and differences in meaning in the mapping process. This provided direction in the construction of probing questions for the interview schedule to explore FQOL's unique meaning within the forensic context.

4.2.1.1.1 Systemic factors

The systemic factors theme identified in the FQOL framework consisted of aspects considered as part of the family's macrosystem. These factors, however, did not appear as relevant domains in the two notable FQOL outcome measures in qualitative or quantitative stages of tool development. Domains were defined in the Beach Center FQOLS as predominantly individual- or family-orientated (Poston et al., 20ff03; Turnbull et al., 2004, p.81). There was also some perceived overlap in classification of family- and individual support factors with systemic factors pertaining to

programs, such as the *service system rendering service delivery* referred to by Chiu et al. (2013); or performance, such as, *health care services rendered* referred to by Zuna et al., 2009). These domains (*physical/ material well-being*, and *support from disability related services*) include items related to programs. As a result, the researcher identified these considerations as pertinent for *potential exclusion of systemic factors from a future FQOL outcome measure for a forensic setting and not to be investigated directly*.

4.2.1.1.2. Family unit factors

As presented in Appendix C, the researcher synthesized the existing FQOL framework (Chiu et al., 2013) family unit factors' related sub-themes (family characteristics and family dynamics), and linked relevant FQOL outcome measure domains and their sub-domains to respective family unit factor's sub-themes. Individual- and family-orientated domains, presented predominantly in the Beach Center's qualitative inquiry stage of outcome measurement tool development, were classified in the table according to final outcome measurement tool relevance to the individual or the family. It is acknowledged that many of the health and wellness related domains can be classified as both individual and family related constructs (i.e. social well-being). However, the researcher categorised to facilitate the meaning mapping process to assert optimal overall understanding while referencing intended use by FQOL authors. It should be noted that according to Brown & Brown (2004, p.39) some but not all individual quality of life well-being related domains core to human life may be applicable to FQOL. Final domains (Appendix C) included in the two predominant FQOL tools are numbered and emboldened for table utility.

i) Family characteristics

In the qualitative stage of Beach Center of Disability's FQOL Scale (2012) tool development many pertinent domains and related sub-domains, deemed by the researcher of this study related to family characteristics (in the FQOL framework), were identified. However, three of these domains (social well-being, emotional well-being, and health) were intended to be individually-orientated. Emotional well-being appears to have developed into a family-related domain. Financial well-being was identified as an initial domain, but was refined as physical/ material well-being, retaining its family-orientation and suitability as a family characteristic. This correlated with the FQOLS-2006's financial well-being or finances domain. In both studies, financial well-being was highlighted as a pertinent area of family life contributing to a family's FQOL.

Furthermore, while comparing final domains related to family health and well-being, both outcome measures exclude social-well-being (of individual or the family), both include financial related well-being, the Beach Center's FQOLS is the only outcome measure which includes emotional

well-being, and the FQOLS-2006 is the only outcome measure which includes health of the family. The Beach Center's outcome initially included an individually-orientated health construct, but appears to have been merged with financial well-being into physical/ material well-being (accessing professional services, access to transport, and safety in the community).

The researcher anticipated that a novel FQOL construct would take into consideration the *unique mental health and emotional well-being factors* likely to have significance due to the burden of care within the unique forensic mental context, and it was expected that *financial well-being* would have particular significance due to the lower socio-economic communities that many forensic MHCUs came from, as well as the express link between poverty and mental illness (Lund et al., 2010; World Health Organization, 2003). It was yet to be seen if *social-well-being* would feature as important in the subjective lived experiences of forensic MHCUs and their families. These health and wellness concepts appeared to categorise family-orientated characteristics well.

ii) Family dynamics

Family dynamics (FQOL framework) is described as the quality of interactions performed by the family unit (Zuna et al., 2009), or it alludes to the action, active participation, or engagement by the group of family members with one another in important areas of family life. This can be concluded from authors Samuel, Rillotta & Brown (2012) who describe FQOL as indicating a family's engagement in key areas of family life.

In consideration of the FQOL framework's family dynamics sub-theme, the Beach Centre of Disability's FQOL Scale (2012) identified three family-orientated domains during the qualitative inquiry, namely, family interaction, daily family life, and parenting. One individual orientated domain, advocacy, was included within the family unit factors' family dynamics category (Appendix C) due to the potentially interactive and shared nature of these activities or responsibilities within a family. Of these four domains, only two were included in the final Beach Centre FQOLS, namely, family interaction and parenting. Interestingly, family interaction appears to have been included as a family dynamic, and possibly thus excluding social well-being within the family as a family characteristic. According to the researcher of this study, parenting is predominantly an individual-orientated responsibility or activity by a caregiver or parent. Furthermore, it was deemed as surprising that daily family life was excluded from the final tool in light of the clear contribution that human occupation or "doing" (Wilcock, 1999; Wilcock, 2005; van Niekerk, 2005, 2014; Park et al. 2003, p.368) has on individual or family related health and well-being.

The FQOLS-2006 similarly includes a family relationships domain when compared to the Beach Center FQOLS's family interactions domain. It differs however in excluding parenting

responsibilities as a pertinent area of family life, and includes two (2) other valuable domains in light of an occupational science perspective, namely, 1) careers and planning for careers, and 2) leisure and recreation. These family interactions consist of and contribute meaningfully towards the quality of dynamics or interactions within the family. Clear alignment is seen through inclusion of these domains with an occupational perspective of "doing" where shared activity contributes towards shared well-being (Wilcock, 1999).

For the development of a novel FQOL construct with relevance to occupational therapy for a forensic mental health setting, it was a concern that family dynamics, especially, participation in *pertinent everyday family life* be included as per the FQOLS (2006). However, it would be essential to gain this insight from focus group participants to indicate whether inclusion of occupation-based activities, reflecting the dynamics within the family, was meaningful. Parenting was likely irrelevant for families of forensic MHCUs. However, other intra-familial caring, or support roles would likely include *being a custodian or caregiver* of adult family members experiencing mental illness, and receiving forensic mental health care. The role of *Family Relationships and Family Interaction* was expected by the researcher to have great importance similarly to existing/available FQOL outcome measures.

4.2.1.1.3 Family level support factors

Throughout existing literature, individual and family support factors have been highlighted as being of great importance (Boelsma et al., 2018; Chiu et al., 2013; Kyzar et al., 2012; Schippers & van Boheemen, 2009). Particularly emotional and physical support rendered by varying sources of support. This is noted in the final domains included in the two FQOL outcome measures being compared.

When categorizing respective outcome measure domains (Uys, 2003; Braun et al., 2006; Waltz et al., 2010; Mabuza et al., 2014) with the FQOL framework's Family-level support factors (Turnbull, et al., 2004, pp. 81-83; Zuna et al., 2009, p.27; Zuna et al., 2010; Hu et al., 2011; Chiu, et al., 2013, p. 367) (Appendix C), it appeared that particular supportive microsystems (defined during the qualitative phase of the Beach Centre FQOLS) were not included as final domains, but were included within other domains (such as emotional well-being and physical/ material well-being) as measurable indicators. These included family-centred support related indicators, namely, the existence of support decreasing stress, friends or others providing support, family-centred medical care, and good relationships with disability related service providers. Unfortunately, a medical model of disability may have influenced the terminology used as "medical" did not clarify whether this included professional rehabilitative services. It is unclear to the researcher of this study whether

indicators related to dental and medical care refer to families' ability to access service delivery, have monetary capacity to access service delivery, or whether service delivery is available. These elements are notably distinct. These family support related indicators do not merit to be categorized under family-level support factors during this comparative exercise. However, these indicators ought to be noted for future reference. Lastly, the predominantly individual-orientated support, namely, support from disability related services, includes reference to the relevant professionals rendering family-centred support, but is not included as a distinct family-orientated domain. Similarly, this is observed in the FQOLS-2006 as well. The meaning of family-centred support by disability related services thus appears unclear, with primary focus being placed on the individual with a disability.

In contrast to the Beach Center FQOLS, the FQOLS-2006 ID/DD (Brown et al., 2006) included predominantly family-related support-orientated domains in the final outcome measurement tool, namely, 1) community interaction, 2) support from other people, and the 3) influence of values for the family to experience FQOL. Interestingly, influence of values referred to the support received from *religious, spiritual, and cultural beliefs or affiliated community members.* The FQOL framework does not recognize a shared belief, but is rather included as an individual member factors' sub-theme, where the FQOLS - 2006 ID/DD refers to a potential collective belief or value system from which collective support is received or experienced (i.e. from a family affiliated religious or cultural support system). No other specific professional family-centred support factors were identified, where these mainly addressed individual-centred support needs. In terms of community interaction, a bidirectional relationship between community and family appears to be referenced. It is possible that through involvement in community projects or organizations, that both support received and advocacy for persons with disabilities by families could take place. Therefore, advocacy could be viewed as a collective endeavour, rather than an individual-orientated domain. In accordance to dimensions of occupation (Wilcock, 1999), the alluded sense of belonging described as connection with the community and the presence or absence of discrimination, is alignment with occupational science. The domain related to support from other people refers to the invaluable informal support received from neighbours, extended family, etc. described as a participation society which includes both individual and family (Boelsma et al., 2018). There appears to be a similarities between FQOLS-2006 domains related to community interaction and support received from other people.

It was expected that a novel FQOL operational definition for forensic MHCUs and their families would likely include unique family-level support factors due to the nature of the unique health related and demographic considerations of this population group (i.e. age, socio-economic status, geographics, etc.). It was unknown whether the three (3) domains identified in the FQOL Survey (2006) ID/DD might have relevance within the unique forensic setting, as well as what the

sources of relevant support would be meaningful or important to forensic MHCUs and their families. It is anticipated that a sense of belonging or community inclusion, support received for the family, rehabilitative support pertinent to life stage would be considered as valuable.

4.2.1.1.4. Individual Member Factors

As described previously, domains were identified by authors of the Beach Center FQOL as being either individual- or family- orientated domains (Poston et al., 2003; Turnbull et al., 2004, p. 81). Both outcome measures compared to the FQOL framework appear to lack domains which are predominantly individual-orientated in nature but rather include some indicators which have individual relevance. It appears that items related to the individual with relevance to the collective family unit is thus excluded, thus negating the value of individual responsibility and empowerment capacity of family members in achieving collective FQOL. This is limiting in acknowledging individual activity participation and involvement in pertinent areas of family life.

According to the Beach Center FQOLS, the individual-orientated domain, productivity (Poston et al., 2003; Turnbull et al., 2004, p. 82), with its related sub-domains (education, work, leisure, and personal development) was identified as valuable in the qualitative phase of tool development. However, it was excluded in the final outcome measurement tool formulation. The other individual-orientated domain, advocacy (discussed under family dynamics), also did not appear in the final outcome measure. Similarly, the FQOLS-2006 refers within certain productivity related domains as family-orientated domains (1) Careers and Planning for Careers, and 2) Leisure and Recreation) which, however, include qualitative questions pertaining to individual family member productivity. Thus, it appears to indicate that daily life activities (as identified in the qualitative inquiry of the Beach Centre FQOLS) have individual and shared family relevance. This again is in alignment with occupational science viewing occupational engagement or activity participation as being individual or shared (AOTA, 2014; Wilcock, 1999; Van Niekerk, 2005, 2014)

This marks a clear omission of individual-level occupational activities or activity participation that are relevant to the family's collective quality of life, despite definitions of FQOL and QoL being related in doing things which are important to them (Park et al. 2003, p.368)) as an individual impacting on individual and collective perceived well-being, health, and quality of life. Brown & Brown (2003) is referenced by Samuel, Rillotta, & Brown (2012) identifying individual functioning as having importance, namely, "the focus is to maintain adequate levels of functioning in areas that are important to the individual or the family for as long as possible".

The FQOL Framework identifies three particular sub-themes or characteristics of the Individual family members, namely, 1) demographics, 2) characteristics, and 3) beliefs.

Demographics were recorded both outcome measurement tools through particular demographic related sections (i.e. FQOL Survey (2006) ID/DD, "About the Family"). However, the final domain related to health of the family incorporated questions pertinent to both the collective family and the individual. Characteristics appeared to be predominantly vocational and leisure related, and beliefs were predominantly a collective experience according to the FQOL Survey (2006) ID/DD, and thus placed in Appendix C as a family dynamics related domain.

A new FQOL construct for a forensic setting using an occupational lens was likely to specify between individual versus shared productivity, and belief related concepts.

4.2.1.1.5. Individual level support factors

Individual Level Support Factors as defined in the FQOL framework (Chiu et al., 2013; Zuna, et al., 2009) were incorporated in both final validated FQOL outcome measurement tools. Similarly, disability related support (Beach Center FQOLS) and support from disability related services (FQOLS-2006) presented primarily as support received at an individual level (i.e. indicators stating "the family member with special needs..."), where support from other people (FQOLS-2006) was presented as a family-level form of support.

Irrespective of the source of support, pertinent external support is required at both individual- and family-levels of care. Informal/ formal support rendered to forensic MHCUs and their families could also be individual- or family- centred. This research study would likely identify what sources of support, and types of support were particularly required by this unique forensic mental health population group.

Both existing/available FQOL outcome measures for a developmental paediatric disability context consist of FQOL domains and measurable indicators which are directed at the family unit as a whole, the family member with a disability (Beach Center on Disability, 2012), and non-specified other family members (individuals). These measurable indicators pertaining the individuals and the collective are often merged within the same domain and not separated in terms of the FQOL framework's family level support factors, and individual level support factors.

4.2.1.2. Human occupation terminology

It was also essential for the researcher to understand the meaning of occupation optimally as it would relate to an individual and collective experience of human occupation. This ensured that the researcher applied an occupational lens while developing the interview schedule for data collection. Key characteristics discovered are presented in Table 4.1 below.

Table 4.1: Human occupation characteristics or descriptors

Occupation characteristics or descriptors			
OTPF (AOTA, 2014)	**PEO Model** (Law et al., 1996; Crouch & Alers, 2005, p.436; Krupa et al., 2009)	**Dimensions of Occupation** (Wilcock, 1999; Wilcock, 2005; Hitch & Pepin, 2021)	**Occupational Justice** (Pettican & Bryant, 2007; Blank et al., 2017; Ingeborg & Townsend, 2010; Chui et al., 2016)
• Everyday life activities (occupations) • Individual or group based • Enhanced or enabled participation • Promoting health and well-being • Participation in life • Participation in desired life situations • Engagement in occupation • Meaningful occupational performance • Meaningful to individual or social context	• Occupational performance through transaction between person, occupation, and environment. • Performance is the act of doing • Improvement of everyday performance • Valued occupations (wants and needs to do) • Meaningful occupations • Valued roles, tasks, and activities • Meaningful participation in the world • Participation in important life roles • Competency in performance ability and mastery of occupations • Internal factors match activity demands	• Synthesis of doing, being, and becoming • Healthier lifestyle • Doing • Doing well • Being • Well-being • Being oneself (true to self/ identity) • Becoming • Becoming healthy or one's potential • Sense of future • Potential • Self-actualization • Transformation • Growth and development • Individual level • Social level through shared activity • Occupational benefits • Complete physical, mental, and social well-being • Identify and realize aspirations • Satisfy needs • Cope with environment • Belonging • Healthy relationships • Social interaction • Healthy habits • Enable others as occupational beings	• Enabled opportunity • Occupational inclusion • Supported externally to be included in occupation • Do what is necessary in one's life • Balancing occupations • Ideally occupied (not under-or over- occupied) • Belonging • Structured use of time and activity • Purposeful everyday life • Meaningful everyday life • Access to meaningful and enriching opportunities • Activities promoting health and well-being • Experiencing autonomy • Making occupational choices

4.2.1.3. Final interview schedules

These final interview questions (Table 4.2) focused on drawing out the meaning attributed to the FQOL construct in a simple and concise manner by focusing on key themes - experiential activity, family concept, FQOL construct, and OT support. These theme based questions were formulated similarly in all three (3) focus group interview schedules. Semantics differed minimally with phrases differing between focus groups, such as, "your family", or "the family". Furthermore, the researcher ensured an understanding of "human occupation" and "outcome" to ensure understanding of the purpose of the study particularly with the MHCP focus group.

Table 4.2: Final Interview Schedule (forensic MHCU example):

Interview Schedule (forensic MHCU example):			
Main Question to be answered:		What is the ideal Family Quality of Life for families of forensic MHCUs, and which parts of family life are important for OTs to support to achieve the ideal family life?	**Prompts (examples)** - What would families like to achieve/ would like to change with their family life? - And what parts of family life would they like support in? - The ideal or expectations?
Interview Schedule Questions:	**Experiential activity:**	Let us imagine the ideal family of a forensic MHCU. This family is living the best life possible and their needs have been met.	- Where is this family? What are they feeling? What are they thinking? - What is the family doing? What are they planning? What did you imagine?
	Family Concept:	What is a "family"? What does the word "family" mean to you?	- How do you know if someone is part of a family? - Maybe family looks different today, what is a family to you?
		What is the ideal family?	- In terms of qualities

	FQOL Construct:	What do the words "Family Quality of Life" mean to you?	- What is the ideal family life? - What does everyday life of the ideal family look like? - The best family life possible? - Important parts of family life?
		What are good things to do together as a family?	- What are the good things that the ideal family/ your family is doing together? - What important things to do together - Better life / best life/ improved life/ changed life/ good life - While on LOA, what good things done together as a family? - Want to do, need to do, enjoy to do
		What other things makes your family life better?	-What enhances your Family Quality of Life? -Internal or external -Within the family or outside your family
	OT Practice:	You have shared some lovely ideas for me to consider while planning what goals to set for family centred Occupational Therapy. Are there any other areas of life or needs that you would like OTs to focus on for family therapy? What would you like occupational therapists to do to help your family and improve the life of your family?	-How can OTs be involved with the family? Help/ support/ improve the life of the family? - Important parts/ areas of family life - Support needs - Goals

A few relevant terms were translated into isiZulu to ensure that participants whose home language was isiZulu would have maximal understanding of questions asked in the focus groups (particularly, the forensic MHCUs and the family members' focus groups). These were used as

supportive prompts to promote understanding if required, but were not included to facilitate communication in isiZulu. For example, phrases translated by isiZulu proficient research assistant included - “Family Quality of Life” translated as “Isimo sempilo/ senhlalo ekhaya”, and “Ideal Family Life” translated as “Iimpilo yomndeni ekahle”.

4.2.2. Sub-objective 1.2 - Biographical information and Initial FQOL themes, domains, and items

Sub-Objective 1.2 concluded Objective 1 by identifying FQOL constructs that might inform the inclusion of indicators in a proposed FQOL outcome measurement tool through the implementation of focus groups with various participant focus groups and thematic analysis of qualitative data generated.

The following biographical information of focus groups’ participants, and initially identified FQOL themes, domains, and items are presented.

4.2.2.1. Focus group biographical results

Generic biographical information of participants from the three (3) focus groups, namely mental health care professionals (MHCPs), forensic mental health care users (MHCUs), and family members, are as follows (Table 4.3).

A total of fifteen (15) participants participated in the three (3) focus groups (MHCPs (n=6), MHCUs (n=7), FMs (n=2)). In recruitment of research participants, difficulty was experienced in securing sufficient family member participants. Due to sufficient participants (> 6) being secured for the other two (2) focus groups, the researcher and supervisors agreed that despite the limited family member involvement, it would be sufficient and valuable to include their voice within the study.

Of these participants, the majority (60%) were between the ages of 20 and 39 years old, probably due to the forensic MHCUs inclusion criteria being young adults (Age: 18 - 35%). There was a fairly equal gender representation of male (55.3%) and female (46.6%) focus group participants. Most male participants were from the forensic MHCU focus group (n=6). Race classification correlated with provincial population trends identified in 2011 (Statistics South Africa, 2011). All participants of the study consisted of three (3) population or race groups, namely, African (66.6%), Indian (20%), and Coloured (13.3%). The majority of participants being African correlated with a majority population or race group in KwaZulu-Natal (86.8%). Hereafter, there was participant representation of two (2) other predominant population groups in the province - Coloured (20%), and Indian (13.3%) participants. With a high representation of participants viewed as indigenous

(African sub-population), their subjective lived experience was viewed as invaluable, not representative of a Western view point, and a relevant representation of the KZN population landscape. Most participants recorded multiple home languages, however, the predominant home languages were as follows: isiZulu (66.6%), English (26.6%), and isiXhosa (6.6%).

In compliance with the Inclusion Criteria (Chapter 3.4.2.1.2; Table 3.3), only participants with acceptable English Proficiency were included in the study. Most participants in the focus groups identified themselves as having a "Very Good" (26.6%) to "Good" (53.3%) level of English Proficiency. Despite predominance of the isiZulu language as home language, this confirmed that participants were reasonably comfortable in expressing themselves in English contributing to the truthfulness of data collected.

Table 4.3: Generic biographical information of three (3) focus groups

Biographical Information (Generic)	MHCPs (n.)	MHCUs (n.)	Family Members (n.)	Total (n.)	Percentage Participants (%)
Total n.	6	7	2	15	100%
Age (years old)					
18 – 19	0	0	0	0	0
20 – 29	1	3	0	4	26.6
30 – 39	0	4	1	5	33.3
40 – 49	3	0	0	3	20
50 – 59	2	0	0	2	13.3
60 – 69	0	0	1	1	6.6
Gender					
Male	2	6	0	8	53.3
Female	4	1	2	7	46.6
Race					
African	5	4	1	10	66.6
Coloured	1	2	0	3	20
Indian	0	1	1	2	13.3
White	0	0	0	0	0
Home language					
isiZulu	4	5	1	10	66.6
isiXhosa	1	0	0	1	6.6
English	1	2	1	4	26.6
English proficiency					
Very good	2	1	1	4	26.6
Good	4	4	0	8	53.3
Average	0	2	1	3	20
Bad	0	0	0	0	0
Education level					
No schooling	0	-	0	0	0
Primary school (Gr 1 to 7)	0	2	0	2	13.3
Secondary school (Gr 8 to 10)	0	2	1	3	20
High school (Gr 11 and 12)	0	2	1	3	20
Undergraduate Studies	1	1	0	2	13.3
Postgraduate Studies	5	-	0	5	33.3

Employment Status					
Unemployed	0	5	2	7	46.6
Part-time	2	2	0	4	26.6
Full-time	4	0	0	4	26.6
Education	0	0	0	0	0
Residential district					*n=9*
uMgungundlovu	N/A	2	1	3	33.3
eThekwini	N/A	5	1	6	66.6

Regarding the highest level of education, the majority of all study participants (53.3%) only had basic education (primary, secondary, and high school education), where 46.6% had attended either undergraduate (degree or diplomas) or postgraduate studies post schooling. Only two (n=2) participants had participated in primary school education (not completed), where the rest of the participants had higher levels of education. Generally, forensic MHCUs (n=7) had only obtained a degree of basic education, family members had completed a grade between 8 - 12 (n=2), and all MHCP participants had obtained a tertiary qualification, with most having completed post-graduate studies (n=5). Only one (n=1) MHCU had completed a post schooling diploma obtaining tertiary education.

In terms of employment status, 60% of participants indicated being unemployed (only forensic MHCUs and family members), where 40% were employed (full time and part time employment).

Finally, residential data was generated from the forensic MHCUs and family member groups, to establish the ratio between participants residing in the eThekwini or the uMgungundlovu districts (66.6:33.3). A majority of participants resided within the eThekwini district (66.6%) including urban and peri-urban areas. Forensic facilities are known to experience logistical challenges with transportation to and from the facility of forensic MHCUs and their family members (McKeown et al., 2019). This study excluded those residing in rural areas, but a degree of logistical challenges was experienced by those residing in a different district to where the provincial facility was located.

Population specific biographical information of the MHCP focus group is as per Table 4.4. Participants included those practicing in both nursing (66.6%) and social work (33.3%) professions. Both these professions have extensive family work experience (Pule, 2016; McKeown et al., 2019; Davies & Hannigan, 2019) thus optimizing truthfulness of data collected. Of the MHCP participants, 83.3% had management experience thus indicating understanding of strategic and operational planning, as well as monitoring and evaluation functions. This presented an inherent insight of participants in setting and measuring of pertinent treatment outcomes.

Half of the MHCP participants (50%) had 11-15 years of mental health professional experience. However, experience within a forensic specialization ranged from 2 - 22 years of work experience. 66.6% of participants had completed tertiary studies specializing in mental health, especially, an Advanced Psychiatric Nursing Diploma. 33.3% of participants had participated in mental health research and 33.3% had participated in tool development activities to date. MHCP participants shared their rich lived experience from years of specialization. Interestingly, all participants indicated familiarity with key concepts of FQOL, and outcome measurement. Furthermore, all participants (100%) also indicated using FQOL as an outcome for practice with forensic psychiatry.

Table 4.4: MHCP Population Specific Biographical Information

Biographical Information (MHCP Population Specific)	MHCPs Total (n.)	Percentage Participants (%)
Total n.	6	100%
Profession		
Nursing	4	66.6
Social work	2	33.3
Psychology	0	0
Psychiatry	0	0
Designation		
Facility top management	2	33.3
Facility middle management	2	33.3
Facility junior management	1	16.6
No management responsibilities	1	16.6
Mental Health experience (years of service):		
3-5 years	2	33.3
6-10 years	0	0
11-15 years	3	50
>15 years	1	16.6
Professional development evidence		
Completed studies (non M or PhD) in mental health	4	66.6
Specify: Advanced psychiatric diploma	3	50
Published in field of mental health	0	0
Participation in mental health research	2	33.3
Participated in measurement tool development	2	33.3
Familiarity with key concepts		
Family Quality of Life (FQOL)	6	100
Outcome Measurement	6	100
FQOL outcome at work	6	100

MHCU Population specific demographics (Table 4.5) identify the prevalence of specific diagnosis amongst participants. A majority of participants (85.7%) had a Schizophrenia spectrum or other Psychotic disorder, as compared to a minority of participants (14.9%) who presented with a Bipolar Mood disorder and related disorders. Substance abuse and addictive disorders were not

highly recorded (28.8%). It is suspected by the researcher that substance abuse and addictive disorders were underreported or under-diagnosed due to the high prevalence within this forensic psychiatric facility (Houidi & Paruk, 2018). There was no indication of the following disorders diagnosed amongst participants, namely, 1) personality disorders, 2) trauma and stressor related disorders (PTSD), 3) other mood disorders, 4) other anxiety disorders, 5) neurodevelopmental, or 6) neurocognitive disorders.

Length of longest leave of absence (LOAs) granted varied greatly amongst the group. Overall, 57.1% of participants had differing lengths of LOA ranging from more than 3 months to 1 year. This length of stay indicates increased levels of insight into the lived experience of residing in the communities with their respective families, and thus their insight into what meaning they would attribute to FQOL.

Table 4.5: Forensic MHCU Population Specific Biographical Information

Biographical Information (MHCU Population Specific)	MHCPs Total (n.)	Percentage Participants (%)
Total n.	7	100%
Diagnosis		
Substance abuse and Addictive Disorders (abuse of alcohol, cannabis, intoxication, withdrawal, psychosis)	2	28.8
Schizophrenia spectrum and other Psychotic disorders (SAD, Delusional disorder, Psychosis unspecified etc.)	6	85.7
Bipolar mood disorder and related disorders	1	14.9
Longest Leave of Absence (LOA)		
1 year	1	14.9
> 6months – 11months	2	28.8
>3 – 6months	1	14.9
0 – 3 months	3	42.8

Lastly, the family member population specific biographical information indicated that all participants identified as forensic MHCUs custodians or primary caregivers in the community, and the participants represented family relationships of both parent and sibling.

4.2.2.2. Initial FQOL themes, domains, and items

Initial FQOL themes, domains, and items were identified through thematic analysis. The findings of all three (3) focus groups are presented separately below in Tables 4.6-4.8.

Table 4.6: Quotes, initial categories and themes of MHCP focus group

Findings: MHCP Focus Group Thematic Analysis			
Themes	**Domains**	**Sub-domains**	**Quotes**
FQOL conceptualization	Key experience	Experience of excellence Total Health Experience of Life preservation FQoL versus socio-economic experience	"It's a matter of enhancing … that which preserves life. It could be social, psychological, physical and spiritual… You turn that which preserves life into a good habit for everybody in the family, secure, exercising…" (MHCP Participant 4, Male, African, 43 years old) "It can equate to total health… I think my colleagues have touched on … spiritual, physically, emotionally,….but also I think it ….is also important to deal with issues of depravation." (MHCP Participant 5, Male, African, 51 years old) "Quality of life is when you excel in your physical, your mental and your social standing, you must excel and we tend to forget spiritual" (MHCP Participant 6, Female, Coloured, 57 years old)
	Unique characteristics	Family specific Contentment and satisfaction Meaningful participation for basic needs Unique emotional experiences Unique relational experiences Shared experience (time, activities)	"Quality of life will differ, from one family to another" (MHCP Participant 5, Male, African, 51 years old) "Even if we're playing cards with my family that's enough, even if, for you, you can afford to go to the beach with your family but me I cannot. Quality time I spend it with my family" (MHCP Participant 1, Female, African, 49 years old) "It's when the family … find joy and peace and happiness in what they are doing together, in what they believe it brings them together" (MHCP Participant 2, Female, African, 43 years old) "...is quality because you are able to meet your needs… While the … standards will differ, but there are shared basic needs...I was trying to link the issues of poverty…., while standards can differ according to choices there are things that are needs, there are things that are likes… when you exclude the likes, the basic needs become very fundamental for the quality of life" (MHCP Participant 5, Male, African, 51 years old)
	Community informed	Societal compliance Act of Living in Society	"you should be a quality family that provides quality" (MHCP Participant 5, Male, African, 51 years old)

			"so long as the standards are not in contrast to the societal norms and expectations" (MHCP Participant 4, Male, African, 43 years old) "This ideal family, can even be supportive to other families" (MHCP Participant 6, Female, Coloured, 57 years old)
	Theoretical definition	Maslow's Hierarchy of Needs (Progression) Basic needs met Non-essential desirables met	"Example of basic needs …If water is one of the basic needs, and I cannot access clean water, can I come and say "I am having a quality of life?"... for me to lack the needs of elimination and food, that is the basic, because the …minute I suffer in a poor intake, automatically my physical condition will deteriorate. So the … basics of living becomes very critical." (MHCP Participant 5, Male, African, 51 years old)
Family characteristics	Being family (formation)	Family structure Family formation Shared family norms Preserved family identity	"For where I am sitting the …family is of two dimensions. … the first one which is … understood in the conventional thinking is the one that is biological, but it's not limited to biological family, it also involve people who are within that nuclear setting. The people who can be extended family members, others would not even be related biologically to you as a family." (MHCP Participant 5, Male, African, 51 years old) "And in a manner that there is a culture when one of the family members or one of the members of that setting is not adhering, any other member can be able to pick up that "hey, you are out of the norms and values of our family"." (MHCP Participant 5, Male, African, 51 years old)
	Meaningful intra-familial family relationships/ Family roles	Trust Depth Peace Acceptance of other Commitment Cohesiveness/ unity Sense of belonging	"A sense of belonging. For me to live without someone who loves me,… I would never claim to be … having quality of life" (MHCP Participant 5, Male, African, 51 years old) "that is like we are sharing the family values that we stick together no matter what" (MHCP Participant 1, Female, African, 49 years old) "a family would be set up where there is close socialization, you know, there is a bond, unity , sense of love, you know, beliefs, set beliefs" (MHCP Participant 6, Female, Coloured, 57 years old)
	Family resilience	Strength Empowerment Resourcefulness with systemic barriers Spiritual resilience	"the winds of change will impact on the family, it shakes the cornerstone of the family and its resilience to suffering, and the I see a family that is going through this process together, trying to accept" (MHCP Participant 5, Male, African, 51 years old) "Then they go to an extent of trying to regroup, and find new ways of sustaining this quality of life of the family" (MHCP Participant 5, Male, African, 51 years old)

			"they just accepted, you know, and they are working together with the MDT I would say, they are working together, and they are getting strength" (MHCP Participant 6, Female, Coloured, 57 years old) "I am looking at them being empowered in terms of you know, obtaining that strength" (MHCP Participant 1, Female, African, 49 years old) "Their emotion changed to be a happier family knowing that there is help and there is a direction, where should they go for help, and looking at the person now um recovering and becoming part of the community again I saw a family that is like well empowered." (MHCP Participant 3, Female, African, 25 years old)
	Family emotional processing ability	Emotional progression Positive emotions Coping with negative emotions Grieving process Dealing with stigma Shared emotional experiences	"I find this family who has accepted they are past their denial stage, anger, they've accepted" (MHCP Participant 6, Female, Coloured) "this excited family that you know they've been sent from pillar to post until this child of theirs is now or this part of the family member is now here at the forensic hospital" (MHCP Participant 1, Female, African, 49 years old)
	Mental illness agency	Mental illness knowledge Systemic perspective Insight for shared responsibility Shared mental illness prevention	"this idea of a circular nature of mental illness,… in (isi)Zulu when … a family member is sick, we say "siyagula" which means… there is a problem in the system … Not like you take the person to find the person outside the system so it like the whole system is not functioning properly" (MHCP Participant 4, Male, African, 43 years old) "Towards the end when the family has accepted the sick role of one of their own, they respond in a collective response … shared responsibly to say, "it is not our brother who is sick, it is the family""... Whatever planning going forward is a collective response so they don't define themselves outside that person, they define themselves in that new sick role to say if they recover they recover as a family" (MHCP Participant 5, Male, African, 51 years old)
	Shared responsibility	Family ownership Family agency Inclusivity	"They are part of everything, they are part of the programme, like they will take the patient out like maybe to church on a Sunday, to functions" (MHCP Participant 6, Female, Coloured, 57 years old)

			"The shared responsibly begins with understanding the illness itself - what is it that we are dealing with? What could be possible causes?" (MHCP Participant 5, Male, African, 51 years old)
	Shared family goal setting	Family directionality Attitude for goal setting Collective goal setting Shared objectives Shared vision (Long term goals) Shared recovery goals Unified pursuit of goals Role performance goal setting Occupational and financial goals	"...them sitting with this person around the table… and they were like again redressing the goals of the family" (MHCP Participant 1, Female, African, 49 years old) "I am looking at them redirecting and looking at the goals and now like gaining that strength as a family to to say now we can see our goals" (MHCP Participant 1, Female, African, 49 years old) "This person is attending therapy within the hospital and this person also when he comes home for LOA. He is taking that responsibility. He is implementing what he is learning." (MHCP Participant 1, Female, African, 49 years old)
Family functionality	Fulfilled life roles	Fulfil family expectations Fulfil family responsibilities Fulfil family roles Optimal functionality	"You have this … homogenous expectation among yourself and then way of doing things, it's so homogenous, it about you." (MHCP Participant 5, Male, African, 51 years old)
	Shared family specific lifestyle	Likeness in action Likeness in family dynamics Unique family expression Being together	"You can easily make a distinction to say "Ei! That one doesn't belong to the family", because you look of that homogeneity that exist within these people" (MHCP Participant 5, Male, African, 51 years old)
Support	Community informed	Acceptance Attitude Shared responsibility	"...it (the family) looks at prevention programmes for other people that are in the same family setting or you know even within the extended family… because it doesn't also include only the immediate family, but even the extended family, even the neighbours, even people from church… Once they see the change in this one family member, the whole community's attitude will change. So I am talking about the change, if a person was maybe known as a person who was like not responding so well within the community, their behaviour is not acceptable, then if the person comes back into the community having changed everyone learns from that family, that "can you see, if you work together as a family, or if we are all working together as a community this is the outcome" (MHCP Participant 1, Female, African, 49 years old) "when you have fully…recovered, the community accepts you as a person without disability" (MHCP Participant 3, Female, African, 25 years old)
	Professional	Access expert support	"Some of the skills can only be acquired professionally - so consultation, not only by the person who is the diagnosed

	support	Attitude towards support	individual, but even the family in the form of family therapy is very critical… That's what I call 'collective response' to a family problem, because the illness is a … family illness, so when we respond we should know what we are dealing with" (MHCP Participant 5, Male, African, 51 years old) "it should not end there because as we talk about collaboration and the role of the family, the very skills same skills that are given to the patient should be extended, not to say you teach the family how what we taught the patient in totality, but how would the family assist that patient in in sustaining those skills" (MHCP Participant 5, Male, African, 51 years old)

Table 4.7: Quotes, initial categories and themes of Forensic MHCU focus group

Findings: Forensic MHCU Focus Group Thematic Analysis			
Themes	**Domains**	**Sub-domains**	**Quotes**
Family characteristics	Existing family	Specified/ identified Conservative Socially constructed	"The people who have same blood, they never let you down." (MHCU Participant 3, Male, African, Unemployed) "the brothers I'm staying with,… our colleagues, … we see each other every day so "family" - I call it like that – the people who live together whether they understand each other, whether they don't understand each other, but end of the day you are to be there and you live together" (MHCU Participant 2, Male, African, Employed) "but the staffs to me, when I see (you) I see my mum because you the one who knows when … I'm hungry, you know what time I need to eat to be right, you know what I need here like medication, you'll see when I'm not right. You know. So, to me its like a family" (MHCU Participant 2, Male, African, Employed)
	Life roles	Specific life roles Family roles Societal roles Coping with roles	"see for my family, but when I go stand on my own… make sure that my families support …, you know all those ways, and then even if eh I leave them and they not secured, any time they need me, these two my nephews, they can have me, they can talk to me, they can visit me, they can do that" (MHCU Participant 2, Male, African, Employed)
	Family relationships	Care Appreciation Respect Commitment Togetherness Interest Understanding/ insight Monitor well-being Provision	"quality of life is (having) a person who spends … all things (they) got on you, sacrifice everything they got" (MHCU Participant 1, Male, African, Unemployed) "People that care for you, that always there. They look after you, guide you…, lead you in the right direction" (MHCU Participant 5, Male, Coloured, Unemployed)
	Communication	Characteristics Context Content	"I saw understanding between each other and especially understanding towards the mental care user. I understand the situation… there is communication, there is flowing communication as to …what that person needs daily, what the family itself …expects from the mental care user…. So I think communication was the biggest thing that I saw there, that

		Self-expression Offer advise Show understanding	there was an understanding all across" (MHCU Participant 6, Male, Coloured, Employed) "Greeting each other … Say, "hi, ya, are you ok?", … tell them how what you do that certain place, and life like this, how I was at work, this is what happen, … so the work today was like this, the weather it was like this at work, the situation, the mood you know, I wasn't happy, something that went wrong … I did something wrong, something you know, something went wrong, … then just the talking, a conversation, having a conversation, … freely." (MHCU Participant 2, Male, African, Employed) "they were in… the lounge, they were having a discussion, … the discussion centred around… the mental care user - where how can that mental care user express themselves daily …I got a picture of a diary in my mind, so that (the) mental care user can write down their thoughts or whatever they wanna express in the diary …., and they can … select one family member … that will be allowed to read it…, and then that family member can express to the rest of the family." (MHCU Participant 6, Male, Coloured, Employed)
	Intra-familial support	Support expectation Shared support responsibility Practical support	"know … what …your family wants and what he needs, and at …same time at a certain time … having that willingness to help them." (MHCU Participant 2, Male, African, Employed)
	Mental health insight	Personal prevention Family prevention Illness progression insight Health management (recovery)	"Families ...need us … to be stabilising well and … know our condition and taking medication right and … psychological understanding about our mental health … and … they need to understand us" (MHCU Participant 1, Male, African, Unemployed) "they need …experience to (speak) about …you can speak to them, what you we are doing at the hospital that give us the mind - we are happy now, we are right, … we don't feel bad now" (MHCU Participant 3, Male, African, Unemployed)
Family goal setting	Shared goal setting	Collective Specific Motivation to plan Encouragement of one another Celebrate MHCU achievements	"Knowing … what they want so that you can help them… to achieve that." (MHCU Participant 2, Male, African, Employed)
	Personal goals	Personal plans Independence goals Long term goals	"It's a person that the time when you grow, he got ideas for you, and he got certain goals how you gonna grow, and when you grow up he wishes you to be something that you want to be." (MHCU Participant 1, Male, African, Unemployed)

Shared family activities	Ideal activities	Togetherness Intentional time Quality time	"we need to cherish that time… when you know you are living in the family, sometimes … don't really have that time for each other… I have time for my "bras" … out there, but my family or my mother or my sister or my brother or my father or my kids or my nephew or whoever's here … I don't have much time for them….But now if one pass away, when one passes…then that's when you realise how much that person meant to you, then" (MHCU Participant 2, Male, African, Employed) "(family quality of life is) spending quality time with your family, time to spend with your family" (MHCU Participant 4, Male, Indian, Unemployed)
	Routine shared activities	Communication Shared mealtime Family excursions/ leisure Shared household responsibilities	"…knowledge (of) what they need, every day we just … the morning we talk together, what they need or what they ate at the morning." (MHCU Participant 3, Male, African, Unemployed) "keep on gathering together" (MHCU Participant 1, Male, African, Unemployed) "eating together you know like lunch time or dinner or sometimes going out as a family … just family… just a family going out, maybe to the beach or watch birds or like something like that, or play you know some sports" (MHCU Participant 2, Male, African, Employed) "eat together, clean the house together" (MHCU Participant 5, Male, Coloured, Unemployed)
	Life improvement activities (shared)	Job search Financial management Therapeutic activity involvement	"helping our friends to find …and part of our family to find… jobs so that … they come back… in the house … because sometimes you struggling too much and our families they all struggling. Ya its bad and I won't lie. So finding jobs ourselves and our family members at school." (MHCU Participant 2, Male, African, Employed) "you get torn because you got nothing, always putting the money in it, putting money in the pocket, take it out the money, next thing you got no money. You start asking for …two rands, then … it's no good. You working, … most of the money goes (to) your budget and the money you have to buy a skuif (cigarette) you know so that's not right…" (MHCU Participant 2, Male, African, Employed)
	LOA Activities	Family centred Meaningful activities Acts of service Household activities	"before I came back from my one month leave, my aunt wanted her roof painted at her house, so us as a family, my little cousin we were actually on top of the roof painting the roof, but then this was for her party her birthday party which was coming up …on the last Sunday before I came back, so like doing that and then being able to celebrate at a birthday and being able to look back at the house and say we did that, so that was nice" (MHCU Participant 6, Male, Coloured,

		Shared celebrations	Employed)
	Community responsibility	Awareness of community Personal impact	"That you helpful to the community" (MHCU Participant 1, Male, African, Unemployed)
Sources of Support	OT Program Support (MHCU directed)	Job search Employment preparation skills Formal education/ training Dealing with societal exclusion Skills development	"it's almost like you're discriminated against almost in every job if you have a previous mental history or whatever, they cut off" (MHCU Participant 6, Male, Coloured, Employed) "…like a place where we can work …jobs out there because it's difficult, especially if they (the companies) know our sicknesses." (MHCU Participant 4, Male, Indian, Unemployed) "specific education to mental care users, like…you won't be paying for the education but they will train you in something that would allow you to then go out and get a job…Like …have the department of education on board or the department of health come up with a plan for situations like those" (MHCU Participant 6, Male, Coloured, Employed) "helping us with skills to do our own things because when we work we don't have…high … mental issues, we have this problem not like the discrimination, … we can't do something that would give us more money, like higher rate of money, so … maybe skills if we do our own things or give us the strength that we can do our own, we can do …our own businesses and because we are afraid to start, so and then making ourselves … useful, earning our own money, making," (MHCU Participant 2, Male, African, Employed) "maybe give us skills and push our skills" (MHCU Participant 1, Male, African, Unemployed)
	OT Program Support (Family directed)	Information sharing Mental health insight	"my family is setting goals about … and participating in therapies and ….understanding something." (MHCU Participant 1, Male, African, Unemployed)
	Access personal support	Identified support needs Environmental needs	"When you are stressed out you need to go … somewhere else to release the stress" (MHCU Participant 2, Male, African, Employed)

Table 4.8: Quotes, initial categories and themes of family member focus group

Findings: Family Member Focus Group Thematic Analysis			
Themes	**Domains**	**Sub-domains**	**Quotes**
FQOL Conceptualization	Presence of Family Support Structure	Relationship identified Relationship characteristics	"That's what I consider family. Not blood sister and blood brother. People are there for you when until you are rock bottom, not financially" (Family Member Participant 1, Female, Indian, Unemployed) "No families……only the friends, people from outside, not from the inside" (Family Member Participant 2, Female, African, Unemployed) "(family means) unity, when you'll stand together, when y'all help each other" (Family Member Participant 1, Female, Indian, Unemployed)
	Family Support Attitude	Availability Insight	"I was the only one in the family who supporting him…only one who used to come here alone…no family used to come with me" (Family Member Participant 2, Female, African, Unemployed) "No one is supporting us, only the outsiders only, the families, no… They won't involve themselves. They (say) …, "we not going to intervene", … and it is very painful" (Family Member Participant 2, Female, African, Unemployed) "Family is someone supposed to be there for you every time whether it's bad or good… Supposed to be there with you, they supposed to support you" (Family Member Participant 2, Female, African, Unemployed) "they don't understand …they just saying drugs… (but) It's the sickness. There's so much sickness out there now. There's just so much of sickness." (Family Member Participant 1, Female, Indian, Unemployed)
	Family Support Skills	Relational skills Crisis management skills Emotional support skills	"If I'm having a problem with (family member with mental illness), and I need my brother to be there with me, or if I need my sister to be there with me, to go to places with these people… Sometimes you have to go to court, sometimes you need to go there, you're going yourself and that's a kind of support." (Family Member Participant 1, Female, Indian, Unemployed)
	Shared	Shared meaningful activities	"Family that give each other advise… Advice is … important" (Family Member Participant 1, Female, Indian,

	Meaningful Family Life	Shared decision making activities	Unemployed) "When they are down (experiencing) setbacks during the recovery phase they will share that momentum to say …"how do we pick up ourselves and advance to the desired outcomes"" (Family Member Participant 2, Female, African, Unemployed)
Sources of Support	Peer Family Support (PFS)	Establish Available PFS Support PFS Value Affirmed Solidarity/ Togetherness Psycho-education	"I feel like I have got another family" (Family Member Participant 2, Female, African, Unemployed) "I learnt a lot, … because sometimes … I felt like … I'm alone, I'm the only person you know who need to deal with … this situation, so I've learnt a lot" (Family Member Participant 1, Female, Indian, Unemployed) "I thought I was the only one who was facing that problem." (Family Member Participant 2, Female, African, Unemployed) "I speak to parents about their children, I say that, … cause I didn't listen to mine at the time but now I know… now I (tell) them to look deeper…there's a reason why he's taking drugs. Dig deeper and check what's happening to him" (Family Member Participant 1, Female, Indian, Unemployed) "And … amongst ourselves, some parents won't listen, we need to have one of y'all there, and how are we all going to get hold of each other, because I may take her today, we can exchange numbers, but the others are not here, so it's up to y'all to pull them, bring them, insist that they come" (Family Member Participant 1, Female, Indian, Unemployed)
	Community Support	Community Attitude of Support (Empathy) Community Attitude of Support (Availability)	"...that (was) the challenge I was facing … outside in the township … but now at least … they starting to be friendly" (Family Member Participant 2, Female, African, Unemployed) "…starting to support him and support me" (Family Member Participant 2, Female, African, Unemployed) "Support. That what we need most. Not only from family, from everybody." (Family Member Participant 1, Female, Indian, Unemployed)
	Spiritual Support	Spiritual Knowledge Spiritual Activities	"Learn to take a deep breathe (breathes in and out), what you can't solve, "God, this is yours! You can solve, solve it."" (Family Member Participant 1, Female, Indian, Unemployed)

		Spiritual Resilience	"There is only one person that helps me, hey? I know he's there, definitely. Yes, you just talk to your Maker, he'll help you, believe me." (Family Member Participant 1, Female, Indian, Unemployed)
	Professional Support	MHCU Support Family Support Primary Guardian/ Caregiver Support	"At least that person must be taken away and be assessed… because they got all these things going on into their heads… he didn't tell me, he told his friends, "I'm seeing snakes I am seeing this and this happening". They say "Hey, take a pull here"… when I eventually realised that he needed help I never got help straight away" (Family Member Participant 1, Female, Indian, Unemployed) "Maybe … if y'all educate them, if even outside they must do the same, … they must they must be hands on" (Family Member Participant 2, Female, African, Unemployed) "Don't just feed them medication and leave them one side. From time to time, maybe once in 6 months, they speak to somebody that's gonna remind them how to carry on with us too, how to cope with your parents, how to cope with your guardian, oh how to be a family also." (Family Member Participant 1, Female, Indian, Unemployed) "Its … just include us from time to time where we all sit together with these children so you not talking to them and then talking to us, we all talk together, once or twice a month, that will work fine." (Family Member Participant 1, Female, Indian, Unemployed) "Once or twice a year, y'all include us and have a meeting with all of us" (Family Member Participant 1, Female, Indian, Unemployed) "I just keep on wandering what have they been doing inside the hospital. … what were their duties … that they were doing inside here?" (Family Member Participant 2, Female, African, Unemployed) "The next three weeks, I was panicking, and I phoned here and they said I must bring him in. I must bring *him* in….When he is in that mood, you don't tell him about the doctor, because then he wants to kill you for sure. I even phoned the cops, I never got help" (Family Member Participant 1, Female, Indian, Unemployed)
Unique Support Needs (MHCU)	Emotional Resilience	Emotional maturity Overcoming stigma	"Tell them, "Let go of your mother's apron!"" (Family Member Participant 1, Female, Indian, Unemployed)

		Coping with functional loss	"He don't want to go there. I don't know …maybe he don't want to face the (past)…The stigma, yes …he doesn't want to go there!" (Family Member Participant 2, Female, African, Unemployed) "I spoke to him after he came here and he got help. I said "(MHCU), let go of it. You not gonna get it back my boy. You won't. Cause your medication and you can't leave your medication, you see. Try and refocus your energy somewhere else."" (Family Member Participant 1, Female, Indian, Unemployed)
	Socialisation Ability	Accessing supportive social environment Conversation Peer group insight Close friendships Social connectivity activities	"They've become stronger, they actually made friends in (home town), and it's one of the good things I think I did was change the environment, because here they are being judged. People knew how they behaved, and their bad ways, here they made new friends without anybody thinking "you're like this, you're like that you're like that." (Family Member Participant 1, Female, Indian, Unemployed) "sometimes when I want we sit and chat, we sit and eat together. And then we drive around together." (Family Member Participant 2, Female, African, Unemployed) "They know now their sickness, they don't hide anything. Yes. … I told the friends, please don't give him drugs. Please don't give him liquor, because this is a problem. So the friends know them" (Family Member Participant 1, Female, Indian, Unemployed)
	Independence Skills	Personal goal setting Responsibility Community survival skills Self-advocacy skills	"When are you getting me a wife? You know we muslims, we propose. I'm not getting your wife without a job? I'm going to support YOUR wife? Hell no! I'm supporting you, I'm not supporting..." (Family Member Participant 1, Female, Indian, Unemployed) "They must take responsibility for their own lives" (Family Member Participant 1, Female, Indian, Unemployed) "my panic is now if I were to drop dead tomorrow, I think my children would lose it completely… If I drop dead tomorrow what happens to y'all. Ya, because I want to teach you things, so if I leave y'all in this house, how are you gonna pay rent, lights, this that that that, because y'all don't want to do anything. Learn to do things" (Family Member Participant 1, Female, Indian, Unemployed)

	Balanced Lifestyle	Active participation Meaningfulness Health management Vocational development	"We used to take a walk to him to the park like … to just come out of that like that zone" (Family Member Participant 2, Female, African, Unemployed) "They must do something that will keep their minds fresh." (Family Member Participant 2, Female, African, Unemployed) "I say, "you know why you are having problem with side effects? It's cause you're sitting, just sleeping!"" (Family Member Participant 1, Female, Indian, Unemployed)
Unique Support Needs (Primary Caregiver)	Support Role Attitude	Availability Commitment	"I try and spend as much time as we can together." (Family Member Participant 1, Female, Indian, Unemployed)
	Support Role Skills	Mental illness insight Coping with MHCU emotions Behavioural management Goal setting	"Sometimes … he is short tempered, very short tempered, sometimes …I'm even afraid to come closer when I see his face like, his anger face" (Family Member Participant 2, Female, African, Unemployed) "He tells me stories that are shocking too. Sometimes when he's gone, I cry and say "My child went through so much, bad things I didn't know about." You know when he was hit by people, and where he hit people, and they open up and tell him the stories, like, become so sad" (Family Member Participant 1, Female, Indian, Unemployed)
	Personal Coping Strategies	Self –care Emotional awareness Anxiety management Stress management	"I felt SO abandoned, I felt here they should have sent someone to pick him up at the time. But they didn't. Now I'm telling you it went very bad." (Family Member Participant 1, Female, Indian, Unemployed) "The community will like will be like posing questions "Ah why… did (she) let his brother to come out….I was like I'm the bad person like who's… supporting the wrong guy when he's done the wrong thing" (Family Member Participant 2, Female, African, Unemployed) "You mustn't worry about pain. Actually I … focus on what I want to do…I don't worry about the person that don't give me help, honestly, because you be wasting your time…Focus on where you going with your brother and people that are willing to help you." (Family Member Participant 1, Female, Indian, Unemployed) "we need support on how to deal with the … patients" (Family Member Participant 1, Female, Indian, Unemployed)

4.3. Objective 2: To operationalize the FQOL constructs and their measurable indicators through a process of deductive reasoning towards a synthesized diagram.

This section presents the findings of the final novel FQOL construct in terms of themes, sub-themes, domains, and sub-domains. Both novel FQOL themes 1) Family unit factors, and 2) Individual member factors are presented in depth and supported by relevant quotes. The formulation of proposed behavioural indicators (Addendum B) is also presented. A final list of operational definitions of FQOL constructs (Addendum A) are presented, are compiled in a final meaning map (Appendix D) for discussion in Chapter 5.2.2.1., and finally synthesized into a diagram (Figure 4.5).

4.3.1. Novel FQOL construct findings

To finalize operational definitions of a novel FQOL construct and its concrete concepts for occupational therapy outcome measurement, the items were sorted and categorized and further operationally defined into a list of themes, sub-themes, domains, sub-domains, and their related indicators. This took place through a process of deductive reasoning, data reduction, and synthesis. Deductive analysis took place in consideration of the FQOL framework, FQOL outcome measures meaning maps, and occupation based framework, models, and existing concepts. These constructs would provide relevant comparison during deductive data analysis of the novel FQOL construct. This preliminary meaning map assisted in organizing the meaning of the concept into a pragmatic framework ensuring that key dimensions of meaning were identified were taken into account in outcome measurement (Waltz et al., 2010; Uys, 2003). This was in accordance with the recommended formulation of operational definitions entailing “both active conceptualization and (the) analysis of existing conceptualisations'' (Waltz et al., 2010).

Herewith, a sample of the charts or affinity diagrams (Figure 4.1) from a charting or affinity mapping process (American Society for Quality; Tague, 2005; Mabuza et al., 2014) used to organize, synthesize, and consolidate all constructs and items generated from the three (3) focus groups into similar groupings or themes. This was the stage of naming, defining, categorizing, and sorting (Uys, 2003) with consideration of existing FQOL operational definitions (Appendix C).

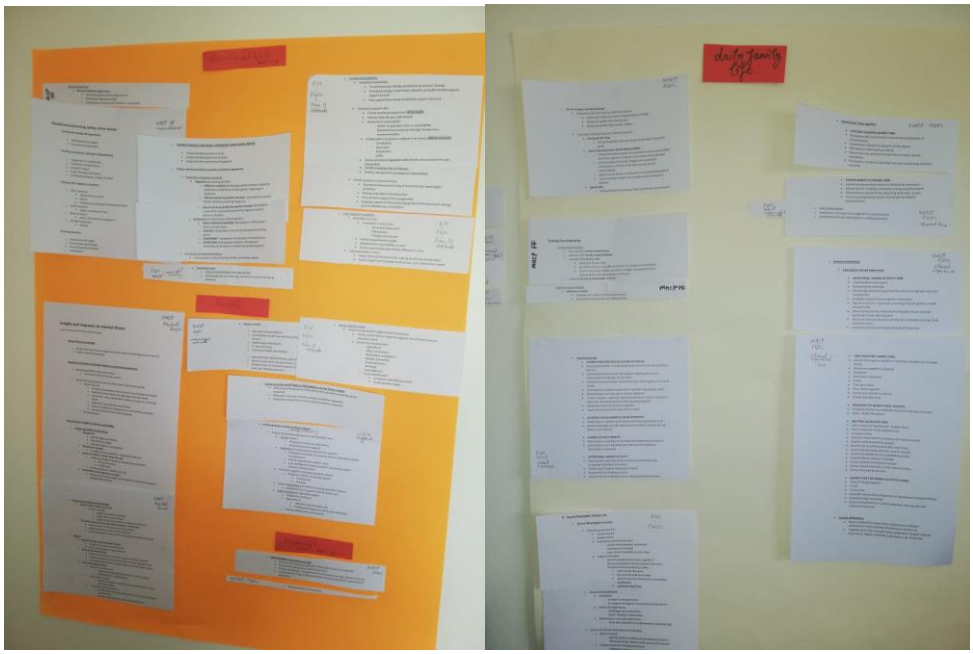

Figure 4.1: Affinity diagrams of themes/ sub-themes of emotional well-being, health, financial well-being, and daily family life

This study extrapolated which constructs, concepts, and variables from the FQOL framework (Zuna et al., 2010), could be included in a new outcome measure for family-centred occupational therapy practice in a forensic psychiatric setting in KwaZulu-Natal, South Africa. Herewith, the final findings of the novel FQOL construct which included two (2) themes, namely, 1) Family unit factors, and 2) Individual member factors.

This newly developed FQOL construct excludes the systemic factors sub-theme from the FQOL Framework (Chiu et al. 2013; Hu et al., 2011), and merges family level and individual level support factors with the family unit factors, and individual member factors, respectively. It was thus framed to optimally establish clear occupational therapy outcomes measuring and directing forensic mental health service delivery.

Systemic factors within this South African forensic psychiatric setting (including societal values, policies, systems, and programs) were identified by participants as areas of importance.

> ***"I know that … that it's not located in your office as OT per se, it's an institutional matter, it's an inter-departmental matter. But this is one of the elements we need to advance to say "Are we relevant to the demands of the society" (MHCP Participant 5, Male, African, 51 years old)***

These systemic factor concerns are predominantly the responsibility of government entities and service providers, and require redress in order to ensure positive FQOL outcomes (Chiu et al., 2013) amongst forensic MHCUs and their families. Pertinent constructs of family empowerment, advocacy, and shared responsibility were though identified as new FQOL domains ensuring that families are empowered in addressing problematic systemic factors. Since systemic factors do not depend primarily on empowered families, and due to this theme not clearly being represented in other FQOL tools for user friendliness, it was thus excluded from the operationalized definition of FQOL for forensic MHCUs and their families. However, participants did reflect on the impact of societal values and norms on their respective lives.

4.3.1.1. Family unit factors

The first theme, family unit factors, consists of three (3) sub-themes, namely, 1) family characteristics, 2) family dynamics, and 3) external family unit support. The Family Quality of Life framework (Chiu et al., 2013) has highlighted the family unit factors variable as the descriptions or interactions amongst individuals identifying as belonging to the family unit, referring to family characteristics and family dynamics sub-themes. The external family unit support sub-theme was incorporated as a description of a state of support experienced by the family as a unit.

The three (3) family unit factors sub-themes thus include a total of fourteen (14) domains, and their related sub-domains (See Figures 4.2 - 4.4).

4.3.1.1.1 Family characteristics

"Family Characteristics" consists of various dimensions of collective well-being within the family.

Social scientists have outlined the "Dimensions of wellness" as – physical, intellectual, emotional, social, spiritual, vocational, financial, and environmental (Stoewen, 2017), as compared to occupational scientists acknowledging key areas of life as physical, mental, social, emotional, and spiritual life (Wilcock, 2006; Pettican & Bryant, 2007).

The newly identified FQOL domains were in alignment with both social science (Stoewen, 2017) and occupational science (Wilcock, 2006; Pettican & Bryant, 2007) disciplines through inclusion of the following domains: 1) social well-being, 2) emotional well-being, 3) mental health, 4) physical health, 5) spiritual well-being, and 6) financial well-being.

As a result, it included uniquely occupationally defined "Family Characteristics" domains, especially the "Financial Well-being" domain.

These six (6) domains and their related sub-domains (Figure 4.2) are thus pertinent to the well-being of the collective family of a forensic MHCU using an occupational lens.

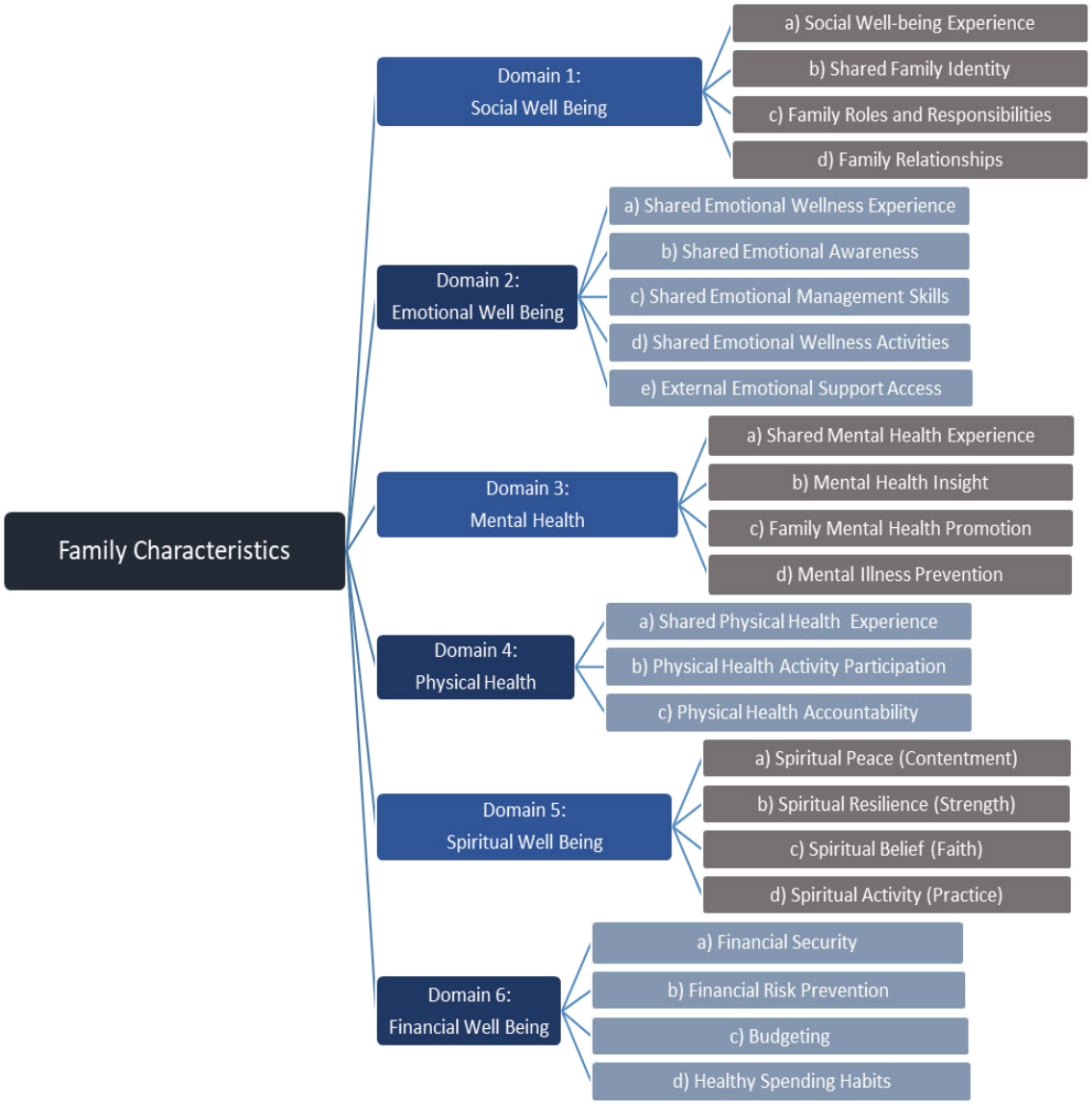

Figure 4.2: Sub-theme 1: Family characteristics domains and sub-domains

Domain 1: Social Well-being is an essential outcome for recovery amongst forensic MHCUs and their families. *Social Well-being* has been defined as "The family experiences social wellness (connection) together while they express their unique family identity, fulfil meaningful family roles and responsibilities, and mature in healthy family relationships." This definition is supported by Stoewen (2017) reporting the "Social Dimension of Wellness" which focuses on the maintenance of healthy friendships, relationships, and community based interactions. As per Figure 4.2, sub-

domains within the *Social Well-being* domain for a forensic psychiatric context included a) Social Well-being Experience, b) Shared Family Identity, c) Family Roles and Responsibilities, and d) Family Relationships.

a) This *Social Well-being Experience* concept includes the existence and unique structure of the family of a forensic MHCU. Participants indicated that families of forensic MHCUs could be conventional/ biological or progressive/ inclusive of various individuals in nature. It was even described as including non-biological individuals, such as MHCPs, peer MHCUs, or extended family members. Uniquely, this study highlights an ideal family structure as being dynamic, conventionally inclusive, progressively inclusive, and actively inclusive of the MHCU family member (irrespective of his or her mental illness).

b) The *Shared Family Identity* sub-domain included a number of indicators that describe the homogenous nature of the unique family unit. Homogeneity can be seen in shared values; shared expectations; shared family norms; compliance by all to these unique norms, values and standards; shared behaviours; as well as having a shared family identity.

c) *Family Roles and Responsibilities* indicators included the clarification of family roles of biological/ non biological family members, as well as adapted roles due to change. This construct further included specific family roles, such as being a caregiver/ guardian, breadwinner (income generation), or by fulfilling clearly defined societal roles. These unique roles could be held by any family member including the mental health care user.

d) Family Relationships was identified as the final sub-domain of social well-being. All three (3) focus groups explored various features of meaningful family relationships with unique characteristics being identified as valued relationships, unity, family belonging, deep and developing relationships, trust relationships, acceptance, interested relationships, understanding relationships, affirming relationships, available relationships, caring relationships, and peaceful relationships. The characteristics of meaningful *Family Relationships* were earnestly expressed by participants. For example:

> ***"A sense of belonging. For me to live without someone who loves me,… I would never claim to be … having quality of life" (MHCP Participant 5, Male, African, 51 years old)***

The qualities of these ideal relationships for forensic MHCUs and their families described the integrity of healthy relational connections between family members, and furthermore, the nature of this social environment within which all could flourish as individuals.

Domain 2: Emotional Well-being was identified as an accepted outcome for recovery, relapse prevention and community integration within occupational therapy intervention amongst forensic MHCUs and their families. This outcome is supported by international occupational therapy treatment programs (Fitzgerald, et al., 2012) which aim to reduce high levels of Emotional Expression (EE) in the family, thus promoting an accepting and supportive home environment. The unique emotional toll that families of forensic MHCUs experience and their desired outcomes for *Emotional Well-being* was clearly highlighted in the findings of this research study through inquiry into the "ideal family" of forensic MHCUs, and "the family that experiences family quality of life". Sub-domains within the FQOL domain of *Emotional Well-being* for a forensic psychiatric context included a) shared emotional well-being experience, b) shared emotional awareness, c) shared emotional management skills, d) shared emotional wellness activities, and e) external emotional support access.

a) The *Shared Emotional Well-being Experience* sub-domain indicators included the family having their basic emotional needs being met, having an optimal emotional wellness experience, as well as sharing in one another's positive and negative emotions as an expectation of being part of the same family. In this way normal life experiences of celebrations and grieving can be shared with one another. Sharing these experiences is identified as the norm.

b) The *Shared Emotional Awareness* sub-domain incorporates both personal emotional self-awareness and awareness of the emotional state of the group (i.e. the family). *Social Emotional Awareness* speaks of the necessity of collective identification of shared emotions, the family progressing from experiencing predominantly negative emotions to more positive emotions, with the ultimate purpose of experiencing acceptance of that which is beyond the family's control. As mentioned earlier, Fitzgerald et al. (2012) discussed common emotions experienced amongst family members being feelings of shame, fear, guilt, and isolation. Appendix B reflected these findings by identifying the following negative-positive emotion pairs: denial/ grief versus acceptance; hopelessness versus hopefulness; depression versus happiness; anxiety versus relief; and shame/ anger/ resentment versus peace/ contentment. The positive emotions were the desired emotional outcomes for families. This desire for acceptance rather than grief highlights the desire of participants (predominantly family members) for the family to successfully gain meaning/sense (Holland & Neimeyer, 2010) or progress through the Kübler-Ross's stages of grief (Kübler-Ross & Kessler, 2005) – from denial and shock to acceptance as reflected as follows:

"I find this family who has accepted they are past their denial stage, anger, they've accepted" (MHCP Participant 6, Female, Coloured)

Despite the grieving process being less linear than this in practice due to complex bereavement and traumatic experiences (McKeown et al., 2019; Mayosi et al., 2009), the newly developed subdomain of *Social Emotional Awareness* highlights the desired end result for emotional experience (acceptance, happiness, hope, peace, contentment, and relief).

c) The *Shared Emotional Management Skills* sub-domain included indicators relevant to occupational therapy rehabilitation outcomes for forensic MHCUs, as addressed in individual and group therapy. These indicators for occupational therapy family work include emotional perceptiveness of others, emotional availability, sharing personal emotions, and collective processing of emotion; emotional regulation skills, pacifying or de-escalation skills; conflict handling skills; anxiety management skills and adaptability; and skills to offer others encouragement to increase their motivation levels. According to participants in this study, these coping skills enable the family members to achieve *Emotional Well-being*.

d) The *Shared Emotional Wellness Activities* sub-domain included shared activity participation promoting happiness, enjoyment, increased levels of motivation, and the prevention of negative emotions. Particular *Shared Emotional Wellness Activities* are unique to each family as long as it promotes increased shared motivation levels and positive emotional experience.

e) The *External Emotional Support Access* sub-domain for a forensic psychiatric context included particular indicators, such as, an awareness of available emotional support services, acceptance of support for family emotional needs, satisfaction and gratitude for professional services received, and an experience of emotional support in particular situations - namely, day-to day life, and during an emergency or hospitalization. The ongoing nature of emotional support for family members on a day to day basis, or at critical moments (pre-admission, Department of Justice processes, and during hospitalization) was highlighted in this FQOL study for forensic MHCUs and their family members. Timely emotional support is thus essential for a supportive stress reducing home environments ensuring “involved families”, “supportive family involvement”, and “community reintegration” (McKeown et al., 2019). However, the family’s ability to access emotional support is invaluable.

Domain 3: Mental Health is a primary treatment outcome for MHCUs and their family members within a forensic psychiatric context, as expressed by all participant groups. Community reintegration, meaningful role acquisition, and prevention of “revolving door” readmissions depends on the value adding mental health services rendered to admitted forensic MHCUs, and as out-patients. However, few facilities or forensic rehabilitation teams prioritize the *mental health* support needs of family members of forensic MHCUs (McKeown et al., 2019). Alongside emotional well-

being, this FQOL study highlighted *mental health* support needs of family members of forensic MHCUs as an essential treatment outcome when delivering family work corroborating the World Health Organization's (2003) mental health plan. Sub-domains within the FQOL domain of *mental health* for a forensic psychiatric context included a) shared mental health experience, b) mental health insight, c) family mental health promotion, and d) mental illness prevention.

a) The *Shared Mental Health Experience* sub-domain for a forensic psychiatric context included particular indicators related to excellent or total family mental health experience, as well as the family having basic mental health care needs met; the family actively participating in mental health promoting activities, and healthy habits preserving existing mental health; family members promoting a sense of belonging for those within the family experiencing mental illness; and family members sharing in the experience of mental illness in terms of "shared sick role", "shared recovery", and "shared functional impact". It is evident that the mental illness impacting on the forensic MHCU family member, or any other family member, impacts on the collective family; and a shared experience of mental health is an indication of improved FQOL.

Participants reflected on *Shared Mental Health Experience,* highlighting the systemic nature, shared identity, and shared impact of mental illness in a family as they set collective mental health goals for a *Shared Mental Health Experience*, as follows:

> ***"this idea of a circular nature of mental illness,… in (isi)Zulu when … a family member is sick, we say "siyagula" which means… there is a problem in the system … Not like you take the person to find the person outside the system so it like the whole system is not functioning properly" (MHCP Participant 4, Male, African, 43 years old)***

> ***"Towards the end when the family has accepted the sick role of one of their own, they respond in a collective response, … shared responsibly to say, "it is not our brother who is sick, it is the family""... "Whatever planning going forward is a collective response so they don't define themselves outside that person, they define themselves in that new sick role to say if they recover they recover as a family" (MHCP Participant 5, Male, African, 51 years old)***

b) The *Mental Health Insight* sub-domain for a forensic psychiatric context included particular indicators related to mental health knowledge (extensive knowledge, value of early

identification of mental illness, ability to collect information, and the accessibility of mental health information for psychoeducation), mental illness insight (in terms of diagnostics, external/ systemic causes, internal/ personal causes, and available treatment), mental illness impact (in terms of behavioural, functional, social, and forensic impacts), and acceptance of mental illness (condition and support needs).

Participants reflected on *Mental Health Insight*, highlighting the need for immediate and extended family members to have suitable Mental Health Insight (i.e. family psychodynamics/ etiology, etc.), to ensure acceptance, and to prevent dismissive or judgemental attitudes towards those experiencing mental illness, as follows:

> ***"Families ...need us … to be stabilising well and … know our condition and taking medication right and … psychological understanding about our mental health … and … they need to understand us" (MHCU Participant 1, Male, African, Unemployed)***

c) The *Family Mental Health Promotion* sub-domain for a forensic psychiatric context included particular indicators related to a family's collective response to stigma (forensic MHCU-directed and family-directed stigma), and the family's shared mental health responsibility for intra-familial mental health promotion (providing an environment of respite, protection against negative environmental factors, valuing of support of one another's mental health, being open to specialist forensic support, and acceptance of shared responsibility for family member(s) with mental illness).

d) The *Mental Illness Prevention* sub-domain for a forensic psychiatric context included particular indicators pertaining to a priority of a motivated family to focus on mental illness prevention, obtain knowledge on mental illness prevention, participation in an environmental audit for mental illness prevention, developed family member mental illness prevention skills, referral of at risk family members, and active prevention of trans-generational mental illness in the younger generation.

Domain 4: Physical Health has been identified as a necessary outcome for forensic MHCUs and their families for FQOL's Family Characteristics. The *Physical Health* domain was defined as "The family experiences physical health through active participation in physical health, wellness, and fitness activities or habits together". This definition is supported by Stoewen (2017) referring to the "Physical Dimension of Wellness" which focuses on the care of one's physical body for current and future physical health. Sub-domains within the FQOL domain of *Physical Health* for a forensic

psychiatric context included a) shared physical health experience, b) physical health activity participation, and c) physical health accountability.

a) The *Shared Physical Health Experience* sub-domain for a forensic psychiatric context included indicators related to family members having an experience of excellent physical health, of total/ complete physical health, as well as having basic physical health needs met. A participant's reflection on *Shared Physical Health Experience* is as follows:

> ***"Example of basic needs …If water is one of the basic needs, and I cannot access clean water, can I come and say "I am having a quality of life?"... for me to lack the needs of elimination and food, that is the basic, because the …minute I suffer in a poor intake, automatically my physical condition will deteriorate. So the … basics of living becomes very critical." (MHCP Participant 5, Male, African, 51 years old)***

b) The *Physical Health Activity Participation* sub-domain for a forensic psychiatric context included identified indicators of active participation by family members in activities promoting physical health, healthy habits preserving physical health, shared health and fitness activities, sleep hygiene activities, and relaxation activities.

c) The *Physical Health Accountability* sub-domain for a forensic psychiatric context included indicators relating to family members showing frequent interest in one another's personal health, and monitoring of one another's physical health activities offering family based accountability.

Domain 5: Spiritual Well-being has been identified by participant groups (especially MHCP and Family Members) as a valued treatment outcome for forensic MHCUs and their family members as an area of life that promotes resilience for FQOL. Thus, *Spiritual Well-being* was included as a unique domain for FQOL when compared with previously developed FQOL outcome measures. Despite this, FQOL literature indicated that families of persons with disabilities experienced greater emotional well-being and overall FQOL from spiritual beliefs and practices (Chiu et al., 2013). *Spiritual Well-being* appears to have been identified as a domain providing meaning and purpose during enjoyable or challenging life experiences, irrespective of the specific worldview or religion practiced. Interestingly, this study of FQOL has highlighted a need for *Spiritual Well-being* to be considered as a cultural, contextual, and familial outcome for occupational therapy intervention. This applies to a need highlighted in Pule (2016) for family members of forensic MHCUs to access cultural and spiritual support or practice. Furthermore, this correlates with a "Spiritual Dimension of Wellness" (Stoewen, 2017) which focuses on the ability to establish "purpose, value, and meaning"

in life irrespective of participation in organized religion, and one's participation in activities consistent with one's beliefs and values. Sub-domains within the FQOL domain of *Spiritual Well-being* for a forensic psychiatric context included a) spiritual peace (contentment), b) spiritual resilience (strength), c) spiritual belief (faith), and d) spiritual activity (practice).

a) The *Spiritual Peace (Contentment)* sub-domain for a forensic psychiatric context included particular indicators related to the shared experiences of spiritual well-being, and spiritual fulfilment, while being expressed through practices that enhance these spiritual experiences and the exploration of spirituality, and experiencing having their spiritual needs met.

b) The *Spiritual Resilience (Strength)* sub-domain for a forensic psychiatric context included particular indicators related to the family experiencing strength, support, hope, unity, and a sense of reliance on God (or higher power) of their understanding through spiritual engagement. Participants reflected on reliance on God, as well as the unity experienced through shared spiritual practice for *Spiritual Resilience (Strength)* as follows:

> ***"Learn to take a deep breathe (breathes in and out), what you can't solve, "God, this is yours! You can solve, solve it."" (Family Member Participant 1, Female, Indian, Unemployed)***

c) The *Spiritual Belief (Faith)* sub-domain for a forensic psychiatric context included particular indicators related to knowledge of personal and shared spiritual beliefs, valuing these spiritual beliefs, and upholding spiritual belief above materialistic success. Spirituality or Spiritual Beliefs is a known cultural/ contextual factor which may require family-based intervention when service providers address support needs within beneficiaries' ecosystems. (Maynard, 2003, p. 2)

d) The *Spiritual Activity (Practice)* sub-domain for a forensic psychiatric context included particular indicators related to active participation in spiritual activities which were: shared, habitual, frequent/ time-bound, unique expressions of self, preserving of spirituality, and included activities - but not limited to - prayer, meditation, and spiritual training. This is corroborated by studies related to occupational therapy (Fenech, 2008) which have highlighted the benefits of leisure participation where exploration or enhancement of one's spirituality appears to take place by means of active participation in these spiritual activities or practices.

Domain 6: Financial Well-being has been identified by participant groups as a FQOL outcome for forensic MHCUs and their family members. In a socio-economic context where poverty is increasingly prevalent, and the prominent link between poverty and mental illness is well researched (Lund et al., 2010), the FQOL domain of *Financial Well-being* is invaluable. A positive

correlation exists between family income and its impact on the family's FQOL (Chiu et al., 2013). *Financial Well-being* appears to include content from previous studies (Summers et al., 2005; Beach Center on Disability, 2012; Beach Center on Disability, 2015; Poston et al., 2003; Brown et al., 2006; Brown et al. 2015, p.10), expounding further on how a family can optimally manage their finances as a whole, and financial well-being with its related activities as a form of empowerment. Sub-domains of *financial well-being* for a forensic psychiatric context included a) financial security, b) financial risk prevention, c) budgeting, and d) healthy spending habits.

a) The *Financial Security* sub-domain for a forensic psychiatric context included particular indicators related to basic financial needs being met, basic essential living conditions being achieved, having family members who are gainfully employed, family finances being stable, the family experiencing satisfaction with their financial status, and the family participating in activities that promote and enhance the family's financial well-being. A participant reflected on the frustration related to financial insecurity:

> ***"you get torn because you got nothing, always putting the money in it, putting money in the pocket, take it out the money, next thing you got no money. You start asking for …two rands, then … it's no good. You working, … most of the money goes (to) your budget and the money you have to buy a skuif (cigarette) you know so that's not right…" (MHCU Participant 2, Male, African, Employed)***

b) The *Financial Risk Prevention* sub-domain for a forensic psychiatric context included particular indicators related to the family coping with societal exclusion due to financial limitations, having insight into financial traps/ negative consequences of poor decisions, and the family actively preventing financial instability caused by certain attitudes and activities.

c) The *Budgeting* sub-domain for a forensic psychiatric context included particular indicators, such as, the family planning for financial security; being knowledgeable of financial/ money management; accessing expert opinions related to finance; training of the younger family members in money management; sharing responsibility to support one another financially; planning the family budget (prioritized financial responsibilities, prioritized essential expenses for basic living expenses, non-essential expenses for pleasure, personal/ shared interests, and gift giving); budgeting according to income; and thoughtful budgeting for personal expenses, family expenses, essential expenses, and non-essential expenses.

d) The *Healthy Spending Habits* sub-domain for a forensic psychiatric context included particular indicators, such as, the family complying with budget when spending; the family enjoying responsible spending of their money; and the family presenting with healthy spending habits in terms of i) meeting financial responsibilities, ii) spending on essential items/ activities, iii) Spending on non-essential items/ activities, iv) meeting personal/ shared interests, and v) gift giving. Where unhealthy spending habits could be characterised by compulsive spending, poor impulse control, poor planning of spending, and immediate gratification, the healthy spending habits construct defines what healthy/ constructive spending habits are for forensic MHCUs and their family members.

4.3.1.1.2. Family dynamics

The *Family Dynamics* sub-theme, as part of the FQOL Framework (Chiu et al., 2013; Zuna et al., 2010; Summers et al., 2005; Beach Center on Disability, 2012; Beach Center on Disability, 2015; Poston et al., 2003; Brown et al., 2006; Brown et al. 2015, p.10), was included in the FQOL construct for forensic MHCUs and their families. This is the second sub-theme to have been included under the *Family Unit Factors* FQOL theme. Chiu et al (2013) defined *Family Dynamics* as "aspects of interactions and ongoing relationships among two or more family members" relating to findings of the qualitative inquiry into this forensic psychiatric setting, which defined *Family Dynamics* as "The family unit engages meaningfully with one another through shared time, shared activity participation, shared empowerment related activities, meaningful intra-familial communication, and by providing internal support to one another within the family." This study's definition is more comprehensive, and uses an appropriate occupational lens to the *Family Dynamics* concept.

The domains identified within the *Family Dynamics* construct include a) shared family time, b) shared activity participation, c) family interaction, d) family empowerment, and e) internal family support. The identified sub-domains in this FQOL study provide clear and extensive outcomes for meaningful shared community based family life or family "doing".

These five (5) domains and their related sub-domains (Figure 4.3) are thus clear areas of life characterised by shared activity in family life.

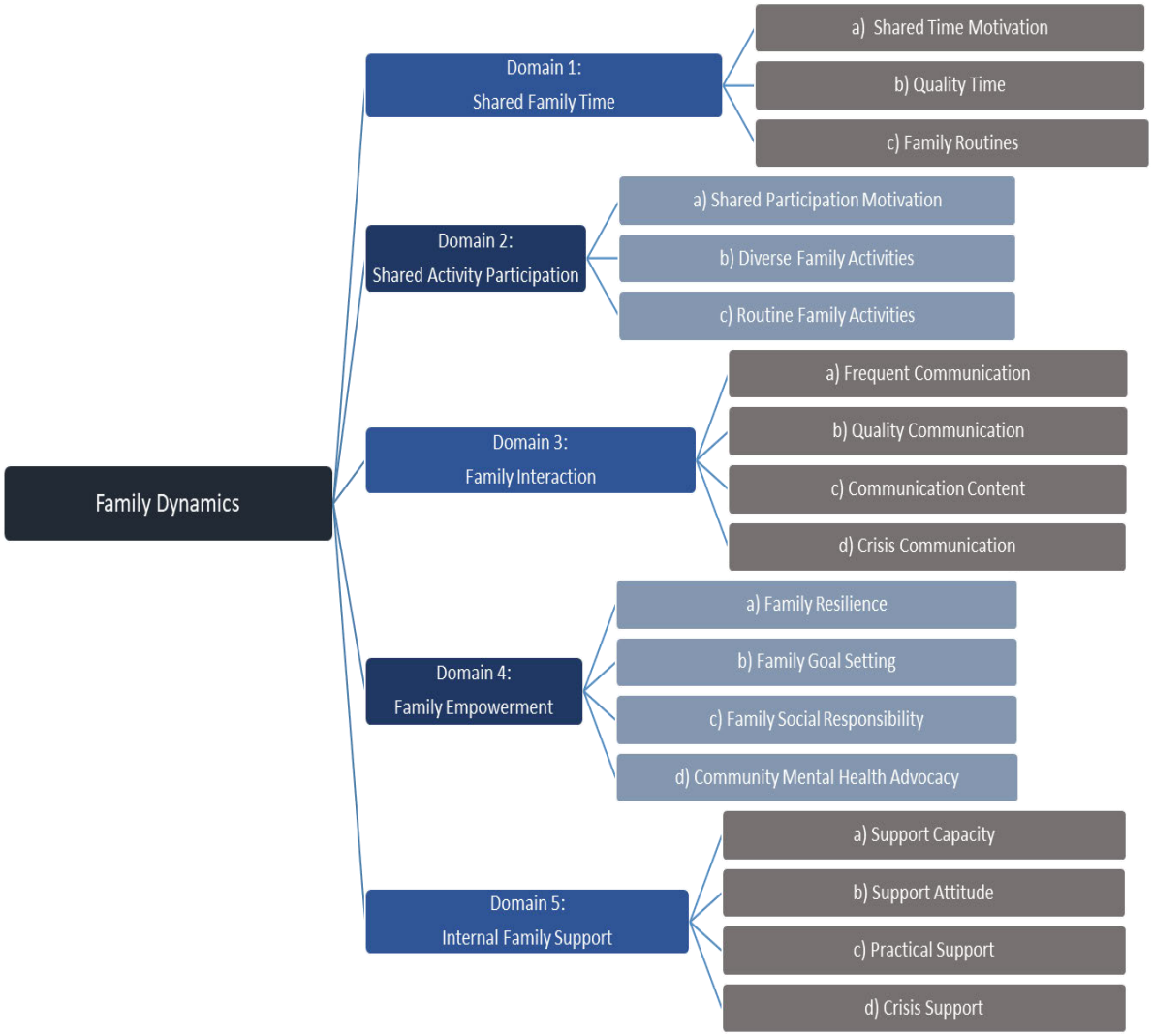

Figure 4.3: Sub-theme 2: Family dynamics domains and sub-domains

Domain 1: Shared Family Time was identified as a FQOL occupational therapy treatment outcome for forensic MHCUs and their family members. This category of outcomes based intervention has usually been addressed at an individual level of practice through goal setting and planning. In occupational therapy mental health outcome research, authors Kirsh et al (2019) described *time-use interventions* as a manner in which activities engaged in during the day could be organized in such a way that it "enable(d) well-being, satisfaction, and a sense of occupational balance." (p. 132) Furthermore, a meaningful time use outcome being established alongside a family centred treatment approach, would prevent the occupational deprivation within the family as they experience balance in their shared time use (Pettican & Bryant, 2007, p.143). The inclusion of *Shared Family Time* as a domain directing occupational therapy practice is thus apt for achieving optimal FQOL within a forensic psychiatric setting. *Shared Family Time* has been set as a *Family Dynamic* as the family would be required to engage with one another to establish mutually beneficial goals on how to spend time meaningfully and experience occupational balance as a family unit. Sub-domains

within *Shared Family Time* for a forensic psychiatric context included a) shared time motivation, b) quality time, c) and family routines.

a) The *Shared Time Motivation* sub-domain for a forensic psychiatric context included particular indicators related to the family being motivated to share time with one another, viewing shared time as an essential need, being committed to sharing time, and showing appreciation of shared family time with one another. Participants reflected on *shared time motivation* as follows:

> ***"we need to cherish that time… when you know you are living in the family, sometimes … don't really have that time for each other… I have time for my "bras" … out there, but my family or my mother or my sister or my brother or my father or my kids or my nephew or whoever's here … I don't have much time for them….But now if one pass away, when one passes…then that's when you realise how much that person meant to you, then" (MHCU Participant 2, Male, African, Employed)***

> ***"(family quality of life is) spending quality time with your family, time to spend with your family" (MHCU Participant 4, Male, Indian, Unemployed)***

b) The *Quality Time* sub-domain for a forensic psychiatric context included particular indicators describing the desired quality of time shared, namely, intentionality to share time, focused time shared, enjoyable time shared, experiencing relational intimacy and family unity through time shared, and expression of their unique shared family identity through time shared.

c) The *Family Routines* sub-domain directing occupational therapy practice in a forensic psychiatric context included relevant indicators - the family planning or scheduling shared time, and logistics thereof with one another; the family sharing frequent time with one another; the family being available to share time with one another, and thus share sufficient time with one another; family routines and boundaries expectations are known pertaining to daily, weekly, and monthly routines; compliance to family boundaries; and having scheduled family meeting times optimizing family communication.

Domain 2: Shared Activity Participation was identified as the following occupation based *Family Dynamics* outcome for forensic MHCUs and their family members. *Shared Activity Participation* is deemed as a valuable outcome for FQOL as it considers the skilled participation in frequent meaningful family activities. The meaningfulness of shared activity within the forensic

MHCU's family is validated by Wilcock (1999) who stated that "doing, being and becoming affects health … on a social level through shared activity". Sub-domains of *shared activity participation* for a forensic psychiatric context included a) shared participation motivation, b) diverse family activities, and c) routine family activities.

a) The *Shared Participation Motivation* sub-domain for a forensic psychiatric context included particular indicators describing family motivation to participate together in activities, to participate in activities of mutual interest, in activities that meet individual family member's personal needs, and in mutually encouraging activities with one another.

b) The *Diverse Family Activities* sub-domain for a forensic psychiatric context included particular indicators describing the family participating in activities with one another, such varied activities, life events, challenging or celebratory life experiences, and collaborative family projects). A participant reflected on the *Diverse Family Activities* desired outcome for FQOL as follows:

> ***"before I came back from my one month leave, my aunt wanted her roof painted at her house, so us as a family, my little cousin we were actually on top of the roof painting the roof, but then this was for her party her birthday party which was coming up …on the last Sunday before I came back, so like doing that and then being able to celebrate at a birthday and being able to look back at the house and say we did that, so that was nice" (MHCU Participant 6, Male, Coloured, Employed)***

c) The *Routine Family Activities* sub-domain directing occupational therapy practice in a forensic psychiatric context included relevant indicators relating to activities which were spiritual, wellness related, social, leisure related, and activities related to household responsibilities.

Domain 3: Family Interaction was identified as an occupation based *Family Dynamics* for forensic MHCUs and their family members. The importance of this domain is validated by occupational therapist Wilcock (1999) who identified action within occupation ("doing") as making provision for "the mechanism for social interaction, and societal development and growth, forming the foundation stone of community, local and national identity" (p.4). Sub-domains within *Family Interaction* for a forensic psychiatric context included a) frequent communication, b) quality communication, c) communication content, and d) crisis communication.

a) The *Frequent Communication* sub-domain for a forensic psychiatric context included particular indicators describing regular communication, inclusive of MHCU family members, at set meeting times, and frequently making inquiries into one another's well-being and unique needs.

b) The *Quality Communication* sub-domain for a forensic psychiatric context included particular indicators describing communication in terms of taking place in a safe environment; being valued by one another; being clear, open and honest, focused, bidirectional, inclusive of active listening, being enjoyable, being meaningful, and including mediation/ representation when required; and beneficial to one other (in terms of relational strength, developed caring relationships, and having comprehensive understanding of one another). Narrative data reflected on the *Quality Communication* desired outcome as follows:

> ***"I saw understanding between each other and especially understanding towards the mental care user. I understand the situation… there is communication, there is flowing communication as to …what that person needs daily, what the family itself …expects from the mental care user…. So I think communication was the biggest thing that I saw there, that there was an understanding all across" (MHCU Participant 6, Male, Coloured, Employed)***

c) The *Communication Content* sub-domain for a forensic psychiatric context included particular indicators describing meaningful content in family communication, namely, words/ phrases showing interest in one another, words of encouragement, good humour, words of love and care, words affirming belonging of one another, words of advice/ guidance, disclosure of personal thoughts, disclosure of personal feelings, disclosure of personal and shared expectations, reflection of past and present lived experience, and forensic MHCU directed content (especially in terms of encouragement, guidance, and personal disclosure).

d) The *Crisis Communication Ability* sub-domain for a forensic psychiatric context included particular indicators pertaining to the ability to communicate a need for help in a crisis, maintaining communication with forensic MHCU during hospitalization, and communication of interest in one another during forensic hospitalization (perceived as a family crisis).

Domain 4: Family Empowerment was identified as an original occupation based *Family Dynamics* outcome for forensic MHCUs and their family members. The inclusion of *Family Empowerment* as a domain directing occupational therapy practice aligns with the gold standard of psycho-social rehabilitation (Muller & Flisher, 2006; Lund et al., 2010; Kramers-Olen, 2014; McKeown et al., 2019) which ensures MHCUs and their families/ communities are enabled and empowered in a relevant manner ensuring community reintegration of MHCUs. This is therefore befitting for appraising FQOL within a forensic psychiatric setting. Extensive sub-domains *Family*

Empowerment for a forensic psychiatric context included a) family resilience, b) family goal setting, c) family social responsibility, and d) community mental health advocacy.

a) The *Family Resilience* sub-domain for a forensic psychiatric context included particular indicators related to family strength, family responsibility/ ownership, and family adaptability. Where the enabling of personal control and responsibility has been identified as a key individual-level occupational outcome (Kupla et al, 2009), collective control and responsibility is of great importance.

b) The *Family Goal Setting* sub-domain for a forensic psychiatric context included particular indicators related to the family having a shared family vision, shared ideal family objectives, shared realistic family objectives, shared family goal setting, adaptability in terms of goal setting, and shared MHCU family member goal setting. A participant reflected on the *family goal setting* desired outcome for FQOL as follows:

"...them sitting with this person around the table… and they were like again redressing the goals of the family" (MHCP Participant 1, Female, African, 49 years old)

c) The *Family Social Responsibility* sub-domain for a forensic psychiatric context included particular indicators related to the family's compliance with community values, the family's social consciousness, the family's response to deprivation factors, and the family acting as change agents within the community.

d) The *Community Mental Health Advocacy* sub-domain for a forensic psychiatric context included particular indicators related to the family participating in community directed mental health advocacy, mental illness prevention, public mental health education activities, education of other peer families, and participating in support groups; while inspiring attitudinal change in the community, and sharing testimonies of success of successful community and family collaboration efforts as well as successful community reintegration of the forensic MHCU family member. Narrative data pertaining to the *community mental health advocacy* sub-domain was as follows:

"...it (the family) looks at prevention programmes for other people that are in the same family setting or you know even within the extended family… because it doesn't also include only the immediate family, but even the extended family, even the neighbours, even people from church… Once they see the change in this one family member, the

whole community's attitude will change. So I am talking about the change, if a person was maybe known as a person who was like not responding so well within the community, their behaviour is not acceptable, then if the person comes back into the community having changed everyone learns from that family, that "can you see, if you work together as a family, or if we are all working together as a community this is the outcome" (MHCP Participant 1, Female, African, 49 years old)

Domain 5: Internal Family Support was identified as a unique occupation based outcome in a forensic psychiatric setting. *Internal family support* was included within the *family unit factors* theme due to the rationale that this domain pertains to the manner in which family members engage with one another in actively supporting one another. This domain was of particular importance to family members. Sub-domains within the FQOL domain of i*nternal family support* for a forensic psychiatric context included a) support capacity, b) support attitude, c) practical support, and d) crisis support.

a) The *Support Capacity* sub-domain for a forensic psychiatric context included particular indicators related to the family acting as an existing support system for individual family members, reciprocity of support within the family, family members sharing the support role pertaining to the forensic MHCU, receiving valuable support from the forensic MHCU family member, and family members being available to share in life's positive or negative experience together, as well as in emotionally difficult times.

b) The *Support Attitude* sub-domain for a forensic psychiatric context included particular indicators describing the expectation of family members to accept and share responsibility to support one another in a manner which is intentional, and committed; as well as sharing motivation to offer compassionate support towards the forensic MHCU family member.

Narrative data pertaining to the *support attitude* sub-domain was as follows:

"No one is supporting us, only the outsiders only, the families no… They won't involve themselves. They (say) …, "we not going to intervene", … and it is very painful" (Family Member Participant 2, Female, African, Unemployed)

c) The *Practical Support* sub-domain for a forensic psychiatric context included particular indicators describing the manner in which the family offers practical help and support to one

another (ongoing, unconditional, unlimited, and generous), the aspects of practical support offered by family members to one another (achieving personal and collective goals, meeting one another's personal needs, accommodating one another's functional loss, and showing care through acts of service), the family offering a safe place of respite to one another, and the family offering practical support to the forensic MHCU family member during their hospitalization.

d) The *Crisis Support* sub-domain for a forensic psychiatric context included significant indicators related to the manner in which the family collectively responds to crisis situations (accepting of responsibility to support the forensic MHCU family member practically, available to support one another, insight into one another's treatment support needs, as well quick and responsive help offered to one another), as well as family relationships being affirmed during a crisis, and a particular commitment to providing unconditional support during the MHCU family member's admission/ hospitalization. A participant reflected on the *crisis support* desired outcome as follows:

> ***"If I'm having a problem with (family member with mental illness), and I need my brother to be there with me, or if I need my sister to be there with me, to go to places with these people… Sometimes you have to go to court, sometimes you need to go there, you're going yourself and that's a kind of support." (Family Member Participant 1, Female, Indian, Unemployed)***

4.3.1.1.3. External family unit support

The *External Family Unit Support* sub-theme was included in the FQOL outcome for forensic MHCUs and their families. This is the third sub-theme to have been included under the *Family Unit Factors* theme. *External family unit support* can be viewed as a strategic outcome in addressing occupational deprivation of the family (Pettican & Bryant, 2007) as various types of support would assist families "to overcome the discrimination and stigma that people with mental health problems experience, in order to facilitate their having equal access to mainstream employment, education and leisure opportunities" (p.143).

The domains identified within the *external family unit support* construct include a) professional family centred support, b) peer family support, and c) community support.

These three (3) domains and their related sub-domains (Figure 4.4) include pertinent sources of support, the nature, and content of support directed at a family-level. These forms of support are validated by Pule (2016, pp.62-65) who recommended the following support of South African forensic MHCUs and their families, namely, psycho-education, support groups/ self-help

groups with those with shared lived experience, family therapy addressing EE, family-centred involvement in decision making and appropriate referrals, and family directed or community directed public mental health.

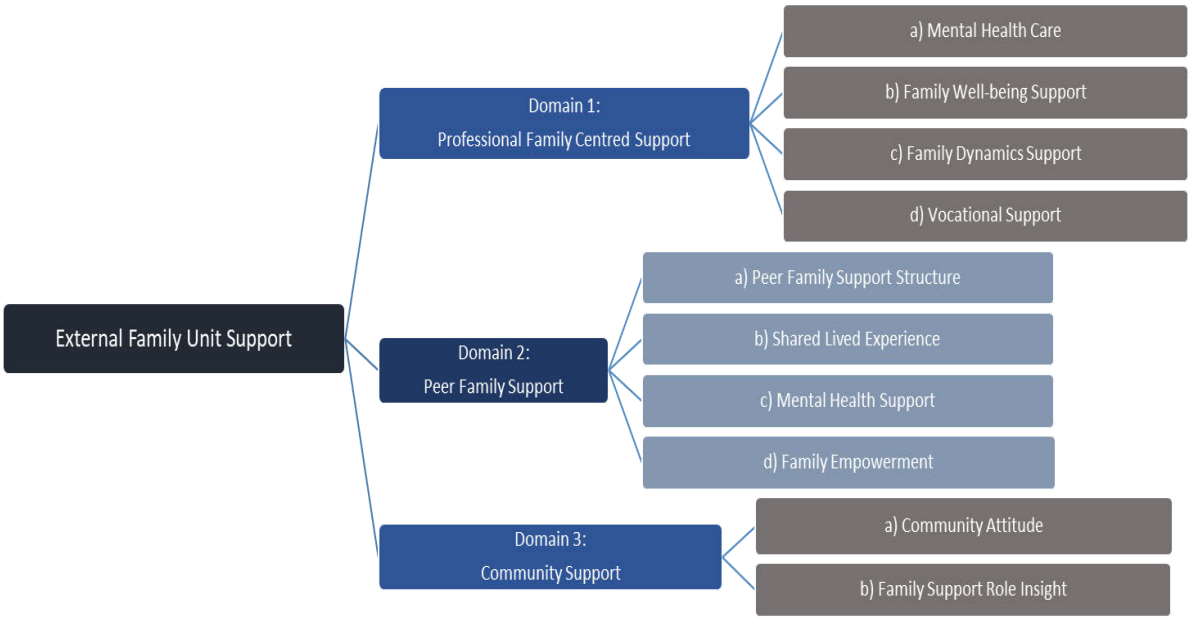

Figure 4.4: Sub-theme 3: External family unit support domains and sub-domains

Domain 1: Professional Family Centred Support was identified as an occupational therapy treatment outcome for forensic MHCUs and their family members.

Sub-domains within the FQOL domain of *professional family centred support* for a forensic psychiatric context included a) mental health care, b) family well-being support, c) family dynamics support, and d) vocational support.

a) The *Mental Health Care* sub-domain for a forensic psychiatric context included significant indicators related to professional support access for the family, crisis support, psycho-education, community based and facility based mental health care support. Indicators describe relevant and particular areas of focus as a means in which MHCP could evaluate the effectiveness of family centred service delivery rendered. Authors Kirsh et al. (2019) reinforced a focus on psycho-educational OT intervention within mental health as psycho-educational approaches were viewed as being significantly more beneficial than conventional OT practices (p.150). This validates the desired outcome for expert mental health care as expressed by study participants. A participant reflected on *mental health care as follows:*

"Some of the skills can only be acquired professionally - so consultation, not only by the person who is the diagnosed individual, but even the family in the form of family therapy is very critical… That's what I call 'collective response' to a family problem, because the illness is a … family illness, so when we respond we should know what we are dealing with" (MHCP Participant 5, Male, African, 51 years old)

b) The *Family Well-being Support* sub-domain for a forensic psychiatric context included indicators measuring family gaining support for family emotional well-being, and support for healthy family relationships as highlighted in the family characteristics sub-theme.

c) The *Family Dynamics Support* sub-domain for a forensic psychiatric context included indicators related to the receipt of family-centred professional support promoting a healthy family lifestyle, facilitating quality family interaction, enabling family goal setting, strengthening the family's support role skills, and empowering family members for social responsibility within their community. Narrative data pertaining to the *Family Dynamics Support* domain included:

"it should not end there because as we talk about collaboration and the role of the family, the very skills same skills that are given to the patient should be extended, not to say you teach the family how what we taught the patient in totality, but how would the family assist that patient in in sustaining those skills" (MHCP Participant 5, Male, African, 51 years old)

d) The *Vocational Support* sub-domain for a forensic psychiatric context included indicators related to the family receiving professional or occupational therapy support for the development of forensic MHCU vocational goals (job search knowledge, job search skills, and knowledge pertaining to the access of education or training opportunities).

Domain 2: Peer Family Support was identified as an invaluable FQoL occupational therapy treatment outcome for forensic MHCUs and their family members. This domain was predominantly identified by family members as pertinent to an experience of FQOL.

Sub-domains within the FQOL domain of *peer family support* for a forensic psychiatric context included a) peer family support structure, b) shared lived experience, c) mental health support, and d) family empowerment.

a) The *Peer Family Support Structure* sub-domain for a forensic psychiatric context included indicators related to family members belonging to a peer family support structure while valuing this support, having insight into the beneficial nature of this support, and being motivated to participate in peer family support groups. Participants reflected emphatically on the benefit of a *peer family support structure*. For example:

"I feel like I have got another family" (Family Member Participant 2, Female, African, Unemployed)

b) The *Shared Lived Experience* sub-domain for a forensic psychiatric context included indicators pertaining to the family members connecting with other families through shared lived experience which is reflected on together (whether challenges or success stories).

c) The *Mental Health Support* sub-domain for a forensic psychiatric context expounded on the unique *mental health support* value of *peer family support* through family members accessing forensic mental health advice within this support group setting, as well as family members receiving psycho-education, counsel on accessibility of emergency or crisis support services, and advise on handling principles in managing difficult behaviour of family members, such as the forensic MHCU family member, within this *peer family support structure*.

d) The *Family Empowerment* sub-domain for a forensic psychiatric context included indicators pertaining to the Peer Family Group Structure providing family members with insight into effective family communication skills, collaborative problem solving, the family support role towards the forensic MHCU family member, and how to access external support and develop help seeking skills. Participants highlighted the need for a peer family support structure to provide particular support towards empowerment of the family members in this unique context which is not usually understood by broader community members.

Domain 3: Community Support was identified as a key FQOL occupational therapy treatment outcome for forensic MHCUs and their family members. Participants indicated that various community structures, groups, and individuals were essential in rendering meaningful support for community reintegration, and health and wellness of the family, to be achieved.

Sub-domains within the FQOL domain of *community support* for a forensic psychiatric context included a) community attitude, and b) family support role insight. The researcher perceives *community support* as having potential to be extended beyond these two (2) sub-domains towards other forms of critical community support. For example, *community support* could include sub-domains such as crisis support, and practical support by the community. However, for the purposes

of this study, sub-domains included were in accordance with data collated in participant focus groups regarding their valuable life experience.

a) The *Community Attitude* sub-domain for a forensic psychiatric context included indicators related to the experience of receiving empathic support from various family members, and supported individuals. Community members included, but were not limited to, friends, neighbours, as well as the broader community. For example:

"...that (was) the challenge I was facing … outside in the township … but now at least … they starting to be friendly" (Family Member Participant 2, Female, African, Unemployed)

b) The *Family Support Role Insight* sub-domain for a forensic psychiatric context predominantly related to the family receiving community support pertaining to the family's unique support role of the forensic MHCU family member.

4.3.1.2. Individual member factors

The second FQOL theme, Individual Member Factors, consisted of four (4) sub-themes, namely, 1) well-being characteristics, 2) productivity characteristics, 3) empowerment characteristics, and 4) individual member support factors. These sub-themes, however, were defined differently for forensic MHCU individual family members, and custodian or caregiver individual family members. Furthermore, the caregiver individual member factors excluded productivity characteristics, but consisted of the three (3) remaining aforementioned sub-themes. These sub-themes and domains differ in definition somewhat from the Zuna et al.'s (2009) description of individual family member (the descriptive aspects of members in the family in terms of specific demographics, behaviours and beliefs).

Individual Member Factors sub-themes, domains, and sub-domains do not consist of a comprehensive description of individual Quality of Life (QoL), or occupational performance. It, however, highlights key aspects of individual "doing, being, belonging, and becoming" (Wilcock, 1999, Hitch & Pepin, 2021) which are pertinent to the individual, and have been identified to be essential for a collective FQOL experience.

Pertinent indicators within individual member factors domains are presented in Appendix B (FQOL construct domains, sub-domains, and indicators).

4.3.1.2.1. Well-being characteristics

Well-being Characteristics is described in this study as "The individual family member (forensic MHCU or caregiver) experiences unique health and wellness in pertinent areas of life."

Table 4.9 compares the well-being characteristics sub-theme domains of forensic MHCU family members and caregiver family members.

Table 4.9: Comparison of well-being characteristics domains of Forensic MHCU and Caregivers

	MHCU Individual Member Factors		**Caregiver Individual Member Factors**	
Sub-themes	***Domains***	***Sub-domains***	***Domains***	***Sub-domains***
Sub-theme 1: Well-Being Characteristics	Social Well-being	Inclusive Social Network Healthy Relationship Goals Healthy Attachment Communication Skills		
	Emotional Well-Being	Emotional Maturity Adaptability	Emotional Well-being	Personal Emotional Regulation Stress Management Skills Emotional Resilience
	Mental Health	Personal Mental Health Insight Personal Mental Health Management Overcoming Stigma		
	Financial Well-being	Financial Growth Financial Security		

Domain 1: Social Well-being is a forensic MHCU (only) domain with its related sub-domains including a) inclusive social network, b) healthy relationship goals, c) healthy attachment, and d) communication skills.

Domain 2: Emotional Well-being is a forensic MHCU and caregiver related domain. Sub-domains differ however, with the forensic MHCU related sub-domains including a) emotional maturity, and b) adaptability; and the caregiver related sub-domains including a) personal emotional regulation, b) stress management skills, and c) emotional resilience. Caregiver emotional well-being health outcomes are validated by Pule (2016, p. 61) who highlighted the emotional toll of fulfilling caregiver roles with forensic MHCUs in South Africa due to chronic stress, unpredictability, and deteriorating overall health.

Domain 3: Mental Health is a forensic MHCU (only) domain with its related sub-domains including a) personal mental health insight, b) personal mental health management, and c) overcoming stigma.

Domain 4: Financial Well-being is a forensic MHCU (only) related domain with its related sub-domains including a) financial growth, and b) financial security.

Thus unique conceptual definitions for individual member specific "well-being characteristics" sub-theme have been developed (Appendix A).

4.3.1.2.2. Productivity characteristics

The productivity characteristics sub-theme is described in this study as "The forensic MHCU family member optimally engages in meaningful community functioning, work, and leisure activities of daily living."

Table 4.10 presents the productivity characteristics sub-theme's domains of forensic MHCU family members. Evidently, no productivity characteristics are recorded for the caregiver family members.

Domain 1: Community living is a forensic MHCU (only) related domain with its related sub-domains including a) healthy lifestyle, and b) community survival skills.

Domain 2: Work is a forensic MHCU (only) related domain with its related sub-domains including a) work perspective, b) work ability insight, c) work habits, and d) work agency.

Domain 3: Leisure Participation is a forensic MHCU (only) related domain with its related sub-domains including a) leisure structure, and b) active leisure participation.

Table 4.10: Productivity characteristics domains of forensic MHCUs

	MHCU Individual Member Factors		Caregiver Individual Member Factors	
Sub-themes	***Domains***	***Sub-domains***	***Domains***	***Sub-domains***
Sub-theme 2: Productivity Characteristics	Community Living	Healthy Lifestyle Community Survival Skills		
	Work	Work Perspective Work Ability Insight Work Habits Work Agency		
	Leisure Participation	Leisure Structure Active Leisure Participation		

4.3.1.2.3. Empowerment Characteristics

Empowerment characteristics is described in this study as "The individual family member (forensic MHCU or caregiver) practices self-agency in various life roles and activities." This is a valuable family centred outcome as standards of mental health services in South Africa affirms the empowerment of MHCUs, caregivers, and family members as choice and self-agency is facilitated (Muller & Flisher, 2006).

Table 4.11 compares the empowerment Characteristics sub-theme's domains of Forensic MHCU family members and Caregivers.

Table 4.11: Comparison of empowerment characteristics domains of forensic MHCUs and caregivers

	MHCU Individual Member Factors		Caregiver Individual Member Factors	
Sub-themes	***Domains***	***Sub-domains***	***Domains***	***Sub-domains***
Sub-theme 3: Empowerment Characteristics	Self-Agency	Independence Goal Setting Support Access (Beneficiary) Support Offer (Support Role)	Support Role	Support Role Attitude Support Role Skills Support Role Capacity

Domain 1: Self Agency is a forensic MHCU (only) domain with its related sub-domains including a) independence, b) goal setting, c) support access (beneficiary), and d) support offer (support role).

Domain 2: Support Role is a caregiver (only) domain with its related sub-domains including a) support role attitude, b) support role skills, and c) support role capacity.

Thus, unique conceptual definitions for individual member specific empowerment characteristics sub-theme have been developed (Appendix A).

4.3.1.2.4. Individual member support factors

Individual member support factors is described in this study as "The individual family member (forensic MHCU or caregiver) receives support from relevant external individuals, groups, or service providers, in addressing pertinent individual support needs to improve personal and collective FQOL"

Table 4.12 compares the individual member support factors sub-theme's domains of forensic MHCU family members and Caregiver family members.

Domain 1: Professional Support is a forensic MHCU and caregiver related domain. Sub-domains differ however, with the forensic MHCU related sub-domains including a) forensic MHCU mental health, b) forensic MHCU social well-being, c) physical health, d) balanced lifestyle, e) skills transference, and f) goal setting; and the caregiver related sub-domains including a) caregiver mental health, b) emotional well-being, and c) caregiver social well-being.

Domain 2: OT Support is a forensic MHCU (only) domain with its related sub-domains including a) skills development, b) work, c) formal education/ training access, and d) financial well-being.

Domain 3: Community Support is a forensic MHCU and caregiver related domain. Sub-domains differ however, with the forensic MHCU related sub-domains including a) community inclusion, b) community mental health insight, and c) community mental health responsibility; and the caregiver related sub-domains including a) community interest, and b) peer caregiver support.

Thus, unique conceptual definitions for individual member specific "individual member support factors" sub-theme have been developed (Appendix A: Operational definition(s) of a novel FQOL construct).

Table 4.12: Comparison of individual member support factors domains of forensic MHCUs and caregivers

	MHCU Individual Member Factors		Caregiver Individual Member Factors	
Sub-themes	***Domains***	***Sub-domains***	***Domains***	***Sub-domains***
Sub-theme 4: Individual Member Support Factors	Professional Support	Mental Health Social Well-being Physical Health Balanced Lifestyle Skills Transference Goal Setting	Professional Support	Mental Health Emotional Well-being Social Well-being
	OT Support	Skills Development Work Formal Education/ Training Access Financial Well-being		
	Community Support	Community Inclusion Community Mental Health Insight Community Mental Health Responsibility	Community Support	Community Interest Peer Caregiver Support

4.3.2. Measurable behavioural indicators formulation

Measurable behavioural indicators were formulated according to the process stipulated in Chapter 3.6. Items generated from focus groups were thus converted into indicators using a similar format to that of the Beach Centre of Disability's FQOL Scale (2012). These descriptive statements of families and individuals stated the ideal or desired end result, which required further rating.

Examples of family and individual related behavioural indicators are as follows:

1) Family Unit Factors > External Family Unit Support > Community Support: "The family is supported in their support role of the MHCU by community members"

2) Individual Member Factors (Forensic MHCU) > Individual Member Support Factors > Professional Support > Mental Health: "The MHCU family member receives accessible emergency professional support during a crisis."
3) Individual Member Factors (Caregiver) > Well-being Characteristics > Emotional Well-being > Personal Emotional Regulation: "The caregiver is able to deal with his/her negative emotions:
    a) Isolation/ abandonment from others
    b) Shame/ stigma
    c) Grief"

4.3.3. Summary of novel FQOL operational definitions

The FQOL construct, concepts, domains, and sub-domains were clearly operationally defined. Appendix A provides a comprehensive list of all formulated definitions.

Table 4.13 contains an excerpt of FQOL operational definitions as pertaining to family unit factors themes and sub-themes:

Table 4.13: Operational definitions for novel FQOL operationalization

FQOL Themes	Related Sub-themes
Theme 1: Family Unit Factors: The family experiences a state of intra-familial well-being while meaningfully engaging with one another, and receiving external family support.	**Sub-theme 1:** Family Characteristics: The family unit is characterised by an experience of well-being related to various aspects of life; namely, social well-being, emotional well-being, mental health, physical health, spiritual well-being, and financial well-being.
	Sub-theme 2: Family Dynamics: The family unit engages meaningfully with one another through shared time, shared activity participation, shared empowerment related activities, meaningful intra-familial communication, and by providing internal support to one another within the family.
	Sub-theme 3: External Family Unit Support: The family unit receives support from relevant external individuals, groups, or service providers, in addressing pertinent family support needs to improve their collective FQOL

Theme 2: Individual Member Factors: The individual family member (forensic MHCU or caregiver) experiences optimal personal well-being, productivity, agency, and receives needed external support.	**Sub-theme 1: Well-being Characteristics:** The individual family member (forensic MHCU or caregiver) experiences unique health and wellness in pertinent areas of life
	Sub-theme 2: Productivity Characteristics: The forensic MHCU family member optimally engages in meaningful community functioning, work, and leisure activities of daily living.
	Sub-theme 3: Empowerment Characteristics: The individual family member (forensic MHCU or caregiver) is empowered to practice self-agency in various life roles and activities
	Sub-theme 4: Individual Member Support Factors: The individual family member (forensic MHCU or caregiver) receives support from relevant external individuals, groups, or service providers, in addressing pertinent individual support needs to improve personal and collective FQOL

Therefore, a novel FQOL construct was specifically defined for ongoing tool development (Francis et al., 2017, p.65) which would direct forensic occupational therapy practice.

4.5. Operationalized novel FQOL construct for forensic OT outcome measurement

In comparison to the constructs of existing/available FQOL outcome measures particularly developed for persons with intellectual disability and their families (Poston et al., 2003; Turnbull et al, 2004, p.81 – 83; Park et al., 2003; Beach Center on Disability, 2015; Summers et al., 2005; Beach Center on Disability, 2012; Brown et al., 2006; Chiu et al., 2013), the uniqueness of the novel FQOL construct for the future *FQOL ForOT* outcome measure can be seen. Appendix D presents a final meaning map of the FQOL construct as it outlines the similarities and differences between existing and novel constructs, and between these distinct mental health population groups (forensic MHCUs versus persons with intellectual impairment). The final meaning map of the newly developed FQOL construct is discussed in Chapter 5.2.2.1.

A diagrammatic presentation of the novel FQOL construct (Figure 4.5), based on the FQOL framework (Turnbull, et al., 2004, pp. 81-83; Zuna, Turnbull & Summers, 2009, p.27; Zuna et al.,

2010; Hu et al., 2011; Chiu, et al., 2013, p. 367), presents the outcomes of this study with visual representation.

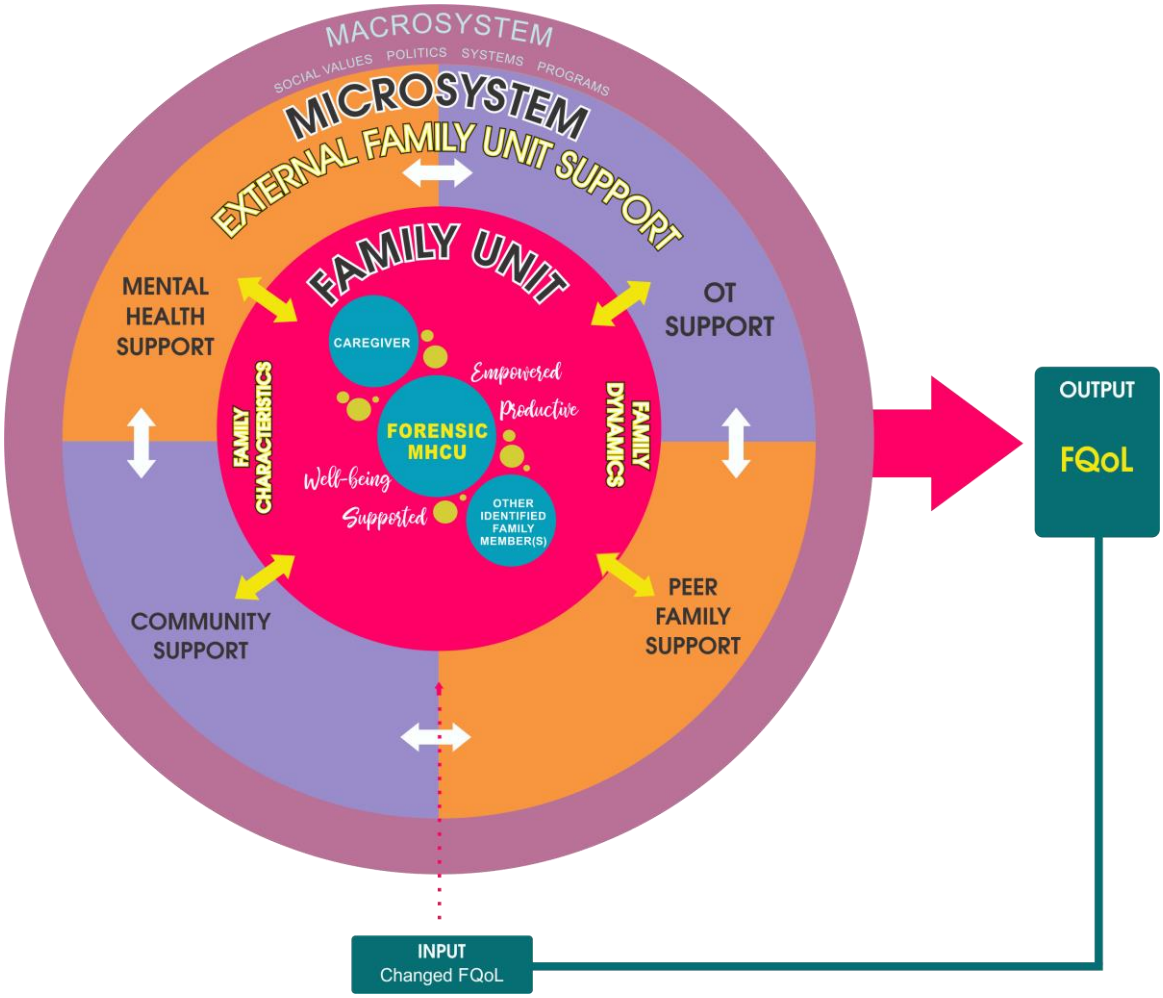

Figure 4.5: Novel FQOL construct for forensic psychiatric rehabilitation (diagrammatic presentation)

The forensic MHCUs social system is presented predominantly as a macrosystem, microsystem, and family unit (consisting of individual family members, inclusive of the caregiver). All aspects within the family unit and microsystem are particularly relevant "meaningful areas of family life" in which family members individually or collectively participate. Optimal shared participation by the family (family unit factors) in aspects of family characteristics, family dynamics, and external family unit support contributes to a FQOL output. Furthermore, optimal individual member participation (particularly by forensic MHCUs and caregivers) in individual member factor aspects of life, namely, 1) well-being characteristics, 2) empowerment characteristics, 3) productivity characteristics, and 4) individual member support factors, also contributes to an experience of FQOL. As the output collective subjective experience of FQOL changes, the changed FQOL state is input into

this social system. Changes can be described as improved quality or regression noted in family unit factors and individual member factors alike. Inputted changes also include what has been referred to by Chiu et al (2013) as adjusted or new strengths, needs, and family priorities. Any changed meaningful aspect or changed relationship within this social system has potential to change an overall subjective shared experience of FQOL.

Particular relationships highlighted within this diagram are bi-directional at all levels. These include 1) the macrosystem, providing indirect external family unit support, 2) the microsystem, providing direct family unit support, 3) the family unit directly providing an optimal social support structure to one another or individual family members. Bi-directional relations with particular relevance to the family's subjective experience of FQOL take place between family members (individuals), and between the family unit and particular microsystem external family unit support sources, (professional forensic mental health support, professional forensic OT support, immediate community support, and peer family support). Further bi-directional support relationships take place between all the microsystem external family support sources producing a mesosystem for the forensic MHCU and their family unit.

In light of the findings of this original qualitative study, the FQOL construct for occupational therapy outcome measurement in this forensic psychiatric setting can be defined as:

"The family unit actively participates together in meaningful areas of family life within a broader supportive social environment achieving 1) collective health and wellness, 2) desired intra-familial engagement, 3) optimal individual member productivity and agency, and 4) empowered interaction with extra-familial support."

4.6. Summary

This chapter has presented the operationalization of the FQOL construct for forensic MHCUs and their family members in the province of KwaZulu-Natal, South Africa.

These uniquely defined FQOL themes, sub-themes, domains, sub-domains and their related indicators for this forensic psychiatric context have been expounded in depth for the development of a future FQOL outcome measure (e.g. *FQOL ForOT*) directing assessment prior to strengths based family-centred occupational therapy service delivery.

Discussion of the findings of this novel study and its significance in FQOL, occupational science, and occupational therapy fields takes place in Chapter 5.

5. Discussion

5.1. Introduction

This chapter discusses the meaning and relevance of findings according to Objective 2 of the research study and critically reviews the novel FQOL construct through discussion of a final meaning map and visual representation of FQOL construct(s). Objective 1 was addressed in Chapter 3 and Chapter 4.

The research question posed was: What are the FQOL constructs that could be included in a FQOL outcome measure that directs family centred occupational therapy for MHCUs and their families in a forensic setting? The study's aim to identify and operationally define FQOL for family centred OT practice within this unique forensic psychiatry context in KwaZulu-Natal, South Africa, was successfully addressed. This study highlighted and responded to this existing gap of operationalizing relevant outcomes for family centred OT practice within a forensic mental health setting.

Through this research, previously established FQOL constructs, as well as newly identified FQOL constructs were included by means of qualitative inquiry into the unique context in KwaZulu-Natal, South Africa. This study extrapolated which constructs, concepts, and variables from the FQOL theory, such as the FQOL framework (Turnbull, et al., 2004, pp. 81-83; Zuna, Turnbull & Summers, 2009, p.27; Zuna et al., 2010; Hu et al., 2011; Chiu, et al., 2013, p. 367), could be included in a new outcome measurement tool for family centred OT practice in a forensic psychiatric setting. This was in accordance with the recommended formulation of operational definitions entailing 1) conceptualization of a construct, and 2) the analysis of existing conceptualisations of a construct (Waltz et al, 2010). In terms of involvement of forensic MHCUs and their family members in the design and implementation of the novel FQOL construct, unique subjective perspectives of pertinent expert groups were included into the meaning of this construct thus identifying pertinent occupation related family support needs. Thus, the immense value of subjective lived experience has been incorporated.

The study's primary relevance was the successful operationalization of the abstract FQOL construct and its related concrete concepts using an occupational lens. Operationalization of the FQOL construct took place with particular application to young adult state patients.

This chapter addresses the compatibility between two (2) theoretical perspectives (FQOL and OTPF) and presents how they have been successfully merged into a relevant FQOL construct for use in forensic occupational therapy. Furthermore, this chapter includes a final meaning map comparing FQOL constructs with particular discussion of the novel FQOL construct's two (2) themes (namely, family unit factors, and individual member factors); the operational definition(s) of FQOL; and a diagrammatic representation of the novel FQOL construct for forensic mental health are presented and interpreted.

5.2. Family Quality of Life as a forensic mental health occupational therapy outcome

5.2.1. Compatible frameworks

Findings of this study have contributed towards and expounded both FQOL theoretical framework (Chiu et al., 2013; Hu et al., 2011) and occupational science (Van Niekerk, 2005, 2014; Ingeborg, & Townsend, 2014; Blank et al., 2015) related to a subjective family health and wellness experience. These two frameworks inform health care practice and were successfully integrated to address family-centred support needs of young adult forensic MCHUs.

The novel FQOL operational definition in development of the *FQOL ForOT* outcome measurement tool merged two (2) compatible frameworks, namely, 1) FQOL theory, and 2) occupational science or OTPF. Furthermore, this study reinforced the researcher's review of existing literature that FQOL theory had relevance for family-centred OT practice, and that in applying a clear occupational lens to FQOL theory, the FQOL construct would be optimally enhanced. Theorists and researchers in various areas of interest (FQOL, occupational science, public health, and social science theorists) have recommended applying a systemic or contextual frame of reference to practice (Lehman et al. 2017; Lund et al., 2010; Muller & Flisher, 2006; World Health Organization, 2003; Zuna, Turnbull & Summers, 2009, p.25). This is further informed by Fogelberg & Frauwirth (2010, p.136) who had argued that 'like individuals, collective entities such as groups, communities and populations also engage in occupational behaviours, and that occupation produced at each of these levels represents a legitimate unit of analysis for occupational science'." Borg & Kristiansen (2008) posit that recovery as taking place primarily within a social environment through daily occupational activities, thus affirming valuable contextual and occupational considerations to mental health service delivery.

It is apparent that FQOL theory provides great value to occupational science by offering a means for occupational therapy practice to be rendered at a systemic family-centred level and be evidence-based, while occupational science expands FQOL theory in expounding occupational expressions of pertinent areas of family life (Chiu et al., 2013). These clearly defined areas of family life provide OTs with behavioural indicators that can be measured to track change over one's lifespan thus informing relevant goal-orientated OT practice.

5.2.2. A deconstructed FQOL construct for OT outcome measurement

In comparison with existing/available FQOL outcome measurement tools, the novel FQOL construct presented in this original study, shares the following characteristics of existing/available FQOL tools discussed by Samuel, Rillotta, & Brown (2012) (initially recommended by "Verdugo et al.(2005b,p.707)"): 1) FQOL is a multidimensional construct including key domains and measurable indicators, 2) FQOL uses a systems perspective evaluating how micro-, macro-, and meso-environments influence people, and 3) FQOL involves the persons with disabilities in the design and implementation of the assessment, research and evaluation. Future quantitative research would ensure further shared characteristics, namely, 1) FQOL uses methodological pluralism in collecting objective and subjective data, and 2) FQOL uses a multivariate research design to "evaluate the ways personal characteristics and environmental variables relate to the person's assessed QOL".

The novel FQOL construct as a multidimensional construct including key domains and measurable indicators is further discussed.

5.2.2.1. Final Meaning Map - comparison with FQOL themes with existing outcome measures

Previous outcome measures consist of particular individual- and family-orientated domains with their related sub-domains (Poston et al., 2003; Turnbull et al., 2004, p. 81). This study operationalizing the novel FQOL construct in the development of the *FQOL ForOT* outcome measure includes existing domains and novel domains with unique content pertinent to this forensic context. A preliminary meaning map (Appendix C) compared the two (2) existing/available outcome measures, namely, the Beach Center FQOL Scale, and the FQOL Survey (2006). Meaning was generated pertaining to the FQOL construct and potential application to a forensic context prior to meaning included by expert participants. The following discussion of the final meaning map explores

the two (2) themes of the novel FQOL construct; namely, 1) the family unit factors, and 2) the individual member factors; in comparison or contrast to existing QoL and FQOL constructs.

Appendix D outlines the similarities and differences between FQOL constructs, outcome measures, and between these distinct mental health population groups (forensic MHCUs versus persons with intellectual impairment).

5.2.2.1.1. Family unit factors

The first theme, family unit factors, consists of three (3) sub-themes, namely, 1) family characteristics, 2) family dynamics, and 3) external family unit support. Fourteen (14) domains and their related sub-domains have particular relevance to this forensic mental health setting. These emphasize areas of family life contributing to collective health and well-being of the family, as well as areas of life where active participation within the family takes place, and finally the types of support rendered by relevant external sources of support.

Comprehensive shared well-being domains were included as ***family characteristics*** for forensic MHCUs and their families. Despite Brown & Brown (2004, p.39) indicating that not all individual QoL well-being related domains core to human life may be applicable to collective FQOL. This study resulted with inclusion of various all-encompassing health and wellness domains as validated by the OTPF's priority, namely, "health, well-being and participation in life through engagement in occupation." (AOTA, 2014, p.S2). This is validated by The Ottawa Charter of Health Promotion, promoting wellness at various levels as quoted "Health … is created and lived by people within the settings of their everyday life; where they learn, work, play and love' and furthermore "… to reach a state of complete physical, mental and social well-being, an individual or group must be able to identify and to realize aspirations, to satisfy needs, and to change or cope with the environment' (WHO, 1986). Social scientists have outlined the "dimensions of wellness" as – physical, intellectual, emotional, social, spiritual, vocational, financial, and environmental (Stoewen, 2017), as compared to occupational scientists acknowledging key areas of life as physical, mental, social, emotional, and spiritual life (Wilcock, 2006; Pettican & Bryant, 2007). The newly identified FQOL domains were in alignment with both disciplines through inclusion of social well-being, emotional well-being, physical health, spiritual well-being, and financial well-being. Domain formulation was uniquely relevant to occupation.

Social well-being featured as an invaluable family-orientated domain included by study participants. Extensive content related to the nature of ideal relationships in a family was included. The extensive social well-being domain as defined within this study highlights the family need of

being satisfied with a state of social well-being, as opposed to purely the act of social engagement. It included the existence and nature of a family unit which is usually compromised for forensic MHCUs. This domain uniquely differentiated between unique family roles and responsibilities, and ideal family relationship characteristics as compared to the Beach Center FQOLS focusing on an aspect of relationship, namely, acceptance. Optimal occupational performance in meaningful family roles and responsibilities is a vital treatment focus within occupational therapy practice. Social well-being is an apt family-orientated outcome.

Emotional well-being proved to be a valuable family-orientated well-being domain for forensic MHCUs and their families affirming findings of emotional well-being needs of family members in South Africa (Pule, 2016, p.61). Fitzgerald, et al. (2012) indicated the value and use of the Emotional Expression (EE) outcome within a family of a forensic MHCU and its aptness in indicating positive change due to cognitive-behavioural treatment. EE is a core family centred health outcome in PSR (Kramers-Olen, 2014). This approach ensures the reduction of high levels of EE in the family, thus promoting an accepting and supportive home environment. As a result, the emotional well-being state of the family facilitates a supportive environment facilitating maintained sobriety goals, and acquisition of community roles. Emotional well-being within this study referred to the state of shared emotional well-being within the family. Both the Beach Center FQOLS's initial sub-domain and this study's emotional well-being domain include access ability to emotional support, as well as participation in essential stress reduction activities (Fitzgerald et al., 2012). However, the new FQOL domain includes emotional self and family awareness, skills and activities pertinent to the unique forensic context (for example, de-escalation, and conflict management skills) which are essential for families who have experienced trauma, loss, and grief; mental illness within the family; and criminal processes (McKeown et al., 2019).

Health of the family (Beach Center FQOLS initial qualitative enquiry, and FQOLS-2006 final domain) was included as an essential area of health and well-being for forensic MHCUs and their families. However, mental and physical health were identified as separate domains in this study, with particular focus on a state of collective mental health as emphasized by study participants ("siyagula" - we are ill). Pertinent insight into mental illness was included as an outcome of successful psycho-education as recommended by WHO (World Health Organization, 2003) and public mental health experts (Muller & Flisher, 2006).

Other family characteristic domains included were unique in inclusion (spiritual well-being) and formulation (financial well-being) in comparison to existing/available FQOL outcome measures. Spiritual well-being, highlighted primarily by family members and MHCPs, reflects a unique well-being domain expected within a deeply cultural and spiritual social environment (KwaZulu-Natal)

(Lehohla, 2006) and where meaning and purpose is essential within troubling circumstances, namely, family mental illness and criminal activity (McKeown et al., 2019). This correlates with FQOL research which indicated that families of persons with disabilities experienced greater emotional well-being and overall FQOL from spiritual beliefs and practices (Chiu et al., 2013). This domain differs from the FQOLS-2006's influence of values domain which highlights support received rather than family strength actively gleaned.

Financial well-being appears to be the only family-orientated domain included throughout previous FQOL studies and this study. Financial security is deemed as invaluable for both Beach Center FQOLS and this study. This study is clear in its formulation of both budgeting and healthy spending of essentials and non-essentials contributing to overall family health and wellness. This domain's importance is further affirmed through Pule's (2016) study highlighting the financial and employment impact that having a forensic MHCU has on the significant others/ family members; as well as standards of best practice in mental health (World Health Organization, 2003; Muller & Flisher, 2006).

Particular ***family dynamics*** domains were included for forensic MHCUs and their families as it was established that occupation-based activities where families engaged with one another was deemed as meaningful. These five (5) domains correlated with particular family-orientated domains within the Beach Center FQOLS and the FQOLS-2006, for example, daily family life, family interaction; and leisure and recreation, family relationships; respectively. Chiu et al. (2013) defined family dynamics as "aspects of interactions and ongoing relationships among two or more family members" which describe findings of the qualitative inquiry into this forensic psychiatric setting. Interactive aspects of family life within which clear occupational engagement takes place included family unit occupation-based domains, namely, 1) shared family time, 2) shared activity participation, 3) family interaction, 4) family empowerment, and 5) internal family support.

This study uniquely highlighted shared family time, shared activity participation, family empowerment, and internal family support as unique FQOL domains promoting meaningful family life.

Shared family time highlights the family unit's need for shared time for family "belonging" (Wilcock, 1999), time spent on "valuable and satisfying activities" (Kirsh et al., 2019, p.134), and establishing occupational balance in the family's everyday life. Kirsh et al. (2019, p.134) further refers to Eklund, et al. (2017), endorses application of time use outcomes for OT intervention to improve long-term QoL in MHCUs.

The shared activity participation domain identified within this study correlated with the Beach Center FQOLS's daily family life domain during qualitative inquiry of FQOL. Daily activities were initially included, but finally excluded from the final outcome measure. The FQOLS-2006 consists of similarities to the newly developed FQOL construct, as it incorporates leisure and recreation activities, as well as household responsibilities (indicator within family relationships domain). This study unique incorporates collective motivation (as per creative ability theory) (de Witt, 2014), a wide range of relevant diverse activities, and those that take place on a daily basis. The value of this domain is affirmed by authors Kirsh et al. (2019) who concluded in their study of mental health OT interventions, that interventions focused on developing skills, habits, and motivation levels greatly benefited MHCUs health outcomes, and achieves occupational justice for the individual and the collective. Furthermore, as indicated by Ingeborg & Townsend (2010), mental health OT practice is committed to the empowerment and social inclusion of vulnerable persons or groups through "everyday occupations" of their communities.

Family empowerment was uniquely incorporated as a family-orientated domain differing from the Beach Center FQOLS individual-orientated domain of advocacy. This refers to the family's shared ability to be resilient, set pertinent goals, and fulfil social responsibility within the community which specifically focuses on community mental health advocacy. This does not exclude the individual family member's unique advocacy roles. Furthermore this domain affirms the initial community and civic involvement domain during the FQOLS-2006 qualitative inquiry. Collective and individual empowerment is aligned with FQOL's empowerment paradigm, and is prioritized by public health experts (Muller & Flisher, 2006; Lund et al., 2010); FQOL theorists (Schalock, 2004; Turnbull et al., 2004, p.71; Brown & Brown, 2004; Poston et al., 2003; Schippers & van Boheemen, 2009; Samuel, Rillotta & Brown, 2012; Kyzar et al., 2012; and Boelsma, et al., 2018), psycho-social rehabilitation experts (Kramers-Olen, 2014), occupational science theorists (Casteleijn, 2010; and Ingeborg & Townsend, 2010) , and by governmental policy (National Department of Health, 2015, p.14), thus asserting this invaluable domain for FQOL of forensic MHCUs and their family members. Family empowerment can thus be viewed as a domain affirming individual and collective choice, advocacy for one's support needs, ability to access support, and the ability to facilitate one's own inclusion in society.

The internal family support domain presents a unique domain to existing FQOL constructs, where the family enjoys optimal intra-familial support of one another. The Beach Center FQOLS incorporates support of one another as a sub-domain to family interaction. It however was deemed as uniquely important for this study. Similarly to the FQOLS-2006 support from other people, this domain includes emotional and practical support from immediate and extended family members. It

particularly addresses a support need for crisis situations from family members who have a willing attitude to support or to be present. This was highlighted as invaluable by study participants, namely, family members.

A similar domain to existing/available outcome measures, Family Interaction, refers to the family's ability to optimally communicate with one another. This was highlighted as being of particular importance by forensic MHCU study participants.

The final sub-theme, ***external family unit support*** incorporates three (3) particular sources of support (professional family centred support, peer family support, and community support), and the types of support required by forensic MHCUs and their families. These forms of support are validated by Pule (2016, pp.62-65) who recommended the following support of South African forensic MHCUs and their families, namely, psycho-education, support groups/ self-help groups with those with shared lived experience, family therapy addressing EE, family-centred involvement in decision making and appropriate referrals, and family directed or community directed public mental health.

Professional family centred support is a family-orientated source of support which similarly refers to disability specific services addressed in both FQOLS-2006 (family-orientated), and the Beach Center FQOLS (individual-orientated). It was however emphasized that the family needed family-centred support, not only psycho-education, or providing an update of forensic MHCU treatment gains. The quality of this support was essential, for example, accessible, frequent, and community based.

Peer family support was essential to family members. This was defined as not only addressing individual support needs of caregivers/ custodians, but the collective family. It correlates with the FQOLS-2006 domain, support from other people, but specifies that the other people are those who share solidarity in having a forensic MHCU in their family.

Community support was included as a source of support. Despite it being short, it was highlighted as contributing towards FQOL, and correlated with the FQOLS-2006 which included community interaction (providing community support) to the family. Hereby, a participation society (Boelsma et al., 2018) could be established ensuring individual and family orientated inclusion prior to deinstitutionalization of forensic MHCUs into their respective families and communities.

5.2.2.1.2. Individual member factors

The second theme, individual member factors, consists of two (4) sub-themes, namely 1) well-being characteristics, 2) productivity characteristics, 3) empowerment characteristics, and 4)

individual member support factors. These sub-themes, however, were defined differently for forensic MHCUs, and custodians/ or caregivers. Furthermore, the caregiver individual member factors excluded productivity characteristics, but consisted of the three (3) remaining aforementioned sub-themes.

Due to little correlation for individual-orientated member factors existing between previous FQOL constructs and the findings of this study, comparison also included reference to the eight (8) core individual quality of life domains (Schalock, 2004, pp. 14-15), as well as the eight (8) domains of the activity participation outcome measure (Casteleijn, 2010; Casteleijn, & Graham, 2012). Quality of life domains (developed by social scientists) included interpersonal relations, emotional well-being, physical well-being, material well-being, personal development, self-determination, rights, and social inclusion. The APOM included occupation specific domains including, process skills, communication/ interaction skills, life skills, role performance, balanced lifestyle, motivation, self-esteem, and affect.

The well-being characteristics domains for both forensic MHCUs and caregivers correlated well with health of the family indicators (FQOLS-2006), with QoL domains, and with some activity participation domains. In terms of forensic MHCUs, social well-being related with interpersonal relations (QoL) and communication/ interaction skills and role performance (APOM); emotional well-being related to QoL's emotional well-being domain, and the APOM's self-esteem, and affect domains; and financial well-being related to material well-being (QoL), to life skills in terms of money management (APOM), and to indicators within the FQOLS-2006 domain, namely, careers and planning for careers. In terms of caregivers, only emotional well-being was identified as pertinent to FQOL, correlating well to QoL theory. A forensic MHCU caregiver's emotional well-being health outcome has been validated by Pule (2016, p. 61).

The productivity characteristics domains were only relevant to forensic MHCUs, where further career orientated domains for other family members were addressed within family unit factor domains, namely, financial well-being as well as family empowerment. The productivity characteristics domains correlated well with initial Beach Center FQOLS, with indicators within family-orientated domains pertaining to careers in the FQOLS-2006, with the personal development domain of QoL, and with life skills (APOM). Most (excluding QoL) included education, work or vocational skills of having utmost importance. This is highly relevant to forensic mental health OT practice focusing on pre-vocational and vocational rehabilitation. This study highlighted the particular need of forensic MHCUs to engage in formal education for personal development. Most (excluding QoL) included leisure activities as indicators of the productivity related domains. Only the newly developed community living and APOM life skills domain refer to community based survival skills necessary for individual and collective QoL.

Empowerment characteristics related to both forensic MHCUs and caregivers. This highlighted the necessity of empowerment of individuals and the collective. For the forensic MHCU, the QoL domain, self-determination, relates well to the newly developed self-agency domain where both relate to independence/ autonomy, and goal setting. Only occupation based constructs appeared to have included pertinent support roles which were highlighted as valuable for both forensic MHCUs and caregivers. It is noteworthy that parenting roles and responsibilities (Beach Center FQOLS) has been excluded from this study with highlighting a different caring support role, namely, fulfilling a support role as a caregiver or custodian.

Individual-level support factors were relevant to both forensic MHCUs and family members. Pertinent individual-level support for a person with a disability has been viewed as essential by various sources. This study highlighting particular professional and community support correlates well with FQOL constructs previously developed (FQOLS-2006, and Beach Center FQOLS). However, the professional support indicated is predominantly mental health care related. Some correlation exists with QoL core domains, namely rights where human rights and legal rights are achieved through access to health care. Access to health care is not particularly highlighted by the APOM. Uniquely, this study emphasized the professional support from caregivers, namely, mental health, emotional well-being, and social well-being support from rehabilitation experts. Community support for both forensic MHCUs and caregivers was included as being of importance. These correlate well with the QoL domain, social inclusion.

5.2.2.2. The FQOL operational definition for OT outcome measurement

FQOL was deconstructed into an operational definition for use by occupational therapists in forensic mental health care, particularly, in OT outcome measurement. The newly formulated FQOL operational definition was finally presented as ***"The family unit actively participates together in meaningful areas of family life within a broader supportive social environment achieving 1) collective health and wellness, 2) desired intra-familial engagement, 3) optimal individual member productivity and agency, and 4) empowered interaction with extra-familial support."***

The formulated construct consisted of key concepts, namely, 1) the shared activity participation within the family, 2) identified meaningful areas of family life, and 3) the family unit positioned within a supportive social environment. Furthermore, it expanded on which areas of family life were considered to be meaningful and thus contributing to a FQOL experience, namely, 1) collective health and wellness, 2) desired intra-familial engagement, 3) individual member factors (i.e. productivity and agency), and lastly 4) interaction with extra-familial support as a family.

This operational definition thus summarized findings of this study which correlated with existing FQOL and OT literature.

Participation of the family refers to the group's ability to be individually and or collectively involved in life situations (WHO, 2001, p.10, as referenced in AOTA, 2014) or everyday family life activities. This "act of doing" (Krupa et al., 2009; Law et al., 1996; WIlcock, 1999, 2005) or occupational performance can be enhanced or enabled so that subjective experience is optimal. Participation would include active fulfilment of roles, tasks, habits, and activities (Bronfenbrenner, 1994; Krupa et al., 2009; Law et al., 1996; Wilcock, 1999) and increased capacity (OTASA, 2017), competency and mastery of family based occupations. Through active participation, family members are enhanced as occupational beings (Wilcock, 1999), and are ideally occupied achieving occupational justice in society (Ingeborg & Townsend, 2014; Blank et al., 2015; Van Niekerk, 2005, 2014). This occupational focus on existing FQOL literature expands on FQOL's reference to occupation or family functioning and affirms a focus on occupation. This can be seen in existing literature referring to FQOL as having opportunity to actively "pursue important possibilities" (Brown & Brown, 2014), having opportunity to do things as a family unit (Park et al. 2003, p.368), and having "adequate levels of functioning" (Brown & Brown 2003, as quoted by Samuel, Rillotta, & Brown, 2012). The novel FQOL construct reflects active participation in important areas of life in all domains. Active participation in life roles (e.g. social well-being domain > family roles and responsibilities > breadwinner), tasks/ habits (e.g. financial well-being > healthy spending habits), and activities (e.g. Shared activity participation > Routine Family Activities > Leisure activities) are examples of how the FQOL constructs relate to occupational performance.

Meaningful areas of family life is where the family "doing" or activity participation takes place. *Family life* refers to the state ("being") and activity ("doing") taking place within the family unit. This correlates with Wilcock (1999) referring to shared activity happening within a social environment (namely, the family environment). *Meaningful* describes the subjectively perceived quality or value of the areas of family life. As stipulated in the OTPF (AOTA, 2014), meaningfulness applies to both the individual and social context, and is that which is personally desirable. Meaningfulness is identified as a generic feature of occupation reflected throughout occupational science and occupational therapy literature (AOTA, 2014; Law et al., 1996; Krupa et al., 2009; Wilcock, 1999; Ingeborg, & Townsend, 2014). An occupational lens to FQOL thus refers to the meaningfulness of family life and its related activities, thus making the FQOL construct uniquely occupational. FQOL theory reframes meaningfulness similarly as subjectively perceived "importance" (Brown & Brown 2003, as quoted by Samuel, Rillotta, & Brown, 2012; Park et al. 2003,

p.368) or pertinence (Chiu, et al., 2013). Thus, meaningfulness as a means to describe FQOL is relevant to FQOL and occupation based existing literature.

The family unit is recognized within both existing literature and this study as being ***positioned within a supportive social environment.*** The dynamic bi-directional relationship between the supportive social environment and the increasingly empowered family unit contributes immensely to the family's experience of FQOL. Family participation or occupational engagement is enhanced or enabled through the supportive environment (AOTA, 2014). Thus family participation needs to be viewed as taking place within an existing broader social environment and in a transactional relationship with this environment (Krupa et al., 2009; Law et al., 1996). This environment is thus inclusive and facilitates occupational justice (Ingeborg & Townsend, 2014; Blank et al., 2015; Van Niekerk, 2005, 2014) of both individual members and the family unit as a whole. Uniquely, this supportive social environment refers primarily to the immediate sources of support which have a direct relationship with the family unit (i.e. professional forensic support, or peer family support), and can also be perceived as incorporating the presence, relationships, and expectations of the social environment as defined in the OTPF (AOTA, 2014). Existing FQOL literature (Brown & Brown, 2014) acknowledge that subjective experience of FQOL takes place within "the community and the society of which it is a part". Hence, the family unit experiences an optimal experience of "belonging" to the broader community from which they seek and receive support (Wilcock, 1999).

Meaningful areas of family life which are desired by the family unit (and family members), as presented in the novel FQOL operational definition, firstly includes desired ***collective health and wellness***. This refers to both a personal and a shared health and wellness experience thus referring to both shared family unit factors, i.e. family characteristics, as well as to individual member factors, i.e. well-being characteristics. As explored in Chapter 2, "health and wellness" is highlighted as key outcomes in various fields of inquiry, including FQOL theory, social science (Bronfenbrenner, 1994), health science, and occupational science literature (Ingeborg & Townsend, 2014; Blank et al., 2015; Van Niekerk, 2005, 2014; AOTA, 2014). The OTPF (AOTA, 2014) particularly refers to health and wellness within a mental health context as being achieved through occupational performance, and is experienced as a total state of well-being within all areas of human life. Existing FQOL outcome measurement tools (Poston et al., 2003; Turnbull et al, 2004, p.81 – 83; Park et al., 2003; Beach Center on Disability, 2015; Beach Center on Disability, 2012; Summers et al., 2005; Samuel et al., 2018) include health and wellness related domains (i.e. emotional well-being, and health) thus similarly affirming this essential component to occupation based FQOL. This thus affirms the newly defined FQOL construct as it aligns with Turnbull, Brown, & Turnbull III (2004) referring to FQOL as

dealing with the goodness of or satisfaction with family life, and being a "dynamic sense of well-being of the family" (Zuna, Summers, Turnbull, & Xu, 2010, p.262; Chiu et al., 2013) defined by individuals and as a collective, where individual and family needs intertwine.

Desired intra-familial engagement in the operational definition refers to the novel FQOL sub-theme of family dynamics defined in this study as "The family unit engages meaningfully with one another through shared time, shared activity participation, shared empowerment related activities, meaningful intra-familial communication, and by providing internal support to one another within the family. This does not include active participation to achieve a shared state of health and wellness, but outlines the particular "quality of family interactions" (Zuna, Turnbull & Summers, 2009). This study uniquely highlights key aspects of "family interactions" as 1) shared time, 2) shared activity participation, 3) shared family agency pursuits, 4) communication within the family, and 5) provision of support to one another within the family as supported by Zuna, Turnbull & Summers (2009). This refers to the novel family related aspects of family life identified in this study referring to particular group activities, tasks, and habits (Wilcock, 1999), lifestyle (Wilcock, 1999), structured use of time and activity (Krupa et al., 2009), and social interactions (Wilcock, 1999) pursued by the group together (Wilcock, 1999). Furthermore, empowerment related activities (practicing agency, advocacy, and making occupational choices) is affirmed by both FQOL literature, and occupational justice literature (Ingeborg & Townsend, 2014; Blank et al., 2015; Van Niekerk, 2005, 2014) which highlights the importance of autonomy for an individual or a group to experience occupational justice.

Individual member productivity and agency within the newly developed FQOL operational definition refers to individual member factors which differ from the family member's well-being characteristics (referred to in the operational definition as collective health and wellness), and individual member support factors (referred to in the operational definition as external support). It particularly refers to outcomes related to family member productivity (forensic MHCU related), and family member empowerment, agency, or self-determination (forensic MHCU, and Caregiver related). These individual-level outcomes have been included due to their particular relevance to a collective FQOL experience. Individual member factors highlight pertinent areas of family life but ought not to replace valuable outcome measure(s), namely, individual QoL core domains (Schalock, 2004, pp. 14-15) or activity participation (APOM) (Casteleijn, 2012). These existing outcome measurement tools addressing individual outcomes are augmented by the FQOL individual member factor domains. A comprehensive assessment of the individual family members' (particularly, the forensic MHCU) occupational performance needs (especially, productivity and agency) is essential in

identifying pertinent information on the demands placed on everyday family life activities and thus individual and collective health and well-being.

Interaction with extra-familial support as a family refers not to the existence of the broader social support system, but rather the empowered seeking out or accessing of external family support by the family members and/or family unit. This refers to the importance of a dynamic bidirectional relationship with available support systems. This perspective on pursuit of support sources is supported by FQOL literature (Schippers & van Boheemen, 2009; Boelsma et al., 2018). Boelsma et al. (2018) particularly refers to a need for families to be immersed in accepting and understanding communities or "participation societies" which are inclusive of professional and informal community support (i.e. neighbours etc.). This is the shared understanding of the desired nature of extra-familial support received from the community for families of forensic MHCUs. An occupational lens to FQOL affirms a psycho-social rehabilitation perspective on empowerment (Muller & Flisher, 2006; Lund et al., 2010, p.394; Kramers-Olen, 2014) where families are empowered change-agents in meeting their own family support needs, rather than primarily being passive recipients having their support needs met by others. This is in alignment with FQOL's empowerment paradigm (Schippers & van Boheemen, 2009; Kyzar et al., 2012; Boelsma et al., 2018) where family members are empowered to seek support within a "participation society".

5.4.2.2. Forensic mental health FQOL diagrammatic presentation

With reference to the diagrammatic presentation of the novel FQOL construct (Figure 4.5) for forensic practice, interpretation is herewith further discussed.

As presented in Chapter 4, family unit factors consist of meaningful areas of family life including the family characteristics, family dynamics, and external family unit support represented in both the microsystem, and the family unit. Optimal experience and participation in these family related activities and in these bidirectional relationships enhance a collective occupation-based FQOL experience of the family unit. It is reasoned thus that this is the means to achieving the family unit's shared occupational identity. Shared "doing, being, becoming, and belonging" (Wilcock, 1999) is described within the newly defined FQOL construct. Family characteristics (referring to shared health and wellness) correlates with Wilcock's (1999) "doing" for shared "being" describing how through activity participation in health and wellness activities, a family can achieve a collective sense of self or identity. This is corroborated by Blank et al. (2015, p.198) discusses Christiansen (2004) suggesting that people become who they are through activity, thus creating an occupational

identity. Social relationships and occupational engagement were seen as vital to facilitating a "sense of self, and of being included in the world" (Blank et al., 2015, p. 206).

Family dynamics (referring to aspects of shared life incorporating active engagement between family members within the family unit) correlates with Wilcock's (1999) "doing" for shared "belonging". These particular aspects of family life represent the aspects of family life where family members actively engage with one another through meaningful activities of daily living which enhance a sense of family "belonging". In association, neglect of these meaningful aspects of family life would contribute negatively to the family's sense of "belonging".

Individual members can be described in terms of demographic, characteristics, and beliefs as per the FQOL framework (Turnbull, et al., 2004, pp. 81-83; Zuna, Turnbull & Summers, 2009, p.27; Zuna et al., 2010; Hu et al., 2011; Chiu, et al., 2013, p. 367), but factors that determine an output of FQOL are predominantly the individual member factors as presented in Chapter 4 that relate to individual family members "doing, being, becoming, and belonging" (Wilcock, 1999). These relate predominantly to individual member wellness, productivity, empowerment (agency or self-determination), and an experience of being adequately supported.

This diagram supports ecosystem theory (Bronfenbrenner, 1994; Lehman et al., 2017; Turnbull et al., 2004, pp. 59-60; Maynard, 2003) representation of dynamic interactions taking place between various aspects of the social environment. The diagram clearly represents dynamic bidirectional relationships taking place between external family support factors as they partner with one another to render indirect support to the family unit and particular family members. OTs can use this diagram to be cognisant of the holistic FQOL construct and how its related domains interact with one another, as well as identify particular dynamic relationships requiring enhancement by the forensic MDT (i.e. a relationship between the immediate community and the peer families) in "fixing" the social system, rather than predominantly the individual (Turnbull et al., 2004, pp. 59 - 60).

This diagram furthermore represents an active and living social and occupational environment of individuals and groups living life in relation to one another with the particular occupational demands of everyday life. It can be visualized as a pulsating unit where when one aspect is supported, enhanced, or strengthened; other aspects are supported, enhanced or strengthened. It simplistically represents the complex FQOL output as constantly changing, developing, or morphing into a state of newness, experienced as new priorities, strengths, and support needs (Chiu et al., 2013).

This bird's eye view of the FQOL construct has expanded on the diagrammatic representation of FQOL framework (Chiu et al., 2013, p.367) in visually representing FQOL through an occupational lens. Mabuza et al. (2014) recommend visual representation in conclusion of qualitative findings for clear synthesis of findings. The four (4) major concepts highlighted as part of the FQOL framework by Zuna, Turnbull & Summers (2009), namely, 1) system, 2) performance, 3) individual family members, and 4) family unit, are represented within the newly developed FQOL construct. "*Performance*" (according to FQOL theory) or health services rendered is incorporated as the specialist professional forensic mental health support and relevant OT support sources. However, OT support can also be described as the "*process*" as per the OTPF (AOTA, 2014) referring to the specific OT process in achieving therapeutic outcomes. The novel FOoL's "*system*" (the environment in which the family and individual functions (Zuna, Turnbull & Summers (2009)) is referred to as the macrosystem (providing indirect family-centred support) and microsystem, where the family unit's microsystem consists of family-directed, external, and direct support factors. The researcher of this study defined the microsystem differently from Boelsma et al. (2018) who presented the family unit as part of the microsystem. This study however describes the central subject as the family unit, and thus that which externally and directly influences the family as the microsystem. The "*family unit"* concept in this study, previously defined by Zuna, Turnbull & Summers (2009) as "a description of the family as a whole in terms of characteristics and dynamics states", remained true to the initial definition. It, however, uniquely included external family unit factors in the forensic MHCU's microsystem instead of being separately included in the FQOL framework's category of family-level support factors.

"Individual family members'' (the descriptive aspects of members in the family) excluded specific demographics' within the primary definition, but included individual member factors and individual member support factors instead of characteristics/ behaviours and beliefs as described by Zuna, Turnbull & Summers (2009).

This diagrammatic representation presents the similarity with Bronfenbrenner's Ecological Systems Theory (Bronfenbrenner, 1994) where factors within the presented ecosystem "changes and mutually affects one another over time" or across an individual's lifespan (Lehman et al., 2017), namely the forensic MHCU.

5.3. Relevance of findings

OTs are viewed as invaluable contributors towards achieving forensic MHCUs health and well-being outcomes through occupation (Chui et al., 2016; Duncan et al., 2003), particularly at an individual level of care. This study provided a new construct to inform family-centred forensic OT evidence-based practice, adding to a limited body of research informing family work by forensic OTs (Fitzgerald et al., 2012). It has also contributed towards valuable outcome measurement research for occupational therapy in mental health care in South Africa (Casteleijn, 2010, 2013; Casteleijn & Graham, 2013).

The novel FQOL construct for forensic occupational therapy aligns OT practice with quality of life theory as well as positive psychology by making use of this valuable strengths-based support paradigm (Hu et al., 2011; Chiu et al., 2013), and thus presents a neutral unbiased construct for OT outcome measurement which allows for subjective interpretation of the degree of satisfaction in pertinent areas of family life (Chiu, et al., 2013).

The merging of FQOL theory and occupational science affirms an empowerment perspective of FQOL (Samuel, Rillotta & Brown, 2012) as per a psycho-social rehabilitation perspective (Muller & Flisher, 2006; Lund et al., 2010, p.394; Kramers-Olen, 2014) which emphasizes the great value to the existing FQOL construct. It applies an occupational justice priority to the FQOL construct contributing to an ethical vision by occupational science theorists for an "occupationally-just world supported by public health and societal initiatives" while mental health OT practice is committed to the empowerment and social inclusion of vulnerable persons or groups through everyday occupations of their communities (Ingeborg & Townsend, 2010). It provides a means for the evaluation of family units as occupational units.

This study expands on the FQOL framework application to the forensic sub-specialization in the mental health context. Recommended research priorities for forensic psychiatry (Goethals et al., 2012) in terms of unmet needs (community level support, and rehabilitation related unmet needs) and quality improvement (investigation of instruments, metrics of protective factors, and routine outcome monitoring) have also been addressed.

The newly developed FQOL operational definition is hereby presented as a trustworthy construct informing OT outcome measurement and practice.

5.4 Summary

This chapter has discussed the identification and operationalization of the novel FQOL construct for forensic MHCUs and their family members in the province of KwaZulu-Natal, South Africa.

These uniquely defined FQOL themes, sub-themes, domains, sub-domains and their related indicators for this forensic psychiatric practice have been expounded in depth for further development of an occupation-based FQOL outcome measure (*FQOL ForOT)* directing strengths based family-centred OT service delivery. In comparison to the constructs of existing QoL and FQOL outcome measures particularly developed for persons with intellectual disability and their families (Poston et al., 2003; Turnbull et al, 2004, p.81 – 83; Park et al., 2003; Beach Center on Disability, 2015; Summers et al., 2005; Beach Center on Disability, 2012; Brown et al., 2006; Chiu et al., 2013), the uniqueness of the novel FQOL construct is evident.

Chapter 6 concludes this study by presenting a summary of the study and clinical relevance, as well as a critique or evaluation of the study ending with relevant recommendations for future clinical practice and research.

6. Conclusion

6.1. Introduction

This chapter concludes this novel study which aimed to identify and operationally define FQOL in the development of a FQOL outcome measurement tool that could direct family centred OT services for mental health care users and their families within a forensic psychiatric facility setting in KwaZulu-Natal, South Africa. In this chapter, the conclusion of how the aim of the study was achieved, including clinical relevance, study critique, and lastly, recommendations for future occupation-based FQOL research and practice, will be presented.

6.2. Meeting the aim of the study

This study used a qualitative research approach by conducting focus groups with stakeholders of forensic MHCUs to identify items for a FQOL measurement tool. The existing FQOL theory used primarily in disability and early childhood intervention fields of inquiry (Chiu, et al., 2013); psycho-social rehabilitation prioritized in forensic mental health care (Lund et al., 2010, p.394; Kramers-Olen, 2014, Marquant et al., 2016); as well as occupational science (Van Niekerk, 2005, 2014) and occupational therapy (AOTA, 2014) frameworks; were used to operationalize identified items. This study forms part of the first step in outcome measure tool development of a *FQOL ForOT* which has potential to direct strengths-based, family-centred, evidence-based service delivery using a support-orientated paradigm and a quality of life approach. Occupational justice goals for forensic MHCUs and their families will thus be promoted. Furthermore, this provides a means of shifting within forensic mental health care from custodial care within institutionalized environments to community based service delivery (Pettican & Bryant, 2007) thus creating “participation societies'' (Boelsma et al., 2018) for forensic MHCUs and their family members. Research priorities in forensic psychiatry in terms of unmet needs and quality improvement have also herewith been addressed (Goethals et al., 2012). This study therefore, facilitated the process to address the knowledge and clinical gaps for occupational therapists in mental health context.

An operationalized FQOL construct has been defined which incorporates pertinent areas of family life, namely, FQOL themes, sub-themes, domains, sub-domains, and measurable indicators. This novel FQOL construct awaits further factor analysis and quantitative study for tool development prior to use within forensic occupational therapy practice in KwaZulu-Natal, South Africa.

6.2.1. Constructive findings

Constructive findings within this study concluded with an operational definition of the FQOL construct using an occupational lens for forensic mental health care practice.

The newly formulated novel FQOL operational definition is presented as *"The family unit actively participates together in meaningful areas of family life within a broader supportive social environment achieving 1) collective health and wellness, 2) desired intra-familial engagement, 3) optimal individual member productivity and agency, and 4) empowered interaction with extra-familial support."*

The newly developed FQOL construct consists of two (2) themes, namely, family unit factors, and individual member factors. The first theme, family unit factors, consists of three (3) sub-themes, namely, 1) family characteristics, 2) family dynamics, and 3) external family unit support. Fourteen (14) domains and their related sub-domains have particular relevance to this forensic mental health setting. These emphasize areas of family life contributing to collective health and well-being of the family, as well as areas of life where active participation within the family takes place, and finally the types of support rendered by relevant external sources of support.

The second theme, individual member factors, consists of four (4) sub-themes, namely 1) well-being characteristics, 2) productivity characteristics, 3) empowerment characteristics, and 4) individual member support factors. These sub-themes were defined differently for forensic MHCU individual family members, and custodian or caregiver individual family members. Caregiver's individual member factors excluded productivity characteristics, but consisted of the three (3) remaining aforementioned sub-themes. Individual member factors have been presented as not a replacement for existing individual QoL or optimal activity participation constructs, but rather highlighting which personal factors contribute to this collective FQOL experience.

A diagrammatic presentation of the novel FQOL construct in Figure 4.5 clearly presents the family unit (inclusive of pertinent family members) as the primary subject supported by its uniquely defined microsystem, meso-system, exo-system, and macro-system. This visually portrays how FQOL of forensic MHCUs and their families can be achieved through service delivered at any aspect within the systems which directly impact on the family unit and individual family members. This diagram furthermore represents an active and living social and occupational environment of individuals and groups living life in relation to one another with the particular occupational demands of everyday life.

6.2.2. Challenges

A primary challenge was the non-availability of many family members to participate within this study. Recruitment of a greater number of family member participants from the relevant districts in KwaZulu-Natal, South Africa, would have been preferable to the study. However, findings and discussion of this study pertaining to family support needs and FQOL has potential to facilitate further therapeutic and research engagement with family members.

6.2.3. Clinical relevance

The primary relevance of this study was the successful identification and operationalization of FQOL domains and measurable items for a future OT outcome measure that address MHCUs and their families within forensic psychiatry. An occupational lens was used throughout this process. This study has expanded on existing FQOL theory through application to a unique context of disability, namely, forensic mental health. The novel FQOL construct for forensic OT application to young adult forensic MHCUs and their families, therefore, aligns OT practice with quality of life theory recommended by Andresen et al. (2006), as well as positive psychology by making use of this valuable strengths-based support-paradigm (Hu et al., 2011; Chiu et al., 2013), resulting in an occupation-based neutral unbiased construct for outcome measurement which allows for subjective interpretation of the satisfaction in pertinent areas of family life (Chiu et al., 2013). The operationalized definition can assist occupational therapists in perceiving the meaning of important areas of family life at an individual- and family- level which can primarily inform assessment and service delivery. Empowered self-determined families of forensic MHCUs can be realized once aggregated satisfaction is achieved in these pertinent areas of family life, thus decreasing the burden of disease (Lund et al., 2010; Mayosi et al., 2009; McKeown et al., 2019; World Health Organization, 2003).

The role of occupational therapy in forensic mental health is highlighted when family-centred support needs through structured social support systems are identified as a priority (Houidi & Paruk, 2018; Pule, 2016; Boelsma, et al., 2018). It firmly positions the OT profession within the ForACT MDT team (Marquant et al., 2016) in rendering family-centred psycho-social rehabilitation (Muller & Flisher, 2006). This study has identified intra- and extra-familial support that families of forensic MHCUs require to experience FQOL and asserts the afore-mentioned support paradigm, rather than a disability-orientated and punitive approach common in forensic mental health care. Furthermore, it informs family work pursued by few forensic mental health OTs (Fitzgerald, et al., 2012) by operationalizing relevant family outcomes, thus promoting collective health and well-being, and achieving occupational justice for forensic MHCUs and their families. Inclusion of young adult forensic MHCUs and their families into community-based, health-promoting, occupationally-just

participation societies (Boelsma et al., 2018) in accordance with deinstitutionalisation, can be addressed through occupational therapy. Occupational therapy is thus strategically positioned for impact in forensic mental health.

6.3. Critique of the Study

Evaluation of the operationalization of the novel FQOL construct, strengths and limitations of this study, as well as recommendations for future research and practice are herewith presented.

6.3.1 Evaluation of the novel FQOL operational definition

Evaluation of the novel FQOL operational definition took place in consideration of criteria stipulated by Waltz et al. (2010, p.43). Comprehensive assessment of the adequacy of the construct can only be finalized through factor analysis and statistical analysis which is beyond the parameters of this study. Efforts to maintain truthfulness of the data throughout the identification and operationalization of a novel FQOL construct has contributed to the adequacy of findings.

The following criteria were considered: 1) *Clarity*: definitions and indicators are presented and formulated in an understandable manner and supported by literature; 2) *Precision*: a systematic qualitative approach and data analysis were used to identify indicators and then to develop operational definitions; 3) *Reliability*: during the data collection member checking were used and during data analysis rigorous discussions with supervisors resulted in the newly developed FQOL measure. The processes are reproducible under similar conditions; 4) *Consistency*: Rigour in the research methods will lead to consistent reproducibility of the study. Terminologies used are consistent throughout domains, and appropriate reasoning has guided the selection of indicators; 5) *Meaning Adequacy*: there is congruence in meaning between domains, sub-domains, and indicators, as well as fullness of meaning attributed to concepts as is appropriate in this qualitative inquiry stage of tool development; 6) *Utility*: operationalized definitions are clear and succinct to describe aspects of family life, and can direct further judgement-quantification; and 7) *Feasibility*: practical considerations in FQOL construct have been made in application to age, level of cognition or creative activity, and cultural sensitivity. Further factor analysis and quantitative research (i.e. content validation, and construct validation) and translation is required for operational definitions to be used in a future developed occupation-based FQOL outcome measurement tool.

6.3.2. Strengths

This study's strengths lies within the efforts made to ensure truthfulness of data generated, comprehensive review and integration of relevant existing literature, systematic use of suitable

methodological design, expert participant involvement in optimally generating meaning to the FQOL construct, use of a hybrid thematic analysis process, and the specificity of the study's scope.

A literature review on rigour in qualitative research (Lincoln & Guba, 1985; Mabuza et al. 2014; Francis et al., 2017) identified four strategies to establish trustworthiness in qualitative enquiries: 1) credibility (internal validity, triangulation and member checking), 2) transferability (external validity), 3) dependability (reliability), and 4) confirmability (objectivity). These considerations ensured saturation of data as a result of optimal time spent in focus groups, and the ongoing checking and rechecking of data ensuring rigor. The researcher ensured ongoing consultation with supervisors and expert participants to ensure truthful interpretation and presentation of data.

A thorough literature review enabled the researcher to merge existing frameworks relevant to quality of life and occupational science or occupational therapy. Merging included application of occupational science to forensic mental health care, application of the FQOL framework and its related constructs to forensic mental health occupational therapy and psycho-social rehabilitation. It thus uniquely applied an occupational lens to the FQOL construct for application within forensic mental health care. This literature review process allowed the researcher to operationalize a novel FQOL construct which remained true to terminology in both fields of inquiry (QoL, and OT).

The suitability of the methodological design for identification and operationalization of abstract constructs and outcome measurement tool development contributed towards this study's strength. Using compound underlying paradigms, namely, pragmatism and interpretivism; using a qualitative research method requiring future quantitative research for tool development; incorporating focus groups to establish the subjective meaning of FQOL as per participants lived experience regarding family life; and the use of a hybrid of inductive and deductive data analysis, contributed to this study's strength and ability to successfully operationalize this initially unknown construct for forensic mental health. This study required a focus on the FQOL phenomenon by exploring how different people view the same construct (Samuel, Rillotta, & Brown, 2012). As a result, expert participants have informed the meaning of the FQOL construct thus assisting the researcher of this study to accurately perceive, conceptualize, and operationalize FQOL for a forensic psychiatric setting. Inclusion of the various expert participants ensured saturation of data generated despite few family members having participated. Valuable contributions by expert participants ensured richness of data.

Finally, strength in the study is gained through its specificity of scope. Inclusion and exclusion criteria (e.g. young adult forensic MHCUs; exclusion of tone, self-differentiation, and self-

presentation levels of creative ability (VdTMoCA) (de Witt, 2014); and MHCPs with extensive family work experience) ensured clear boundaries and application or furtherance of this research in the future.

6.3.3. Limitations

This study's findings and discussion are limited in terms of scope or generalizability (i.e. service users, mental health settings, and geographic contexts), recruitment challenges, and language and semantic challenges.

The study is limited in generalizability. Due to the study's specificity, generalization to generic mental health care beyond the forensic sub-specialization is not possible and requires further research. In terms of application to a forensic context, the following limitations are noted. Findings of this study cannot be applied without further FQOL research with regards to forensic MHCUs with primary diagnosis of cognitive impairment (as per high prevalence at this forensic facility noted by authors (Houidi & Paruk, 2018; Houidi et al., 2018), to forensic MHCUs with primary or secondary diagnosis of Personality Disorders (according to the DSM-5 Criteria for the Personality Disorders), to forensic MHCUs and their families residing in rural KZN beyond eThekwini and uMgungundlovu districts, or to forensic populations in the other eight (8) South African provinces. Generalization of findings is limited to young adult forensic MHCUs, and thus excludes unique family support needs of geriatric MHCUs within forensic settings. Particularly, the exclusion of forensic MHCUs presenting on self-presentation (VdTMoCA) limits subjective voice of this large population of OT clients.

The study presents a novel FQOL construct which would inform OT outcome measurement development. However the extensive list of domains and their related indicators is impractical for immediate use in an outcome measure. Therefore, the study was limited in presenting a final list of FQOL constructs and their related measurable indicators and requires further factor analysis. Furthermore, terminology used was not explicitly occupation-based, and would require further consultation with occupational science in reframing the FQOL constructs to be uniquely occupation-based.

Some methodological challenges in terms of recruitment also provide notable limitations to this study. Recruited participants informing operationalization of a novel FQOL construct were limited. MHCPs included nursing staff and social workers, but excluded valuable input of psychologists and psychiatrists with particular insight into a family systems approach to forensic mental health care. This was predominantly due to non-availability. Few family members participated, limiting the voice of forensic MHCU family members. This may have been due to

motivation, insight, logistics, work priority, or socio-economic limitations. No male family members participated in the study which would have provided further depth to findings.

Limitations are viewed in terms of prioritization of scientific terminology which causes difficulty in semantics, and language accessibility for isiZulu families. Further research is required to ensure optimal utility of FQOL constructs for use in an outcome measurement tool by ensuring that semantics of constructs and related items are understandable and interpreted as per the original meaning of FQOL constructs. The hospital where the study took place served forensic MHCUs who were, as well as their family members, mostly isiZulu speaking. By using English proficiency as an inclusion criteria, a significant portion of MHCUs at the hospital were excluded from participation in the study. Communication in one's second language (English), may have also hindered personal expression.

6.4. Future recommendations

It is proposed that FQOL outcome should be further researched and incorporated into practice within forensic mental health care. The possibility for occupation-based FQOL support within mental health care has immense implications on a systemic approach to mental health occupational therapy.

As a result, this study requires further practical action or scientific study pertaining to the following topics, contexts or fields of inquiry: judgement-quantification for finalization of the novel occupation-based FQOL outcome measurement tool, and generalizability of the FQOL construct to generic non-forensic populations, and particular relevant forensic populations (diagnosis: cognitive impairment, personality disorders; age: geriatric forensic MHCUs; Levels of Creative Ability: self-presentation) or contexts (rural KZN, national, and international application). In the finalization of a novel occupation-based FQOL outcome measurement tool, it is recommended that further confirmatory factor analysis takes place refining the list of operationalized constructs and their related behavioural indicators further for OT utility specifically. Further framing of constructs using OT terminology with particular consideration of occupational performance and the demands of everyday life is recommended. This would ensure expanded scope and generalizability of study findings and application thereof.

Furthermore, a final quantitative research step ought to take place according to recommendations for criterion-referenced measures as per steps highlighted by Waltz et al (2010, p.129). These directives will ensure that tool development is concluded, namely, final construction

of the measure (reviewing items for content validity to revise or delete items), assemble the measure with guidelines for test administration, scoring, and interpretation; pilot or field test the outcome measure to investigate statistical or psychometric properties ensuring reliability, validity, and outcome measure adequacy. Considerations ought to be made for scoring and interpretation, as well as respondent burden and presentation. Finally, translation of the outcome measurement tool into isiZulu using user-friendly relevant semantics which remains true to intended meaning, ought to be done. This will assist in decreasing the respondent burden.

As a result of family member participants being predominantly female with unique caregiver roles and perspectives, it is recommended that further FQOL inquiry into family support needs be conducted amongst male family members, custodians, or caregivers. Further recommended research topics include application of FQOL theory to forensic psychotherapy; caregiver centred occupation-based individual quality of life or meaningful occupational engagement or activity participation.

Further merging of social exchange theory and occupational science literature for family-centred practice would benefit this novel field in OT. Furthermore, the particular dynamic interactions between individual forensic MHCU, family unit, and the demands of everyday occupation in the family setting may also develop a conceptual framework for OTs to consult during assessment and mental health intervention.

Practical recommendations include securing financial backing for further research as discussed above, and appropriate dissemination of study findings to relevant parties. Dissemination of study findings needs to be directed towards study participants, forensic OTs practicing in KwaZulu-Natal, ForAct MDTs, management at an institutional level, and towards the Disability and Rehabilitation Department at a provincial KwaZulu-Natal Department of Health level. It is recommended that this study assist in informing rehabilitation policy formulation, strategic and operational objectives formulation, inclusion of OT into the ForACT MDT teams, and inclusion of occupation-based FQOL domains as assessment goals for treatment irrespective of outcome measure finalisation. These recommended actions are supported by Brown (2017, p.8) who stipulated the following actions, namely, “appropriate communication between those with disabilities, their primary carers, managers of agencies, and policy makers. Without this it seems unlikely that effective long-term development will take place”.

Finally, findings ought to be presented in peer-reviewed journals and professional newsletters advocating for family-centred occupation-based mental health care.

6.5. Concluding remarks

A neutral, strengths-based, family-centred, and support-oriented FQOL construct has been operationalized in the development of a *FQOL ForOT* outcome measurement tool directing forensic occupational therapy practice in KwaZulu-Natal, South Africa.

This novel FQOL construct inclusive of its themes, sub-themes, domains, sub-domains, and proposed measurable indicators, has expanded on existing occupational science and FQOL theory presenting family outcomes applicable to a forensic mental health context. Family work within psycho-social rehabilitation for optimal community reintegration of forensic MHCUs is thus directed and informed for occupational therapy practice. Thus, individual and family support needs have been operationally defined to ensure inclusion of not only forensic MHCUs in society, but the inclusion and empowerment of their family units. Herewith, the occupational therapy profession (specializing in human occupation) is strategically positioned to render pertinent evidence-based family-centred care as members of ForACT MDT teams. The operationalization of the FQOL outcome is a step forward towards the vision of an occupationally just society and "mental health for all" through the "inclusion of all", namely, forensic MHCUs in KwaZulu-Natal, South Africa.

"OT is a critical role in rebuilding and shaping the destiny of our societies"

(MHCP Participant 5, Male, African, 51 years old)

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Appendices

Appendix A: Operational definition(s) of a novel FQOL construct and related concepts for forensic OT

FQOL construct

The family unit actively participates together in meaningful areas of family life within a broader supportive social environment achieving 1) collective health and wellness, 2) desired intra-familial engagement, 3) optimal individual member productivity and agency, and 4) empowered interaction with extra-familial support.

Theme 1: Family Unit Factors

The family experiences a state of intra-familial well-being while meaningfully engaging with one another, and receiving external family support.

Sub-theme 1.1: Family Characteristics

The family unit is characterized by an experience of well-being related to various aspects of life; namely, social well-being, emotional well-being, mental health, physical health, spiritual well-being, and financial well-being.

Domain 1: Social Well-being

The family experiences social wellness (connection) together while they express their unique family identity, fulfil meaningful family roles and responsibilities, and mature in healthy family relationships.

Sub-domains:

a) ***Social Well-being:*** The family experiences wellness in their social connections with one another and form part of a clear family structure.
b) ***Family Identity:*** The family members identify as a family through their shared values, agreed upon behaviours/ family norms, understood expectations, and through their shared positive reputation in the community.
c) ***Family Roles and Responsibilities:*** The family members fulfil their unique and clearly defined family roles and responsibilities as they respond to the needs of the family and society at large.
d) ***Family Relationships:*** The family unit is made up of valuable family relationships characterized by family unity; a sense of belonging; relational depth and trust; acceptance of

one other in interested, understanding and committed relationships; and relationships which are available, affirming, caring and peaceful.

Domain 2: Emotional Well-being

The family experiences optimal emotional wellness through awareness of their personal/ collective emotions, development of their emotional management skills, participation in emotional wellness activities, and through accessing emotional support.

Sub-domains:

a) ***Shared Emotional Well-being Experience:*** The family collectively experiences emotional wellness, after their basic emotional wellness needs have been met.
b) ***Social Emotional Awareness:*** The family identifies and processes through their feelings/ emotions.
c) ***Shared Emotional Management Skills:*** The family has the skills and abilities needed to manage or regulate challenging personal and shared emotions.
d) ***Shared Emotional Wellness Activities:*** The family participates in activities that promote emotional wellness and prevent the experience of negative emotions.
e) ***External Emotional Support Access:*** The family is satisfied with timely external support services meeting emotional support needs of family members.

Domain 3: Mental Health

The family experiences mental health collectively, and has the required knowledge, skills and insight to reduce stigma, prevent mental illness in the family, and promote mental health as a family.

Sub-domains:

a) ***Shared Mental Health Experience:*** The family collectively experiences excellent mental health, after their basic mental health needs have been met.
b) ***Mental Health Insight:*** The family accepts their mental health experience through mental health knowledge, particular insights gained of mental illness, and insights into the impact on the personal/ collective family life.
c) ***Family Mental Health Promotion:*** The family shares responsibility in responding to stigma and promoting one another's mental health.
d) ***Mental Illness Prevention:*** *The family has developed knowledge and skills needed to prevent mental illness in vulnerable family members (at risk family members, youth, etc.).*

Domain 4: Physical Health

The family experiences physical health through active participation in physical health, wellness, and fitness activities or habits together

Sub-domains:

a) ***Shared Physical Health Experience:*** The family experiences excellent physical health after basic health needs have been met.
b) ***Physical Health Activity Participation:*** can be defined as “The family actively participates in shared activities or habits that promote physical health, wellness, and fitness.

c) ***Physical Health Accountability:*** can be defined as "The family is interested in holding one another accountable in achieving personal/ shared physical health, wellness, and fitness goals.

Domain 5: Spiritual Well-being

The family experiences fulfillment and strength from their spiritual beliefs and practices.

Sub-domains:

a) ***Spiritual Peace (Contentment):*** The family is content in their spiritual experience (being fulfilled by spiritual beliefs and practices).
b) ***Spiritual Resilience (Strength):*** The family is strengthened through support received from their God, their spiritual beliefs, and their spiritual practices.
c) ***Spiritual Belief (Faith):*** Family knowledge of one another's personal/ shared spiritual beliefs is highly valued.
d) ***Spiritual Activity (Practice):*** The family shares frequent time in actively participating in specific family based spiritual activities and practices, such as meditation, prayer, and scriptural studies.

Domain 6: Financial Well-being

The family experiences financial security by avoiding financial risk factors, and practicing budgeting principles and healthy spending habits.

Sub-domains:

a) ***Financial Security:*** The family experiences financial security and a satisfactory financial status, due to family members having a stable source of income ensuring that at least their basic financial needs are being met.
b) ***Financial Risk Prevention:*** The family identifies and actively prevents financial pitfalls compromising financial security.
c) ***Budgeting:*** The family ensures that financial planning of their income on essential and non-essential expenses takes place prior to spending.
d) ***Healthy Spending Habits:*** The family practice healthy spending habits as they prioritize their planned budget.

Sub-theme 1.2: Family Dynamics

The family unit engages meaningfully with one another through shared time, shared activity participation, shared empowerment related activities, meaningful intra-familial communication, and by providing internal support to one another within the family.

Domain 1: Shared Family Time

The family enjoys sufficient and valuable shared time together as a family.

Sub-domains: *Shared Time Motivation:* The family shows motivation and commitment to spending valued time together as a family.

a) ***Quality Time:*** The family enjoys sharing quality family time with one another; which is intentional and focused, promotes relational intimacy, enhances family unity, and affirms shared family identity.
b) ***Family Routines:*** The family plans and complies with structured routine family activities.

Domain 2: Shared Activity Participation

The family unit collectively participates in various routine and meaningful family life activities.

Sub-domains:

a) ***Shared Participation Motivation:*** The family understands the collective benefit gained from shared participation in family-centred activities, and is thus motivated to actively participate in these shared family activities with one another.
b) ***Diverse Family Activities:*** The family engages in a diverse range of activities, sharing various life events and experiences with one another.
c) ***Routine Family Activities:*** The family routinely engages in a variety of shared family wellness or quality of life activities with one another.

Domain 3: Family Interaction

The family unit engages in optimal communication with one another to maintain healthy family relationships.

Sub-domains:

a) ***Frequent Communication:*** The family communicates regularly and routinely while sharing personal needs and making inquiries of one another.
b) ***Quality Communication:*** Family communication affirms healthy family relationships by promoting safe personal disclosure and comprehensive understanding of one another's expectations (personal/ shared) through dialogue.
c) ***Communication Content:*** Meaningful Family Communication content consists of personal and shared disclosure of expectations and lived experiences, while reaffirming family relationships.
d) ***Crisis Communication Ability:*** The family communicates quickly, intentionally, and personally during an emergency (forensic facility admission/ other) to access help and maintain relationships.

Domain 4: Family Empowerment

The family is empowered to respond to change, pursue family goals, and take responsibility in their surrounding community, especially within mental health advocacy.

Sub-domains:

a) ***Family Resilience:*** The family is empowered to develop strength, accept responsibility in society, take ownership in fulfilling responsibility, and to cope with or adapt to challenging circumstances or change.

b) ***Family Goal Setting:*** The family engages in setting and pursuing personal and collective goals for the future together.
c) ***Family Social Responsibility:*** The family accepts responsibility for their engagement with their surrounding community as community based change agents.
d) ***Community Mental Health Advocacy:*** The family advocates for mental health in their community through shared lived experience, mental health education and mental illness prevention efforts.

Domain 5: Internal Family Support

The family unit (including immediate and extended family) shares responsibility to extend practical, caring, and unconditional support to one another.

Sub-domains:

a) ***Support Capacity:*** The immediate and extended family maintains a capacity to support all its members in all experiences.
b) ***Support Attitude:*** The family expects and accepts shared responsibility for the unconditional support of all family members.
c) ***Practical Support:*** The family continuously provides practical support and caring service to one other to meet personal and shared needs and desires.
d) ***Crisis Support:*** The family accepts shared responsibility for the unconditional support of one another during crisis situations (especially the MHCU family member during admission/ hospitalization).

Sub-theme 1.3: External Family Unit Support

The family unit receives support from relevant external individuals, groups, or service providers, in addressing pertinent family support needs to improve their collective FQOL.

Domain 1: Professional Family-centred Support

Mental health care professionals (facility and community based) provide relevant expert family-centred support ensuring mental health promotion, family wellness, healthy family dynamics, and access to vocational opportunities.

Sub-domains:

a) ***Mental Health Care:*** The family receives quality family-centred mental health care, treatment and rehabilitation during MHCU hospitalization, community living, and in crisis situations.
b) ***Family Well-being Support*** The family receives professional mental health care to improve emotional and social well-being.
c) ***Family Dynamics Support*** The family receives professional mental health care support to improve relevant family dynamics of healthy active lifestyle, family interaction, family advocacy, and family support skills.
d) ***Vocational Support*** The family receives occupational therapy support to access vocational opportunities for the MHCU family member.

Domain 2: Peer Family Support

The family engages with and receives support from other families who have similar lived experience with having forensic MHCU family members.

Sub-domains:

a) ***Peer Family Support Structure*** The family belongs to an established and beneficial Peer Family Support Structure.
b) ***Shared Lived Experience:*** The Peer Family Support Structure promotes connection and solidarity through sharing lived experiences.
c) ***Mental Health Support:*** The Peer Family Support Structure promotes mental health insight for family empowerment.
d) ***Family Empowerment:*** The Peer Family Support Structure promotes family empowerment by providing insight to one another on family dynamics and family support skills.

Domain 3: Community Support

The surrounding community is supportive of the unique needs of the family with a MHCU family member.

Sub-domains:

a) ***Community Attitude:*** Surrounding community members have an attitude of care, interest, and availability in support of the family.
b) ***Family Support Role Insight:*** Community members have insight into the family's support role responsibility and associated needs.

Theme 2: Individual Member Factors

The individual family member (forensic MHCU or caregiver) experiences optimal personal well-being, productivity, agency, and receives needed external support.

Sub-theme 2.1: Well-being Characteristics

"The individual family member (forensic MHCU or caregiver) experiences unique health and wellness in pertinent areas of life"

Sub-theme 2.1.1. Forensic MHCU Well-being Characteristics: The forensic MHCU family member experiences optimal mental health and wellness in social, emotional, and financial areas of life.

Domains:

a) ***Social well-being:*** The MHCU family member is affirmed by his/ her social network in which healthy close relationships are developed or restored through communication.

b) ***Emotional well-being:*** The MHCU family member experiences emotional well-being by being emotionally mature, responsible, and adaptable.

c) ***Mental health:*** The MHCU family member experiences mental health as he/she manages his/her mental health with insight, and overcomes stigma in the community.

d) ***Financial well-being:*** The MHCU family member experiences financial security for him/herself and the family through personal growth and planning activities.

Sub-theme 2.1.2. Caregiver Well-being Characteristics: The caregiver family member experiences optimal emotional wellness related to emotional management and resilience.

Domain:

a) ***Emotional well-being:*** The caregiver is emotionally aware, skilled in managing emotions and stress, and able to conserve emotional energy for his/her caregiver role.

Sub-theme 2.2: Productivity Characteristics
The forensic MHCU family member optimally engages in meaningful community functioning, work, and leisure activities of daily living.

Domains:

a) ***Community Living:*** The MHCU family member lives an active, healthy, safe, and independent life in the community.
b) ***Work:*** The MHCU family member is able to engage in work with personal insight and developed skills.
c) ***Leisure participation***: The MHCU family member participates in structured restorative activities.

Sub-theme 2.3: Empowerment Characteristics
The individual family member (forensic MHCU or caregiver) is empowered to practice self-agency in various life roles and activities.

Sub-domain 2.3.1. Forensic MHCU Empowerment Characteristics: The forensic MHCU family member is empowered to practice self-agency in various personal choice related activities.

Domain:

a) ***Self-agency:*** The MHCU family member is empowered in actively exercising personal control over key areas of life; namely, independent function, goal setting, accessing support, and offering support to others.

Sub-domain 2.3.2. Caregiver Empowerment Characteristics: The caregiver family member is empowered to practice self-agency in his/ her family based support role.

Domain:

a) ***Support role:*** The caregiver is a recognized family member offering meaningful support to other immediate and extended family members.

Sub-theme 2.4: Individual Member Support Factors

The individual family member (forensic MHCU or caregiver) receives support from relevant external individuals, groups, or service providers, in addressing pertinent individual support needs to improve personal and collective FQOL.

Sub-theme 2.4.1. Forensic MHCU Individual Member Support Factors: The forensic MHCU family member receives external professional and community support in addressing pertinent individual support needs in terms of wellness, productivity, and empowerment to improve personal and collective FQOL.

Domains:

a) ***Professional support:*** The MHCU family member receives professional mental health care intervention by forensic mental health care professionals to meet his/her personal well-being, productivity, and self-agency goals.

b) ***OT support:*** The MHCU family member receives relevant occupational therapy support for skills development in pertinent areas of life - work, education, and money management.

c) ***Community support:*** The MHCU family member is supported by community members who are inclusive, accepting, insightful, and feel responsible for those facing mental health challenges.

Sub-theme 2.4.2. Caregiver Individual Member Support Factors: The caregiver family member receives external professional and community support in addressing pertinent individual support needs in terms of wellness to improve personal and collective FQOL.

Domains:

a) ***Professional support:*** The caregiver is able to access specialist forensic mental health care support to ensure personal mental health, emotional well-being, and social well-being within the family.

b) ***Community support:*** The caregiver is understood and supported by surrounding community members.

Appendix B: *FQOL ForOT* domains, sub-domains, and indicators

Theme 1: Family unit factors

Sub-theme 1: Family characteristics

Domain 1: Social well-being	
Sub-domains	***Indicators***
a) Social Well-Being Experience	The family experiences ideal social wellness as a family unit.
	The family experiences social connection with one another.
	The family experiences meaningful social interactions within the family.
	The family actively participates in activities that improve (promote or enhance) their social connection.
	The family actively participates in activities that protect their social connection with one another.
	The family participates in healthy social habits to protect their social well-being/ connection as a family.
	The family's basic social connection needs are being met.
	The family has identified who is part of their family unit structure.
	The family structure is:
	A) Dynamic (changing, increasing in number)
	B) Conventionally inclusive (including biological family members)
	C) Progressively inclusive (including non-biological/ unrelated family members, such as adopted members, others, supportive individuals, health care workers, peers, etc.)
	D) Actively inclusive of the MHCU family member (despite mental illness)
b) Shared Family Identity	***Shared Family Norms***
	The family members act in a similar way to one another.
	The family is in agreement on the specific way in which family members are to act/ behave (family culture).
	The family express themselves in a unique way (action/ behaviour).
	Shared Family Values
	The family shares a value system.
	The family shares a set of beliefs.
	The family views their shared values/ beliefs as more important than having materialistic wealth.
	The family views healthy relationships as more important than materialistic well-being.
	Shared Family Expectations
	The family members shares expectations of one another.
	The family agrees on boundaries to be respected within the family.
	The family lives according to their shared expectations.
	Shared compliance with values
	The family strictly complies with (or keeps to) their shared values and beliefs.
	The family holds one another accountable to comply with their shared values and beliefs.
	Shared Positive Family Identity
	The family shares a unique family identity.
	The family has a positive family identity.
	The family members are proud of being part of the family.
	The family members belong to a successful family.
	The family has a positive reputation in their community.
	The family maintains a positive reputation in the community.
	The family receives recognition for their meaningful contributions in the community.
	The family celebrates one another's achievements.
	The family maintains a shared identity.
	The family consistently identifies as a family in:
	A) Good times
	B) Challenging times (i.e. mental health crisis)
c) Family Roles and Responsibilities	***Family Roles***
	The family members have clearly defined unique roles and associated responsibilities in the family. (i.e. being a son/ a father/ a relative)
	The family defines particular family roles and responsibilities for non-biological members. (i.e socially constructed family roles and responsibilities)
	The family members actively fulfil (or live out) their unique family roles and responsibilities.
	The family accepts change in family roles and responsibilities in the family.
	The family redefines roles and responsibilities in the family, due to change.
	Specific family role: Caregiver/ guardian:
	The family caregiver(s) have insight into particular family members need for guidance. (e.g. the youth/ at risk family members).
	The family caregiver(s) value recovery focused guidance from the family for the youth/ at risk members.
	The family caregiver(s) have insight into the developmental needs of the youth/ at risk family members.
	The family caregiver(s) accept their caregiver or guardian roles and responsibilities in the family.
	The family's allocated caregiver(s) provide care for the youth/ at risk family members.
	The family's allocated caregiver(s)/ guardian(s) act decisively to prevent harm of the youth/ at risk family

	members.
	Specific family role: Breadwinner
	The family has working family member(s) who are recognized as breadwinners.
	The family has working family member(s) who contribute financially to the household.
	Societal roles:
	The family has member(s) who are respected members of society.
	The family has member(s) who are adult role models in society.
	The family has member(s) who accept social responsibility in their community.
d) Family Relationships	***Valued Relationships***
	The family shows appreciation to one another for the time they share with one another.
	The family remembers lost loved ones by sharing memories with one another.
	The family reflects on good memories of time shared with one another.
	The family members gain meaning from being part of the family.
	Unity
	The family spends time to be together.
	The family is together physically. (i.e. living together, visiting one another).
	The family are together unconditionally. (i.e. in good times and challenging times).
	The family is united with one another.
	The family actively maintains their unity.
	The family actively strengthens their unity.
	The family connect with one another through shared activities/ experiences.
	The family is united during a mental health crisis in the family.
	The family has a close bond with one another.
	The family socializes closely with one another.
	Family Belonging
	The family members are recognized as being a part of the family.
	The family members have a feeling that they belong to the family.
	The family members are clearly identified as being part of the family.
	The family participates in activities that provide them with a feeling of belonging to the family.
	Deep Relationships
	The family relationships are:
	A) deep (in connection with one another, not superficial)
	B) developing (maturing)
	The family renews relationships with one another.
	Trust Relationships
	The family members trust one another.
	The family members grow in trust with one another.
	The family members are open with one another.
	The family members are responsible for keeping trust in the family.
	Acceptance
	The family members are accepting of one another.
	The family members accept one another completely (radical acceptance).
	The family members continually accept one another.
	The family members are forgiving of one another.
	The family members are accepted for being themselves (unique self-expression).
	The family members are accepting of one another's:
	A) strengths
	B) weaknesses (or limitations/ quirks)
	Interested Relationships
	The family is interested in one another's well-being.
	The family shows active interest in one another.
	The family members show reciprocated interest in one another.
	The family thoughtfully considers one another.
	The family makes intentional contact with MHCU family members (personal and regular contact).
	The family considers the interests of one another.
	The family members consider the interests of one another above their own personal interests (compromised self-interest).
	Understanding Relationships
	The family members expect one another to be aware of each other.
	The family members are perceptive of change in one another.
	The family is frequently aware of one another.
	The family has in-depth understanding of one another.
	The family understands one another's:
	A) needs
	B) desires
	C) personal goals
	D) personal context/ circumstances
	E) personal strengths
	F) unique talents or qualities
	G) personal weaknesses/ limitations
	Affirming relationships
	The family is encouraging of one another's personal strengths.
	The family is affirming of one another unconditionally (despite personal limitations/ weaknesses, non-shaming).
	The family celebrates one other's unique qualities.
	Committed Relationships
	The family relationships are stable due to deliberate interpersonal commitments made to one another (i.e. spouse, or adoption, etc.).

	The family is present/ available in one another's lives:
	A) during critical moments
	B) during different life stages (i.e. childhood, adulthood)
	C) permanently supporting one another
	D) offering unconditional support
	The family has an attitude of commitment towards one another.
	The family is protective of one another.
	Available Relationships
	The family expects availability from one another.
	The family members are:
	A) available to one another
	B) open to support one another (approachability)
	C) responsive to one another
	D) open to honest communication with one another
	E) not dismissive of one another
	Caring Relationships
	The family relationships are:
	A)meaningful
	B) loving
	C) caring of the other
	D) affirming/ encouraging of the other
	E) comforting
	The family members reciprocate love in their relationships.
	Peaceful Relationships
	The family relationships are:
	A) secure
	B) peaceful
	C) restful

Domain 2: Emotional well-being	
Sub-domains	***Indicators***
a) Shared Emotional Wellness Experience	The family experiences optimal emotional wellness.
	The family actively participates in activities that improve (promote or enhance) their emotional well-being.
	The family's basic emotional wellness needs are being met.
	The family is able to share emotional experiences with one another:
	A) shared positive emotional experience (e.g. joy, contentment, etc.)
	B) shared negative emotional experience (e.g. grieving together)
b) Shared Emotional Awareness	The family is able to name/ identify their shared emotions.
	The family experiences a feeling of:
	A) acceptance (versus denial/ grief)
	B) hope (versus hopelessness)
	C) happiness (versus depression)
	D) relief (versus anxiety)
	E) peace/ contentment (versus shame, anger/ resentment)
	The family is able to work through their emotions progressing from negative to positive emotions.
	The family is accepting of life's challenging circumstances/ experiences. (i.e. mental illness impact, loss in relationship, forensic admission)
c) Shared Emotional Management Skills	The family is aware of one another's feelings/emotions (emotional perceptiveness).
	The family members are emotionally available to one another.
	The family members are open in sharing their emotions with one another.
	The family is able to process through their emotions with one another.
	The family members are able to stay calm in emotionally volatile situations (emotional regulation skills, pacifying skills, de-escalation skills).
	The family is able to resolve conflict (conflict handling skills).
	The family is able to cope with anxiety (anxiety management skills).
	The family is able to be emotionally adaptable to uncomfortable change (adaptability).
	The family is able to offer emotional encouragement to one another.
d) Shared Emotional Wellness Activities	The family actively participates in shared activities that provide happiness in the family.
	The family actively participates in enjoyable shared activities with one another.
	The family develops motivation by participating in enjoyable activities with one another.
	The family actively participates in shared activities that prevent the experience of negative emotions.
e) External Emotional Support Access	The family is aware of available external emotional support for family members.
	The family accepts external support addressing emotional support needs.
	The family feels emotionally supported:
	A) In their day-to-day life
	B) During an emergency (hospitalization)
	The family is satisfied with the specialist professional emotional support received.
	The family is grateful for the specialist professional support received.

Domain 3: Mental Health	
Sub-domains	***Indicators***
a) Shared Mental Health Experience:	The family experiences excellent mental health.
	The family's basic mental health needs are being met.
	The family actively participates in activities that promote or enhance their mental health.
	The family participates in healthy habits to preserve their mental health.
	The family treats those in the family experiencing mental illness as family members who belong to the unit.
	The family shares in the experiences of the family member experiencing mental illness challenges, including:
	A) Shared sick role (Shared experience of mental illness/ mental health decline)
	B) Shared recovery (Shared experience of mental health recovery/ progress)
	C) Shared functional impact - improvement/ deficit (Shared experience of impact of illness/ health on their ability to live life/ function)
b) Mental Health Insight	***Mental health knowledge:***
	The family has extensive mental health (and mental illness) knowledge.
	The family understands the value of early identification of mental illness.
	The family is able to collect mental health information.
	The family has access to mental health information for psycho-education of the family.
	Mental Illness Insight:
	The family has particular mental health (or mental illness) insight in terms of:
	A) Diagnostics (diagnosis, dual diagnosis, acute episode signs and symptoms, medication and side effects)
	B) External/ systemic causes (key undesirable events, e.g. Traumatic events; family social dynamics, e.g. family communication; destructive community structures, e.g. gangsterism; and destructive community leisure activities, e.g. substance abuse)
	C) Internal/ personal causes (genetics, predetermining character traits, psychodynamics, childhood stress)
	The family has insight into mental health (or mental illness) management or treatment (i.e. medication compliance, relapse prevention, health management strategies, external support available)
	Mental Illness Impact:
	The family has insight into the impact of mental illness on personal/ shared family life, including:
	A) Behavioural impact (e.g. unusual thought process, etc.)
	B) Functional impact (changed function in the family, and impact on the family)
	C) Social impact (sick role impact on family)
	D) Forensic impact (relationship between mental illness and impact on criminal activity)
	Acceptance:
	The family is accepting of the personal/ collective mental illness impact. (i.e. accepted sick role, accepted changed functional outcome, changed family structure)
	The family is accepting of their personal/ shared mental health intervention support need.
c) Family Mental Health Promotion	***Mental Illness Stigma:***
	The family responds collectively to stigma, including:
	A) MHCU family member directed stigma (mental illness labels, misconceptions of incapacity)
	B) Family directed stigma (family blame, family associations, societal exclusion, community response)
	Mental Health Shared Responsibility:
	The family provides a place of support and respite to promote family members' mental health.
	The family values the act supporting one another's mental health.
	The family actively protects themselves from negative environmental factors (i.e. move/ proactive response).
	The family accepts shared responsibility for the family member experiencing mental illness.
	The family is open to specialist mental health intervention for the family. (i.e. willing collaboration with forensic experts, open to hospital admission, open to specialist MHC during hospitalization and post discharge)
d) Mental Illness Prevention	The family focuses on the prevention of mental illness in the family.
	The family is motivated to obtain knowledge of mental illness prevention.
	The family audits the environment to identify factors that can impact on the family's mental health.
	The family develops all members' mental illness prevention skills. (immediate and extended family members)
	The family refers at risk family members for mental illness prevention services/ programs.
	The family actively prevents mental illness of the younger generation (trans-generational mental illness).

Domain 4: Physical Health	
Sub-domains	***Indicators***
a) Shared Physical Health Experience	The family experiences excellent physical health.
	The family experiences total/ complete physical health.
	The family's basic physical health needs are being met.
b) Physical Health Activity Participation	The family actively participates in activities that promote or enhance their physical health.
	The family participates in healthy habits to preserve their physical health.
	The family actively participates in physical health and fitness activities together (e.g. exercise, etc.).
	The family experiences quality sleep (i.e. sleep hygiene practices).
	The family actively participates in relaxation activities together that promote physical health.
c) Physical Health Accountability	The family show frequent interest in one another's personal health.
	The family monitors one another's physical health, wellness, and fitness activities to offer accountability.

Domain 5: Spiritual well-being	
Sub-domains	***Indicators***
a) Spiritual Peace (Contentment)	The family experiences spiritual well-being or spirituality (spiritual beliefs and practices).
	The family experiences spiritual fulfilment.
	The family actively participates in activities that promote or enhance their spiritual well-being.

	The family's basic spiritual needs are being met.
	The family achieves their need to explore spirituality (spiritual beliefs and practices).
b) Spiritual Resilience (Strength)	The family gains strength from their spiritual beliefs and practices.
	The family experiences support from their spiritual engagement.
	The family relies on the God (higher power) of their understanding.
	The family gains hope from their spiritual beliefs and practices.
	The family experiences unity through shared spiritual beliefs and practices.
c) Spiritual Belief (Faith)	The family has knowledge of one another's personal/ shared faith or spiritual beliefs.
	The family greatly values their faith in their spiritual beliefs (i.e. God).
	The family values their faith in their spiritual beliefs (i.e. God) more than materialistic success (financial wealth).
d) Spiritual Activity (Practice)	The family actively participates in spiritual activities/ practices together.
	The family shares time focused on participating in spiritual activity/ practice together.
	The family actively participates in habitual spiritual activities/ practices.
	The family actively participates together in frequent spiritual activities/ practices (I.e daily devotions).
	The family uniquely expresses themselves through their unique shared spiritual activities/ practices.
	The family actively participates in spiritual practices of meditation and prayer (i.e shared devotions).
	The family actively participates in spiritual training opportunities (i.e. scriptural studies).
	The family actively participates in activities that preserve and protect their spirituality.

Domain 6: Financial well-being	
Sub-domains	***Indicators***
a) Financial Security	The family's basic financial needs are being met.
	The family has achieved basic essential living conditions.
	The family members are gainfully employed.
	The family's finances are stable.
	The family is satisfied with their financial status.
	The family members actively participate in activities that promote and enhance financial well-being.
b) Financial Risk Prevention	The family copes with being excluded (from society/ activities) due to their financial limitations.
	The family has insight into existing financial traps/ negative consequences (i.e. financial impact of substance abuse, etc.).
	The family actively prevents their own:
	A) poor budgeting
	B) experience of poverty
	C) entitlement to cash/ goods in kind
	D) overvaluing of wealth
	E) unhealthy dependency on money
	F) begging behaviour
	G) theft by family members
	H) the misuse of money
	I) depleting finances/ assets (cost of substance use/ abuse habits).
	The family is skilled in searching for jobs (gainful employment).
c) Budgeting	The family plans for their future financial security.
	The family is knowledgeable of financial/ money management.
	The family is skilled in money management.
	The family accesses expert opinions for family finances (training and guidance).
	The family's youth have money management knowledge and skills (youth training).
	The family members share responsibility to financially support one another.
	The family plans their budget (allocated spending) for:
	A) Financial responsibilities (prioritized)
	B) Essential expenses/ basic needs (prioritized)
	C) Non-essential expenses (desired for enjoyment/ leisure)
	D) Personal/ Shared interests and activities
	E) Gift giving
	The family members are actively involved in financial planning and decision making.
	The family includes the MHCU family member in financial decision making.
	The family sets a budget according to their income/ financial means.
	The family thoughtfully budgets for:
	A) Personal expenses (i.e. personal activities)
	B) Family expenses (i.e. shared family activities)
	C) Essential expenses (i.e. identified needs, transport needs, etc.)
	D) Non-essential expenses (i.e. realistic enjoyable spending, relaxation, eating out, routine leisure, personal financial reward for work commitment)
d) Healthy Spending Habits	The family keeps to their budget when spending.
	The family has healthy spending habits:
	A) Meeting financial responsibilities (i.e. housing etc.)
	B) Spending on essential items/ activities (i.e. health related expenses, food, clean water, transport etc.)
	C) Spending on non-essential items/ activities (choices/ desirables in leisure, etc.)
	D) Meeting personal/ shared interests and activities in spending
	E) Gift giving (i.e. unique gifts, alternating gifts between cash and goods in kind)
	The family enjoys responsible spending of their money.

Sub-theme 2: Family dynamics

Domain 7: Shared Family Time	
Sub-domains	***Indicators***
a) Shared Time Motivation	The family is motivated to share time together as a family. (motivation)
	The family believes that they need shared family time together. (essential need)
	The family is committed to spending time together as a family. (commitment)
	The family appreciates shared time together. (appreciation/ gratitude)
b) Quality Time	The family chooses to spend time together as a family. (intentionality)
	The family focuses on each other during shared family time. (focused)
	The family enjoys sharing time together. (enjoyment)
	The family feels connected to each other while sharing time with one another. (relational intimacy)
	The family experiences family unity while sharing time with one another. (family unity)
	The family expresses their unique shared family identity (themselves) while sharing time with one another. (family identity: beliefs, spiritual/ cultural identity)
c) Family Routines	The family plans scheduled time for members to be together as a family (shared family time).
	The family plans the logistics of family time in detail. (venue and activities - meetings, mealtimes, events, etc.).
	The family shares frequent time together.
	The family has available time to share with one another. (time availability)
	The family has spends enough time together as a family. (sufficient time spent)
	The family routine and its related boundaries are known to all family members, including:
	A) Daily routines
	B) Weekly routines
	C) Monthly routines?
	The family keeps to the established family routine and its related boundaries. (compliance to family routines)
	The family has scheduled family meeting time for family communication.

Domain 8: Shared Activity Participation	
Sub-domains	***Indicators***
a) Shared Participation Motivation	The family is motivated to participate in activities together.
	The family participates in activities of mutual interest.
	The family participates in activities to meet family member's personal needs.
	The family members share their abilities and resources with one another. (internal family support)
	The family participates in mutually encouraging activities with one another.
b) Diverse Family Activities	The family participates in activities with one another. (shared family activities)
	The family participates in various activities with one another. (various shared activities)
	The family participates in meaningful life events with one another. (shared life events)
	The family experiences important life experiences with one another, including:
	A) Challenging life experiences
	B) Celebratory life experiences
	The family collaborates on family projects with one another. (shared family projects)
	The family supports independent activity participation of family members. (personal non-collaborative activity participation)
c) Routine Family Activities	***Spiritual Activities***
	The family participates in routine spiritual activities with one another, such as prayer.
	Wellness Activities
	The family participates in routine health and wellness related activities together, such as relaxation, and exercise.
	Social Activities
	The family participates in routine social activities together, such as extending hospitality to others.
	Leisure Activities
	The family participates in routine leisure activities together as a family, including:
	A) Home based leisure activities
	B) Community based leisure activities (i.e. affordable family excursions, visiting others, shared travel)
	C) Family games (i.e. electronic games, playing cards)
	D) Sports activities and events (i.e. spectator sport)
	The family plans the logistics of family leisure activities. (i.e. finances required, procuring resources, securing venue)
	The family develops personally and collectively through shared leisure activities.
	Household Activities (Responsibilities)
	The family members accept shared responsibility for household activities.
	The family members show evidence of personal maturity by participating in routine household activities.
	The family culture of participating in household activities/ habits together is transferred to all members.
	The family participates together in routine household activities, including:
	A) Mealtimes
	B) Unique acts of household service (i.e. renovations)
	C) Indoor household chores (i.e. cleaning together, washing dishes, etc.)
	D) External household chores (i.e. maintaining external area, sweeping the yard, etc.)
	The family shares routine household activities/responsibilities with the MHCU family member.

Domain 9: Family Interaction	
Sub-domains	***Indicators***
a) Frequent Communication	The family communicates regularly with one another (daily/frequent).
	The family includes the MHCU family member in regular family communication.
	The family communicates with one another at planned family meeting times.
	The family inquires frequently into one another's' well-being and unique needs.
b) Quality Communication	The family provides a safe environment for open communication with one another.
	The family values communication with one another.
	The family communicates with one another with:
	A) Clarity (clearly sharing thoughts and feelings with one another)
	B) Openness and honesty (transparently sharing personal thoughts and feelings with one another)
	C) Focus (intentional communication in the present)
	D) Bidirectional dialogue (engaging bidirectional communication)
	E) Active listening (receptiveness to verbal and non-verbal communication shared for insightful reflection)
	F) Enjoyment (enjoyment experienced through family communication)
	G) Meaning/ depth (communication with one another is meaningful)
	H) Mediation/ representation (assistance in communication, when necessary)
	The family benefits from communication with one another in:
	A) Strengthened family relationships
	B) Developed caring/loving family relationships
	C) Comprehensive understanding of one another
c) Communication Content	*The family communication has the following meaningful content, including:*
	A) Interest in one another
	B) Encouragement (words of comfort, affirmation, and reassurance)
	C) Good humour (enjoyable jokes and entertaining stories)
	D) Care (words of love and care to one another)
	E) Affirmation of belonging (being a part of family)
	F) Guidance (advise, recommendations, helpful solutions, shared insight)
	G) Personal thoughts (personal disclosure of interests, conversations, positive activities, goals)
	H) Personal feelings (personal disclosure of mood, negative emotions, vulnerabilities, unmet expectations, mental health related concerns)
	I) Personal expectations
	J) Shared expectations
	K) Present lived experience (reflection on particular personal/ shared lived experiences in the present)
	L) Past lived experience (reflection on particular memories of negative/ positive personal/ shared past lived experiences)
	Family communication consists of MHCU centred content, including:
	A) Words of encouragement
	B) Guidance (i.t.o. lifestyle, life roles, social well-being, vocation and goal setting)
	C) Personal disclosure opportunity (comprehensive self-expression by MHCU family member)
d) Crisis Communication	The family communicates a need for help in a crisis/ emergency situation.
	The family maintains communication with the MHCU family member while apart (forensic admission/ hospitalization).
	The family (including the MHCU family member) communicates interest in one another's personal well-being (during forensic hospitalization).

Domain 10: Family Empowerment	
Sub-domains	***Indicators***
a) Family Resilience	***Family Strength***
	The family has developed sense of strength. (strength)
	The family is empowered to respond to personal or collective challenges. (empowerment)
	The family is able to cope with suffering together (disempowerment, or systemic barriers). (coping ability)
	The family is resourceful in their response to personal or collective challenges. (resourcefulness)
	The family able to function while coping with personal or collective challenges. (maintained function)
	Family Responsibility/ Ownership
	The family accepts responsibility to work towards their shared goals. (accept responsibility)
	The family actively works towards their shared family goals. (active involvement/ ownership)
	The family collaborates with one another to achieve shared family goals.
	The family acts responsibly in security conscious activities/ habits.
	Family Adaptability
	The family members participate in honest self-reflection.
	The family members identify personal areas needing change.
	The family responds to set backs/ change with:
	A) Proactivity (a proactive ability to respond)
	B) Adaptability (an ability to adapt to, or change with circumstances)
	C) Re-direction (an ability to re-direct goals, or adjust outcomes in response to changed circumstances)
	The family sets new ways of living life (healthy patterns/ habits).
	The family preserves previous healthy ways of life (practical patterns/ habits).
	The family has adequate time to adjust to change.

b) Family Goal Setting	***Shared Family Vision***
	The family has a vision of an ideal future life for the family.
	The family is unified in its shared vision of the family's future life.
	The family is pleased with its shared vision of the family's future life.
	Shared Ideal Family Objectives
	The family has mutually shared long term goals of an ideal future.
	The family plans together to achieve an ideal long term goal or desired end result.
	The family collaborates with one another to ensure success in achieving an ideal long term goal.
	The family celebrates positive change, success, or achievements, through reflection of past and present.
	Shared Realistic Family Objectives
	The family has realistic expectations of the future.
	The family sets long term goals or desired end results for the future, that are:
	A) Realistic
	B) Relevant/ Unique to their personal situation
	C) Achievable
	The family experience is closer to the ideal family future.
	The family is united in its pursuit of shared goals.
	Shared Family Goal Setting
	The family accepts shared responsibility for personal and collective family goal setting.
	The family sets goals which are:
	A) Clearly defined (clarity)
	B) Mutually shared (accepted)
	C) Collaboratively planned together
	D) Insightful of specific family member roles and responsibilities (personalised)
	E) Inclusive of all family members (immediate, extended, social circle defined as family)
	F) Inclusive of MHCU family member
	The family is intentional in making decisions together (set time and venue for decision making)
	Goal Setting Adaptability
	The family adjusts its expectations and goals in response to changes/ setbacks (personal, functional, etc.).
	The family members offer varying perspectives while solving problems.
	The family is compassionately supportive while solving difficult problems together.
	The family is actively involved in solving a problem together.
	Shared MHCU family member goal setting
	The family is actively involved in facilitating MHCU community reintegration together.
	The family is aware of the MHCU's development in preparation for community reintegration. (change, responsibility, gained skills, etc.)
	The family expects the MHCU to successfully (re-)acquire particular family roles. (i.e. active family member, leadership role, etc.)
	The family collectively accepts responsibility to support the MHCU's recovery goal.
	The family offers ongoing support to achieve the MHCU's recovery goal.
	The family is actively involved in decision making around the MHCU's recovery goal.
	The family actively prevents recovery goal set-backs of the MHCU.
	The family actively supports meaningful vocational goals of the MHCU. (meaningful vocational goals)
	The family is actively involved in MHCU vocational goal setting. (family collaborative goal setting)
	The family supports the MHCU's vocational development. (seeks vocational and training opportunities).
	The family is aware of the MHCU's vocational skills and abilities while goal setting.
	The family is aware of the MHCU's vocational interests while goal setting.
	The family supports MHCU independence in vocational goal setting. (planning and job search)
	The family helps prevent undesirable vocational goal setting/ involvement.
	The family offers creative solutions during MHCU vocational goal setting.
	The family ensures an enabling environment for MHCU vocational involvement.
	The family celebrates the MHCU's vocational achievements.
c) Family Social Responsibility	***Community values compliance***
	The family understands what socially acceptable behaviour to the surrounding community is. (community expectations)
	The family understands the values of the surrounding community. (i.e. equality, protection of human rights, protection of society, respect towards others, etc.)
	The family understands what behaviour is legal in the surrounding community.
	The family understands what religious behaviour is acceptable in the surrounding community.
	The family lives according to the community norms and expectations of socially acceptable living.
	The family lives according to the values of the community.
	The family actively participates in wholesome activities that protect society.
	The family actively participates in growth activities showing respect towards other community members.
	The family lives in a legally compliant way.
	The family lives in a religiously compliant way.
	Social Consciousness
	The family views themselves as community members who belong to the surrounding community. (belonging)
	The family accepts responsibility for their actions within their surrounding community (micro, and macro environments)
	The family is aware of the surrounding community's particular support needs and circumstances.
	The family is aware of their potential impact on the surrounding community.
	The family is aware of the surrounding community's potential impact on the family (including, the youth).
	Depravation Factor Response
	The family is aware of the systemic circumstances that prevent personal and collective growth in the family. (i.e. poor socio-economic status, poor standard of living, poverty, inequality, homelessness, poor sanitation)
	The family is aware of the negative community influences on the family. (i.e. media, xenophobia, antisocial behaviour, anti-authoritarian behaviour, illicit substance abuse)

	The family is aware of environmental factors that are unchanging.
	The family has insight of the materialistic expectations (wealth/ status) of their community.
	The family is actively involved in reducing factors that prevent personal and collective growth in the family.
	Community Change Agents
	The family is committed to adding value to the surrounding community.
	The family plans how they will address community needs as a family through community service.
	The family responds proactively to their community's support needs. (collaborative proactivity)
	The family practically adds value to their surrounding community. (reinvestment)
	The family has a positive identity in the community.
	The family is respected for their positive impact in the community. (impactful, quality, value adding)
d) Community Mental Health Advocacy	The family is involved in mental health advocacy in the community.
	The family includes community members to be change agents in their family's journey.
	The family shares testimonies of successful community and family collaboration efforts.
	The family is involved in mental illness prevention of community members. (i.e. church members, neighbours, etc.) (community centred mental illness prevention)
	The family is involved in public mental health education activities in the community.
	The family shares publically the testimony of the MHCU family member's successful community reintegration.
	The family inspires an attitudinal change towards mental illness in the community.
	The family is involved in educating other peer families in mental health/ mental illness.
	The family supports other families in similar situations (through support groups).

Domain 11: Internal Family Support	
Sub-domains	***Indicators***
a) Support Capacity	***Professional Support Access:***
	The family acts as an existing support system for individual family members.
	The family members reciprocates support of one another (incl. extended family members).
	The family (incl. extended) supports the MHCU family member together by sharing the support role and responsibilities.
	The family receives support from the MHCU family member
	The family is available to support one another by sharing in good or difficult circumstances/ experiences.
	The family is available to support one another in emotionally difficult times (emotional exhaustion/ helplessness).
	The family is able to access available external support.
b) Support Attitude	The family expects one another to share responsibility in supporting one other.
	The family chooses to support one other. (intentional)
	The family is committed to support one another.
	The family members accept responsibility to support one another.
	The family is motivated to offer compassionate support to the MHCU family member.
c) Practical Support	The family offers one another practical help and support.
	The family offers practical help and support to one another, which is:
	A) Ongoing
	B) Unconditional
	C) Not limited by restrictive circumstances (i.e. finance availability)
	D) Generous
	The family provides access for one another to an existing peaceful social environment. (safe and restful)
	The family offers practical support to one another to:
	A) Achieve personal growth goals together
	B) Achieve collective growth goals together
	C) Meet one another's' personal needs
	D) Accommodate functional loss of family member(s) (i.e. MHCU family member).
	E) Show care through their acts of service.
	The family practically supports the MHCU family member during hospitalization (visiting, accompanying to appointments, provision of basic and financial needs, and organizing excursions).
d) Crisis Communication Ability	The family as a whole accepts responsibility to support the MHCU family member during crisis situations.
	Family relationships are reaffirmed during crisis situations.
	The family is available to support one another during crisis.
	The family has insight into one another's personal and collective treatment support needs during a crisis.
	The family is determined to provide unconditional support during admission/ hospitalization of the MHCU family member.
	The family is quick and responsive in offering help during a crisis situation.
	The family is able to access early professional support during a crisis.

Sub-theme 3: External family unit support

Domain 12: Professional Family Centred Support	
Sub-domains	***Indicators***
e) Mental Health Care	***Professional Support Access:***
	The family as a whole accesses family centred mental health care (family therapy) provided by mental health experts.
	The family has professional mental health support which is characterised by:
	A) Availability (Available family centred therapeutic support)
	B) Assertive treatment (Proactive professionals initiating intervention in an accessible manner or location)
	C) Structured (Planned/ scheduled contact sessions)
	D) Frequent (Regular scheduled family therapy, i.e. minimum of biannual contact)
	E) High quality (Quality mental health/ psychiatric services)
	F) Professional insight into collective family needs (Collective impact of mental illness and forensic circumstances)
	G) Collaboration (Collaborative interaction between family members and professionals (MDT))
	H) Open and frequent communication (Between family members and professionals (MDT) through accessible and meaningful methods (email, sms, in person))
	I) Community based (Accessible primary mental health care received in the residential community)
	J) Facility based (Accessible mental health services received during forensic facility observation, admission, hospitalization, pre-discharge, and discharge of MHCU family member)
	Crisis Support:
	The family has access to early professional mental health support in an emergency/ crisis. (Immediately available, empathic, affordable, and responsive)
	Psycho-education:
	The family has received family centred mental health education (psycho-education) by trained mental health professionals.
	The family has received valuable information from mental health care professionals on various topics:
	A) Information access skills (resources available)
	B) Diagnosis (family members' mental health conditions)
	C) Behavioural implications of mental illness
	D) Prescribed treatment and compliance standard
	E) Mental health maintenance (Strategies to maintain mental health)
	Community based support:
	The family has access to community based mental health education for mental health promotion and disease prevention. (Focus on: on available support, dependency, substance abuse, the link between mental illness and criminal acts)
	Facility based support:
	The family is involved in family centred facility based training opportunities and activities during the MHCU's hospitalization (pre-discharge stage).
	The family receives helpful information from mental health care professionals about:
	A) MHCU treatment goals
	B) Rehabilitation program content (therapeutic and health promotion activity involvement)
	C) MHCU progress (mental health)
	D) MHCU progress (emotional well-being)
	E) MHCU progress (overall)
	F) MHCU readiness for community reintegration
f) Family Well-being Support	*The family receives professional mental health care support for:*
	A) Family emotional well-being (emotional processing, mental illness, and forensic impact)
	B) Healthy family relationships (Relationship evaluation and skills development)
g) Family Dynamics Support	*The family receives professional mental health care support for:*
	A) Healthy lifestyle promotion (Ensuring a healthy lifestyle and challenging unhealthy habits)
	B) Quality family interaction (communication)
	C) Family goal setting (family and professional collaboration)
	D) Family support role skills (Acquisition of internal family support role skills through professional training)
	E) Family social responsibility (Planning and implementing community based value adding activities)
h) Vocational Support	*The family receives occupational therapy support of MHCU vocational goals, through the development of:*
	A) Job search knowledge (process of accessing work opportunities)
	B) Job search skills (to access suitable work opportunities)
	C) Knowledge of accessing education/ training opportunities (formal/ informal)

Domain 13: Peer Family Support	
Sub-domains	***Indicators***
a) Peer Family Support Structure	The family is part of a peer family support structure.
	The family values being part of the peer family support structure.
	The family has insight into the benefits of accessing peer family support.
	The family is motivated to participate in the peer family support group.
b) Shared Lived Experience	The family connects with peer families who have shared similar lived experience.
	The family reflects on lived experience with the peer family support group, including:
	A) Challenges
	B) Success stories

c) Mental Health Support	The family has access to mental health experts' advice through the peer family support group.
	The family gains mental health insight through the peer family support structure (psycho-education).
	The family receives counsel on accessibility of emergency/ crisis support through the peer family support structure.
	The family receives advice through the peer family support structure on handling principles to manage challenging behaviour. (behavioural management)
d) Family Empowerment	The family gains insight into effective family communication strategies (i.e. active listening skills) through the peer family support structure. (Family interaction skills)
	The family participates in collaborative problem solving with the peer family support structure.
	The family gains insight into the family support role of the MHCU family member through the peer family support structure. (internal family support)
	The family gains insight into accessing external support and help seeking skills through the peer family support structure. (external family support)

Domain 14: Community Support	
Sub-domains	***Indicators***
a) Support Capacity	The family is supported by various available community members (friends, neighbours, broader community).
	The family is supported by interested and responsive community members.
	The family experiences empathy and compassion from community members.
b) Support Attitude	The family is supported in their support role of the MHCU by community members.

Theme 2: Individual member factors

**definitions in italics summarize below-mentioned indicators of relevant individual member factors.*

Sub-theme 2.1.1: Well-being Characteristics (Forensic MHCU)

Domain 1: Social Well-being	
Sub-domains	***Indicators***
a) ***Inclusive Social Network:*** *The MHCU family member is included into an accepting social network which affirms his/ her human dignity.*	*The MHCU family member is part of a social circle (social network/ community) which is:*
	A) accepting
	B) supportive
	C) non-discriminating
	D) understanding
	The MHCU family member is represented by others in his/her social circle when necessary.
	The MHCU family member is treated by others with human dignity.
b) ***Healthy Relationship Goals:*** *The MHCU family member sets restorative relationships goals.*	The MHCU family member is motivated to have restored relationships (reconnected, reconciled, and restored).
c) ***Healthy Attachment:*** *The MHCU family member develops healthy attachments with other family members and participate in socially cohesive activities in the community.*	The MHCU family member bonds appropriately with other family members (developmentally appropriate attachment, dependence/ independence, mature).
	The MHCU family member actively participates in activities that connect him/her with other family members socially.
	The MHCU family member is skilled in developing close friendships in the community.
	The MHCU family member is skilled in maintaining close friendships in the community.
d) ***Communication Skills:*** *The MHCU family member has developed communication skills for use in their social network/ community.*	The MHCU family member is skilled at interacting with community members.
	The MHCU family member is able to:
	A) initiate conversation
	B) greet others in a friendly manner
	C) express him/ herself clearly to others
	D) express him/herself regularly
	E) use his/ her social skills

Domain 2: Emotional Well-being	
Sub-domains	***Indicators***
a) ***Emotional Maturity:*** *The MHCU family member is emotionally mature, and accepts responsibility for change in his/ her life.*	The MHCU family member has developed emotional maturity.
	The MHCU family member is committed to healthy change in his/her life.
	The MHCU family member accepts responsibility for his/ her life.
b) ***Adaptability:*** *The MHCU family is adaptable as he/she copes with role performance anxieties, functional loss, and unmet expectations.*	The MHCU family member copes with anxiety of his/ her family based role(s) (i.e. guardian/ caregiver role).
	The MHCU family member copes with the loss of previous abilities (functional loss).
	The MHCU family member copes with disappointing family members because of unmet functional expectations.

Domain 3: Mental Health	
Sub-domains	***Indicators***
a) ***Personal Mental Health Insight:*** *The MHCU family member has insight into his/her mental illness experience (impact of stress) and is able to prevent loosing mental health gains (relapse*	The MHCU family member has insight into the impact of past stress on his/her current mental health experience. (identified previous stress, trauma or psychological dysfunction; cultural beliefs of mental illness; absence of past family support).
	The MHCU family understands the consequences of relapse (i.e. homelessness, etc.).
	The MHCU family member is able to identify his/her active behaviour patterns (i.e. dependency).
	The MHCU family member has knowledge of the different stages of recovery and the associated behaviours.
	The MHCU family member is satisfied with his/her changed recovery behaviour and goals.
	The MHCU family member is able to cope with his/her fear of relapse.

	prevention insight)	
b)	***Personal Mental Health Management:*** *The MHCU family member manages his/ her personal mental health experience through gaining insight, practicing healthy habits and strategies, and accessing mental health support.*	The MHCU family member is open to receive mental health care intervention.
		The MHCU family member has insight into his/her mental illness diagnosis.
		The MHCU family member is able to identify current stressors impacting on his/her mental health.
		The MHCU family member is compliant with his/her use of prescribed medication.
		The MHCU family member participates in healthy habits (physical exercise, stop smoking, etc.).
		The MHCU family member is able to cope with or release stress.
		The MHCU family member accesses people or environments that are supportive of his/her mental health care needs.
c)	***Overcoming Stigma:*** *The MHCU family member constructively responds to stigma in his/her family or community.*	The MHCU family member thoughtfully plans his/her responses to stigmatizing questions asked.
		The MHCU family member is able to communicate in a constructive way with people (community/family) who have limited knowledge of mental illness or of his/her personal mental illness experience.

Domain 4: Financial Well-being		
Sub-domains		***Indicators***
a)	***Financial Growth: The MHCU family member pursues personal growth opportunities for improved employment and upward socio economic mobility.***	The MHCU family member copes with the difficult aspects of his/ her current financial situation (unemployment, lower income).
		The MHCU family member proactively improves his/ her suitability for desired employment opportunities (with improved salaries).
		The MHCU family member has access to affordable training/ education.
b)	***Financial Security:*** *The MHCU family member plans towards and generates a secure source of income for him/ herself and the family.*	The MHCU family member is able to generate a personal income.
		The MHCU family member is able to secure a source of income for him/herself and the family which is:
		A) Ongoing (i.e. with a long term source such as assets and marketable services).
		B) Unconditional/ not dependent on unpredictable variables in life (i.e. death, disability, functional limitations, etc.)
		The MHCU family member plans for the financial security of:
		A) him/herself
		B) his/her family.
		The MHCU family member makes alternative plans for income generation for when necessary.
		The MHCU family member is confident of his/her family's future financial security (i.t.o. Diet, housing, amenities, and necessities).

Sub-theme 2.1.2: Well-being Characteristics (Caregiver)

Domain 1: Emotional Well-being		
Sub-domains		***Indicators***
a)	***Personal emotional regulation:*** *The caregiver is aware of his/her personal emotions and has the skills to emotionally regulate him/herself.*	The caregiver is able to identify his/her personal need for emotional support.
		The caregiver is able to deal with his/her personal emotions.
		The caregiver is able to deal with his/her negative emotions:
		A) isolation/ abandonment from others
		B) shame/ stigma
		C) grief
		The caregiver is able to deal with personal anxiety and fear. (being unsupported, fear of others, etc.)
		The caregiver is flexible in problematic situations.
		The caregiver is accepting of situations he/she has little control over.
		The caregiver is able to cope with an uncertain future.
b)	***Stress management skills:*** *The caregiver is able to manage his/her personal stress by using various stress management skills.*	The caregiver is able to manage personal stress.
		The caregiver manages his/her personal stress through:
		A) stress management strategies, such as mindfulness, breathing techniques, etc.
		B) personal boundary setting
		C) problem solving
		D) focus on areas of personal control
c)	***Emotional resilience:*** *The caregiver ensures personal self-care and emotional energy as a caregiver.*	The caregiver actively prevents compassion fatigue/ emotional exhaustion from his/her caregiving role.
		The caregiver participates in self-care activities.
		The caregiver conserves his/her emotional energy.

Sub-theme 2.2: Productivity Characteristics (Forensic MHCU)

Domain 1: Community Living	
Sub-domains	***Indicators***
a) ***Healthy lifestyle:*** *The MHCU family member's activities of daily living are active and healthy.*	The MHCU family member participates in an active lifestyle.
	The MHCU family member participates in activities that facilitate health.
b) ***Community survival skills:*** *The MHCU family member has skills for community based survival and independence.*	The MHCU family member functions independently in the community.
	The MHCU family member uses his/her developed survival skills in the community.

Domain 2: Work	
Sub-domains	***Indicators***
a) ***Work perspective:*** *The MHCU family member is hopeful in securing work as he/she understands the contextual values of work.*	The MHCU family member is aware of the family's values regarding work.
	The MHCU family member is hopeful of finding employment/ vocational opportunities.
b) ***Work ability insight:*** *The MHCU family member is understanding and accepting of his/her personal work ability limitations and strengths.*	The MHCU family member has insight into his/her suitability for particular employment (i.t.o. knowledge, qualification, skills/ abilities).
	The MHCU family member copes emotionally with his/her poor job suitability for particular positions during a job search. (i.e. when underqualified)
	The MHCU family member has insight into how mental illness impacts on his/her work performance.
c) ***Work habits:*** *The MHCU family member has developed work habits and entrepreneurial skills for job suitability.*	The MHCU family member has improved work habits.
	The MHCU family member has developed entrepreneurial skills.
d) ***Work agency:*** *The MHCU family is empowered to cope with, seek and secure work opportunities, while being supported by the work environment.*	The MHCU family member adapts in response to vocational disappointments (i.e. unemployment, non-suitability for desired job, etc.).
	The MHCU family member has accommodating and supportive colleagues in the work place.
	The MHCU family member is empowered to seek for and keep his/her employment.

Domain 3: Leisure Participation	
Sub-domains	***Indicators***
a) ***Leisure structure:*** *The MHCU family member has an existing place and time for personal restoration.*	*The MHCU family member has ... to rest and reflect.*
	A) time
	B) a place
b) ***Active leisure participation:*** *The MHCU family member participates in leisure activities allowing a creative outlet and regulating his/her mood.*	The MHCU family member engages in creative activities. (i.e. singing, etc.)
	The MHCU family member participates in enjoyable mood regulating activities.

Sub-theme 2.3.1: Empowerment Characteristics (Forensic MHCU)

Domain 1: Self-Agency	
Sub-domains	***Indicators***
a) ***Independence:*** *The MHCU family member meets age appropriate independence by accepting personal responsibility, making self-reliant choices, meeting his/her own needs, exercising control, and functioning independently from his/her family in key aspects of life.*	The MHCU family member understands his/her family's expectations of age appropriate independence.
	The MHCU family member values personal independence in important areas of life. (stand on own)
	The MHCU family member is able to independently function apart from his/her family in key aspects of life.
	The MHCU family member is able to be self-reliant by meeting his/her own needs.
	The MHCU family member is able to take responsibility for him/herself.
b) ***Goal setting:*** *The MHCU family member engages in short and long term goal setting for various personally meaningful aspects of his/her life, and to meet personal needs (basic needs/ higher human order needs)*	The MHCU family member is able to set long term goals for his/her future.
	The MHCU family member is able to set goals which are:
	A) Personal
	B) Realistic
	C) Culturally relevant (beliefs of being a man/ woman and of role performance)
	The MHCU family member is able to set and pursue personal goals in the following areas:
	A) Relationships
	B) Vocation
	C) Education (accessible, accredited, field of interests)
	D) Skills Training
	E) Financial Independence
	F) Independent Living
	The MHCU family member knows what his/her prioritized short term needs are.
c) ***Support access (Beneficiary):*** *The MHCU family member accesses support from other family members, and benefits through proactively seeking help.*	The MHCU family member has an identified support system that he/she can access.
	The MHCU family member copes with the absence of particular previously supportive family members. (i.e. deceased, etc.)
	The MHCU family member is able to seek help. (help seeking skills)
	The MHCU family member is assertive in communicating requests.
	The MHCU family member is proactive in seeking help.
d) ***Support offer (Support role):***	The MHCU family member accepts responsibility to support other family members.
	The MHCU family member reciprocates support for other family members.
	The MHCU family member is available in supporting other family members.
	The MHCU family member supports other family members is meaningful ways. (needs met, advise/ guidance, make accommodations for)
	The MHCU family member offers unconditional ongoing support to other family members.
	The MHCU family member offers support to the youth and vulnerable family members.

Sub-theme 2.3.2: Empowerment Characteristics (Caregiver)

Domain 1: Support Role	
Sub-domains	***Indicators***
a) ***Support role attitude:*** *The caregiver has a supportive attitude that enables him/ her to support/ care for other family members.*	The caregiver is available to support other family members.
	The caregiver is committed to offer personal support to:
	A) MHCU family member
	B) Immediate family
	C) Extended family
	The caregiver shows unconditional love and support towards other family members
b) ***Support role skills:*** *The caregiver has the necessary skills to support the MHCU family member in goal setting, mental health, and independent living.*	*Goal setting:*
	The caregiver is empowered to assist the MHCU family member in setting realistic goals.
	Mental health management:
	The caregiver has insight into the MHCU family member's diagnosis/ condition and symptoms.
	The caregiver is aware of other family member's emotions.
	The caregiver accepts other family member's current emotional maturity levels.
	The caregiver understands emotional changes in other family members.
	The caregiver has knowledge of how to handle mood swings in other family members.
	The caregiver uses coping strategies to handle mood swings of other family members.
	The caregiver is able to manage difficult behaviour of other family members:
	A) Destabilized emotions (Emotional regulation skills)
	B) Temper/ Anger outbursts (Anger management)
	C) Conflict (Conflict management)
	D) Resistance/ dangerous behaviour (De-escalating communication)

		The caregiver is able to communicate openly with the MHCU family member during a crisis.
		The caregiver is able to report problematic symptoms and behaviours of the MHCU family member during a crisis.
		MHCU family member independence skills:
		The caregiver is aware of the MHCU family member's:
		A) Existing home management skills.
		B) Progression in independent living skills.
		C) Ability to contribute financially (lights, water, rent, etc.)
c)	***Support role capacity:*** *The caregiver has the capacity to care for other family members by seeking support for him/herself and by setting personal goals.*	The caregiver identifies where to access personal support for him/herself.
		The caregiver is able to ask for help in order to receive personal support.
		The caregiver is able to set personal goals for him/herself.

Sub-theme 2.4.1: Individual Member Support Factors (Forensic MHCU)

Domain 1: Professional support		
Sub-domains		***Indicators***
a)	***Mental Health:*** *The MHCU family member receives mental health care services within the community and from the specialist forensic facility.*	The MHCU family member receives accessible client centred specialist mental health care within a facility.
		The MHCU family member receives the following mental health care within a facility:
		A) in-depth investigation/ assessment
		B) early identification of mental illness
		C) observation (monitoring change in behaviour such as progression/ deterioration)
		D) medical management (medication)
		The MHCU family member receives accessible community based mental health support. (i.e. appropriate referrals, etc.)
		The MHCU family member receives accessible emergency professional support during a crisis.
		The MHCU family receives emergency professional support which offers:
		A) immediate emergency retrieval/ containment at home
		B) reliable emergency services (intersectoral)
		C) emergency assessment
		D) access to involuntary admission
		The MHCU family member receives long term mentorship and support through the various stages of change.
		The MHCU family member receives professional support that has insight into his/her mental illness and personal support needs.
		The MHCU family member receives adequate time with his/her professional support.
		The MHCU family member receives psychoeducation for aspects of recovery, including:
		A) medication compliance
		B) symptomatic relief
		C) relapse prevention strategies
		D) function
		E) balanced lifestyle
		F) recovery process
		G) strategies to maintain mental health
b)	***Social well-being:*** *The MHCU family member develops interpersonal skills during rehabilitation activities for appropriate family based interactions and socialization.*	The MHCU family member receives professional support in re-acquiring meaningful life roles.
		The MHCU family member accepts his/her family identity through professional support.
		The MHCU family member receives professional support to comply with the family norms and expectations.
		The MHCU family member is trained to communicate, interact, and behave in an appropriate manner at home.
		The MHCU family member is trained in appropriate communication with authority at home.
c)	***Physical health:*** *The MHCU family member is provided with a healthy diet within the facility to ensure that his/her physical health needs are being met.*	The MHCU family member receives professional support that manages his/her dietary needs.
		The MHCU family member receives professional support that provides routine time for meals.
d)	***Balanced lifestyle:*** *The MHCU family member receives intervention to ensure a healthy routine and a balanced lifestyle.*	The MHCU family member receives an in-depth lifestyle assessment by the professional support network.
		The MHCU family member receives intervention providing routine and structure for a balanced lifestyle.
e)	***Skills transference:*** *The MHCU family member is prepared to transfer skills developed within the*	The MHCU family member receives pre-discharge skills transference intervention. (individual/ group therapy)
		The MHCU family member is prepared for community (re)integration through professional education. (facility to community home)
		The MHCU family member is held accountable to transfer skills into community living. (facility to home)

	specialist forensic facility into daily community living.	The MHCU family member receives professional support for him/ her to comply with a healthy lifestyle in the community.
		The MHCU family member receives professional support for him/ her to contribute meaningfully to the home.
f)	***Goal setting:*** *The MHCU family member receives professional support while setting personal goals.*	The MHCU family member receives professional support or guidance in goal setting.
		THE MHCU family member collaborates with professional support to set long term goals.

Domain 2: Occupational Therapy Support		
Sub-domains		***Indicators***
a)	***Skills development:*** *The MHCU family receives OT intervention focused on skills development.*	The MHCU family member receives OT input to activate motivation levels.
		The MHCU family member progresses in skills development/ up-skilling through OT intervention.
		The MHCU family member is empowered to train others through OT intervention.
b)	***Work:*** *The MHCU family member participates in (pre-)vocational rehabilitation activities to develop relevant work habits, job search skills, and entrepreneurial skills to access future employment.*	The MHCU family member develops work habits training through the OT (pre-)vocational training program.
		The MHCU family member develops marketable skills through the OT (pre-)vocational training program.
		The MHCU family member receives OT support in pursuing his/her employment goal.
		The MHCU family member is able to access employment opportunities through OT support.
		The MHCU family member is empowered with job search skills through OT intervention.
		The MHCU family member is prepared to overcome job search challenges through OT intervention.
		The MHCU family member is prepared to respond constructively to:
		A) mental illness stigmatization in the workplace
		B) limited job availability
		C) unemployment
		The MHCU family member receives OT training in labour law, including:
		A) inclusion in the work place
		B) equity despite disability
		C) labour market accessibility
		D) work place discrimination
		E) unfair labour practices
		F) unfair dismissal
		G)human rights
		The MHCU family member develops money management knowledge and skills through the OT (pre-)vocational training program.
		The MHCU family member develops income generation knowledge and skills through the OT (pre-)vocational training program.
		The MHCU family member researches and explores relevant business ideas during OT intervention.
		The MHCU family member develops a relevant personal business plan through OT intervention.
		The MHCU family member presents a business plan including:
		A) target market
		B) high demand areas
		C) goods (manufacture/ sale) or services
		The MHCU family member develops self-employment/ business management skills through OT intervention.
		The MHCU family member improves his/her personal capabilities for self-employment through OT support.
		The MHCU family member prepares mentally and emotionally for self-employment/ entrepreneurship.
		The MHCU family member has courage to start his/own business.
c)	***Formal education/ training access***: The MHCU family member accesses relevant education or training opportunities through OT intervention support.	The MHCU family member is supported through OT intervention to access education or training opportunities.
		The MHCU family member is supported through OT intervention to access varying educational opportunities of personal interest.
d)	***Financial well-being:*** *The MHCU family member is supported through OT intervention to manage personal finances and financial expectations well.*	The MHCU family member is supported through OT intervention to use his/her skills to meet their personal financial needs.
		The MHCU family member sets realistic financial expectations through OT intervention.
		The MHCU family member learns to cope with financial deficits through OT intervention.

Domain 3: Community Support		
Sub-domains		***Indicators***
a)	***Community Inclusion:*** *The community includes and accepts the MHCU family member despite his/her circumstances.*	The MHCU family member is included by the community despite his/her mental illness.
		The MHCU family member is accepted by the community in terms of his/her:
		A) successful recovery
		B) mental health (improvement)
		C) observed change
		D) changed functionality (i.e. limitations)
b)	***Community mental health insight:*** *The MHCU family member is*	The MHCU family member is supported by community members who have insight into his/her mental health needs.
		The MHCU family member is supported by community members who have received psycho-education.

	supported by a community who values community reintegration and has insight into mental health goals.	*The MHCU family member is supported by community members with specific mental health insight, including:*
		A) diagnosis
		B) prevalence
		C) forensic mental health care goals
		D) value of community reintegration
		E) value of community support
c)	***Community mental health responsibility:*** *The MHCU family member is supported by the community to achieve mental health and wellness.*	The MHCU family member is supported by community members who accept collective responsibility for his/her mental health outcome.
		The MHCU family member is supported by the community to be successful.

Sub-theme 2.4.2: Individual Member Support Factors (Caregiver)

Domain 1: Professional support		
Sub-domains		***Indicators***
a)	***Mental health:*** *The caregiver accesses caregiver centred mental health care support from experts whether at the forensic facility, in the community, or during an emergency.*	The caregiver is able to access specialist mental health care within a forensic facility (where MHCU family member is admitted).
		The caregiver receives community based mental health care support.
		The caregiver receives caregiver centred mental health care support services which are:
		A) Available
		B) Accessible
		C) Responsive
		D) Insightful
		E) Assertive (initiated by professionals)
		F) Inclusive
		G) Collaborative (between professional and caregiver)
		The caregiver receives crisis support from professionals in facilitating emergency admissions.
		The caregiver is able to seek help from available forensic experts.
b)	***Emotional well-being:*** *The caregiver is able to achieve emotional well-being through professional support services.*	The caregiver receives professional support that aims to achieve caregiver emotional well-being.
		The caregiver receives professional support that assists him/her with processing of emotions/ emotional memories.
c)	***Social well-being:*** *The caregiver is able to achieve social well-being in his/her family relationships through professional support services.*	The caregiver receives professional support that aims to achieve caregiver social well-being.
		The caregiver receives professional support assisting the caregiver with family based communication skills, which are:
		A) open
		B) frequent
		C) inclusive

Domain 2: Community support		
Sub-domains		***Indicators***
a)	***Community interest:*** *The caregiver is supported by a surrounding community who is aware of the caregiver's support needs.*	The caregiver receives support from community members who are aware of caregiver support needs.
		The caregiver receives support from community members who are interested in having caregiver support needs met.
b)	***Peer caregiver support****: The caregiver is supported by peer caregivers in the surrounding community who offer solidarity in experience.*	The caregiver has access to peer family support meetings with other caregivers.
		The caregiver is motivated to access existing peer family support meetings.
		The caregiver experiences connection with other peer caregivers.
		The caregiver reflects on personal experiences with other peer caregivers.

Appendix C: FQOL Construct Preliminary Meaning Map: Comparison of FQOL Framework, Beach Center FQOL Scale, and the FQOLS-2006

FQOL Framework *(Turnbull, et al., 2004, pp. 81-83; Zuna, Turnbull & Summers, 2009, p.27; Zuna et al., 2010; Hu et al., 2011; Chiu, et al., 2013, p. 367; Samuel et al., 2018)*		***Beach Centre*** *(QUAL phase)* *(Poston et al., 2003; Turnbull et al, 2004, p.81 – 83; Park et al., 2003; Beach Center on Disability, 2015)*		***Beach Centre FQOL Scale*** *(QUAN-justification phase, and final tool)* *(Summers et al., 2005; Beach Center on Disability, 2012; Beach Center on Disability, 2015)*			***FQOLS-2006*** *(QUAL phase)* *(Poston et al., 2003; Brown et al. 2015, p.10)*	***FQOL Survey 2006 ID/DD*** *(final tool)* *(Brown et al., 2006)*
Theme	***Sub-theme***	***Domains – qual. inquiry***	***Sub-domains – qual. inquiry***	***Domains content validation stage 1***	***Domains content validation stage 2***	***Final Domains***	***Domains – qual. inquiry***	***Final Domains***
Systemic Factors	**Societal Values**							
	Policies							
	Systems							
	Programs					*Physical/ material well-being*		
					Support for Persons with Disabilities	*Disability Related Support*	*Support from Disability-Related Services*	*Support from Disability Related Services*
Family Unit Factors	**Family Characteristics**	Social Well-being *(Indiv. Orientation)*	Social Acceptance Social Relationships Social Support	Social Well-being				
		Emotional Well-being *(Indiv. Orientation)*	Identity Respect Reducing Stress Choice	Emotional Well-being	Emotional Well-being	**1. Emotional Well-being** *(Family orientated - "outside help"/*		

						"support")		
		Health *(Indiv. Orientation)*	Physical Health	Health	Health and Safety		Health of the Family	**1.Health**
			Mental Health					
			Health Care					
		Financial Well-being *(Family orientation)*	Paying for basic necessities	Financial Well-being	General resources	**2.Physical/ material well-being** *(Family orientated)*	Financial Well-being	**2.Finances**
			Paying for health care					
			Paying for other needs					
			Sources of Income					
			Financial security					
	Family Dynamics	Family Interaction *(Family orientation)*	Positive interactional environment	Family Interaction	Family Interaction	**3.Family Interaction** *(Family orientation – "the family")*	Family Relationships	**3.Family Relationships**
			Communication					
			Supporting each other					
			Flexibility					
		Daily Family Life *(Family orientation)*	Family care	Daily Life			Careers/ Preparing for Careers	**4.Careers and Planning for Careers**
			Daily activities					**5.Leisure and Recreation**
			Getting help					
		Advocacy *(Indiv. Orientation)*	Advocacy role	Advocacy				
			Advocacy activities					
			Facilitators of advocacy					
		Parenting *(Family orientation)*	Providing parental guidance	Parenting	Parenting	**4.Parenting** *(Family orientation - "family members/ adults")*		
			Discipline					
			Teaching					
Family-level Support Factors		Environmental well-being/ Physical Environment *(Indiv. Orientation)*	Home environment					
			School environment					
			Work environment					
			Neighbourhood and community environment			*Support from disability related services*		*Support from Disability Related Services*
							Community and Civic Involvement	**6.Community Interaction**
						Emotional well-being	Support from Other People	**7.Support from other People**
							Spiritual and Cultural	**8.Influence of Values**

							Beliefs	
Individual Member Factors	**Demographics**							*Health of the Family*
	Characteristics	Productivity *(Indiv. Orientation)*	Education	Productivity				*Careers and Planning for Careers*
			Work					
			Leisure					*Leisure and Recreation*
			Personal development					
	Beliefs							
Individual-level Support Factors		Environmental well-being/ Physical Environment *(Indiv. Orientation)*	Home environment					
			School environment					
			Work environment					
			Neighbourhood and community environment		Support for Persons with Disabilities	**5.Disability Related Support** *(Individual orientated – "the family member with special needs")*	Support from Disability-Related Services	**9.Support from Disability Related Services**

Appendix D: Novel FQOL construct final meaning map (Family Unit Factors)

FQOL Framework *(Turnbull, et al., 2004, pp. 81-83; Zuna, Turnbull & Summers, 2009, p.27; Zuna et al., 2010; Hu et al., 2011; Chiu, et al., 2013, p. 367)*		***Beach Centre*** *(QUAL phase)* *(Poston et al., 2003; Turnbull et al, 2004, p.81 – 83; Park et al., 2003; Beach Center on Disability, 2015)*		***Beach Centre FQOL Scale*** *(QUAN-justification phase, and final tool)* *(Summers et al., 2005; Beach Center on Disability, 2012; Beach Center on Disability, 2015)*			***FQOLS-2006*** *(QUAL phase)* *(Poston et al., 2003; Brown et al. 2015, p.10)*	***FQOL Survey 2006 ID/DD*** *(final tool)* *(Brown et al., 2006)*	***FQOL ForOT*** *(QUAL phase)* *(d'Hangest d'Yvoy, 2020)*		
Theme	***Sub-theme***	***Domains – qual. inquiry***	***Sub-domains – qual. inquiry***	***Domains content validation stage 1***	***Domains content validation stage 2***	***Final Domains***	***Domains – qual. inquiry***	***Final Domains***	***Sub-themes***	***Domains – qual. inquiry***	***Sub-domains – qual. inquiry***
Systemic Factors	**Societal Values**										
	Policies										
	Systems										
	Programs					*Physical/ material well-being*					
					Support for Persons with Disabilities	*Disability Related Support*	*Support from Disability-Related Services*	*Support from Disability Related Services*			
Family	**Family**	Social Well-	Social	Social Well-					1.Family	**1.Social Well-**	Social Well-

Unit Factors	**Characteristics**	being *Indiv. Orientation*	Acceptance	being					Character-istics	**Being**	Being Experience
			Social Relationships								Shared Family Identity
			Social Support								Family Roles and Responsibilities
											Family Relationships
		Emotional Well-being *Indiv. Orientation*	Identity	Emotional Well-being	Emotional Well-being	**1.Emotional Well-being** *Family orientated - "outside help"/ "support"*				**2.Emotional Well-being**	Shared Emotional Wellness Experience
			Respect								Shared Emotional Awareness
			Reducing Stress								Shared Emotional Management Skills
			Choice								Shared Emotional Wellness Activities
											External Emotional Support Access
		Health *Indiv. Orientation*	Mental Health	Health	Health and Safety		Health of the Family	**1.Health of the Family**		**3.Mental Health**	Shared Mental Health Experience
											Mental Health Insight
											Family Mental Health Promotion
											Mental Illness Prevention
			Physical Health							**4.Physical Health**	Shared Physical Health Experience
											Physical Health Activity Participation
			Health Care								Physical Health Accountability

							Spiritual and Cultural Beliefs *Family level support factors*	**2.Influence of values**		**5.Spiritual Well-being**	Spiritual Peace (Contentment) Spiritual Resilience (Strength) Spiritual Belief (Faith) Spiritual Activity (Practice)
		Financial Well-being *Family orientation*	Paying for basic necessities Paying for health care Paying for other needs Sources of Income Financial security	Financial Well-being	General resources	**2.Physical/ material well-being** *Family orientated*	Financial Well-being	**3. Finances**		**6.Financial Well-being**	Financial Security Financial Risk Prevention Budgeting Healthy Spending Habits
	Family Dynamics	Daily Family Life *Family orientation*	Family care Daily activities Getting help	Daily Life			Careers/ Preparing for Careers	**4. Careers and Planning for Careers**	2.Family Dynamics	**1. Shared Family Time**	Shared Time Motivation Quality Time Family Routines
								5. Leisure and Recreation		**2. Shared Activity Participation**	Shared Participation Motivation Diverse Family Activities Routine Family Activities
		Advocacy *Indiv. Orientation*	Advocacy role Advocacy activities Facilitators of advocacy	Advocacy						**3. Family Empowerment**	Family Resilience Family Goal Setting Family Social Responsibility Community Mental Health Advocacy
		Family Interaction *Family*	Positive interactional environment Communicati	Family Interaction	Family Interaction	**3. Family Interaction** *Family*	Family Relationships	**6. Family Relationships**		**4. Family Interaction**	Frequent Communication Quality

		orientation	on			*orientation – "the family"*					Communication
			Supporting each other								Communication Content
			Flexibility								Crisis Communication
										5. Internal Family Support	Support Capacity
											Support Attitude
											Practical Support
											Crisis Support
Family-level Support Factors		Environmental well-being *Indiv. Orientation*	Home environment			*Support from disability related services*		*Support from Disability Related Services*	3.External Family Unit Support	**1. Professional Family Centred Support**	Mental Health Care
			School environment								Family Well-being Support
			Work environment								Family Dynamics Support
			Neighbourhood and community environment								Vocational Support
						Emotional well-being		**7. Support from other People**		**2. Peer Family Support**	Peer Family Support Structure
											Shared Lived Experience
											Mental Health Support
							Community and Civic Involvement	**8. Community Interaction**		**3. Community Support**	Family Empowerment
											Community Attitude
								Influence of Values			Family Support Role Insight

FQOL Framework *(Turnbull, et al., 2004, pp. 81-83; Zuna, Turnbull & Summers, 2009, p.27; Chiu, et al., 2013, p. 367; Samuel et al., 2018)*		***Individual Quality of Life construct (QoL)*** (Brown & Brown, 2004, pp. 14-15, referencing Schalock & Verdugo, 2002)		***Beach Centre*** *(QUAL phase)* *(Poston et al., 2003; Turnbull et al, 2004, p.81 – 83; Park et al., 2003; Beach Center on Disability, 2015)*		***Beach Centre FQOL Scale*** *(QUAN-justification phase, and final tool)* *(Summers et al., 2005; Beach Center on Disability, 2012; Beach Center on Disability, 2015)*			***FQOL Survey 2006 ID/DD*** *(final tool)* *(Brown et al., 2006)*	***FQOL ForOT*** *(QUAL phase)* *(d'Hangest d'Yvoy, 2020)*		
Theme	***Sub-theme***	***Core Domains***	***Core Indicators***	***Domains – qual. inquiry***	***Sub-domains – qual. inquiry***	***Domains content validation stage 1***	***Domains content validation stage 2***	***Final Domains***	***Final Domains***	***Sub-themes***	***Domains – qual. inquiry***	***Sub-domains – qual. inquiry***
Individual Member Factors	**Demographics**								*Health of the Family*			
	Characteristics			Productivity *Indiv. Orientation*	Education Work Leisure Personal development	Productivity			*Careers and Planning for Careers* *Leisure and Recreation*			
	Beliefs											
Individual Member Factors (Forensic MHCU)		**1. Interpersonal relations**	Interactions Relationships Supports (emotional, physical, feedback)							Well-being Character-istics	**1. Social Well-being**	Inclusive Social Network Healthy Relationships Healthy Attachment Communicati on Skills
		2. Emotional well-being	Contentment Self-concept Lack of stress								**2. Emotional Well-being**	Emotional Maturity Adaptability

		3. Physical well-being	Health								**3. Mental Health**	Personal Mental Health Insight
			Activities of daily living									Personal Mental Health Management
			Health care									Overcoming Stigma
			Leisure								**4. Financial Well-being**	Financial Growth
		4. Material well-being	Financial Status									Financial Security
			Employment								**1.Community Living**	Healthy Lifestyle
			Housing							Productivity Character-istics		Community Survival Skills
		5. Personal development	Education								**2. Work**	Work Perspective
			Personal competence									Work Ability Insight
			Performance									Work Habits
												Work Agency
											3. Leisure Participation	Leisure Structure
												Active Leisure Participation
		6. Self-determination	Autonomy and personal control							Empower-ment Character-istics	**4. Self-Agency**	Independence
			Goals and personal values									Goal Setting
			Choices									Support Access (Beneficiary)
												Support Offer (Support Role)
Individual-level Support Factors (Forensic		**7. Rights**	Hunan rights (respect, dignity, equality)				Support for Persons with Disabilities	**4. Disability Related Support**	**9. Support from Disability Related**	Individual Member Support Factors	**1.Professional Support**	Mental Health
												Social Well-being

MHCU)									**Services**	(MHCU Family Members)			Physical Health
													Balanced Lifestyle
			Legal (citizenship, access, due process)										Skills Transference
													Goal Setting
												2.OT Support	Skills Development
													Work
													Formal Education/ Training Access
													Financial Well-being
		8. Social inclusion	Community integration and participation									**3.Community Support**	Community Inclusion
			Community Roles										Community Mental Health Insight
			Social supports										Community Mental Health Responsibility
Individual Member Factors (Caregiver)		*Emotional Well-being*								Well-being Characteristics		**1.Emotional Well-being**	Personal Emotional Regulation
													Stress Management Skills
													Emotional Resilience
		Self-determination / Interpersonal relations		Parenting *Family orientation*	Providing parental guidance	Parenting	Parenting	**5. Parenting**		Empowerment Characteristics		**1.Support Role**	Support Role Attitude
					Discipline								Support Role Skills
					Teaching								Support Role Capacity
Individual-level Support		*Rights*					*Support for Persons*	*Disability Related*	*Support from*	Individual Member		**1.Professional Support**	Mental Health

Factors (Caregiver)							*with Disabilities*	*Support*	*Disability Related Services*	Support Factors (Caregiver)		Emotional Well-being
												Social Well-being
		Social Inclusion									**2.Community Support**	Community Interest
												Peer Caregiver Support

Appendix E: Biomedical Research Ethics Committee Provisional Approval

UNIVERSITY OF
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07 June 2017

Ms ML d'Hangest d'Yvoy (216073319)
Discipline of Occupational Therapy
School of Health Sciences
College of Health Sciences
margaux.dhdy@gmail.com

Dear Ms ML d'Hangest d'Yvoy

Title: Developing a family quality of life tool directing occupational therapy for mental health care users and their families in a South African forensic psychiatric setting.
Degree: M Occupational Therapy
BREC REF NO: BE297/17

Please note the change in the BREC reference number from BF297/17 to BE297/17.

PROVISIONAL APPROVAL

A sub-committee of the Biomedical Research Ethics Committee has considered your application received on 05 May 2017.

The study is given **PROVISIONAL APPROVAL** subject to the response to the following queries:

1. Please specify total costs of anticipated study on Page 3 of BREC application.
2. If the 3rd phase of testing tool is not conducted, the tool will not have validity, specificity, criteria based on testing in population. So how will the study be able to assess fully if tool is valid?
3. On BREC application page 9, Q.4.7 refers to Townhill hospital as site. Please clarify.
4. Has there been any community consultation with the OT body/network where the study team plans to solicit support re study?
5. For mental health care users on leave of absence, who will pay transport costs to attend the interview/group?
6. Please provide permission from hospital and Department of Health.
7. Please correct on letters to hospital and other gatekeepers that study is "provisionally approved" by BREC.
8. One of the most common primary diagnosis in state patients at Fort Napier Hospital is intellectual disability and then schizophrenia. How will capacity to consent be obtained and will there be any exclusion criteria based on mental state.
9. Patients are expected to provide diagnosis. This may not be reliable. Please review.
10. Page 55 of protocol: refers to SP, SPP and involuntary SPP. Please clarify.

Please could each query be responded to separately e.g. BREC Query 1: (List the query) and below the query state the Answer to Query 1. A tabulated response will not be acceptable.

All changes to the text must be highlighted and the relevant pages of the research application form resubmitted. Only one copy of the responses and amended pages needs to be submitted.
Only when full ethical approval is given, may the study begin. **Full ethics approval has not been given at this stage.**

PLEASE NOTE: Provisional approval is valid for 6 months only - should we not hear from you during this time - the study will be closed and reapplication will need to be made.

Your acceptance of this approval denotes your compliance with South African National Research Ethics Guidelines (2015), South African National Good Clinical Practice Guidelines (2006) (if applicable) and with UKZN BREC ethics requirements as contained in the UKZN BREC Terms of Reference and Standard Operating Procedures, all available at http://research.ukzn.ac.za/Research-Ethics/Biomedical-Research-Ethics.aspx.

BREC is registered with the South African National Health Research Ethics Council (REC-290408-009). BREC has US Office for Human Research Protections (OHRP) Federal-wide Assurance (FWA 678).

Yours sincerely

Mrs A Marimuthu
Senior Administrator: Biomedical Research Ethics
AM/PP

cc supervisor: uysk@ukzn.ac.za
cc postgraduate administrator: nenep1@ukzn.ac.za

Appendix F: KwaZulu-Natal Department of Health Approval of a Research Proposal

health
Department:
Health
PROVINCE OF KWAZULU-NATAL

DIRECTORATE:
Health Research & Knowledge Management (HKRM)

330 Langalibalele street
Private Bag X9051 PMB, 3200
Tel: 033 395 2805/3189/3123 Fax: 033 394 3782
Email: hrkm@kznhealth.gov.za
www.kznhealth.gov.za

Reference: HRKM296/17
KZ_2017RP28_681

11 September 2017

Dear Margaux d'Hangest d'Yvoy
(University of KwaZulu-Natal)

Subject: Approval of a Research Proposal

1. The research proposal titled **'Developing a Family Quality of Life tool directing occupational therapy for mental health care users and their families in a South African forensic psychiatric setting'** was reviewed by the KwaZulu-Natal Department of Health (KZN-DoH).

   The proposal is hereby **approved** for research to be undertaken at Fort Napier Hospital.

2. You are requested to take note of the following:
   a. Make the necessary arrangement with the identified facilities before commencing with your research project.
   b. Provide an interim progress report and final report (electronic and hard copies) when your research is complete.

3. Your final report must be posted to **HEALTH RESEARCH AND KNOWLEDGE MANAGEMENT, 10-102, PRIVATE BAG X9051, PIETERMARITZBURG, 3200** and e-mail an electronic copy to hrkm@kznhealth.gov.za

For any additional information please contact Ms G Khumalo on 033-395 3189.

Yours Sincerely

Dr E Lutge
Chairperson, Health Research Committee
Date: 11/9/17

Fighting Disease, Fighting Poverty, Giving Hope

Appendix G: KwaZulu-Natal Department of Health Disability and Rehabilitation Letter of Support

health
Department:
Health
PROVINCE OF KWAZULU-NATAL

DIRECTORATE:
NCDs – DISABILITY AND REHABILITATION

121 Chief Albert Luthuli Street
Pietermaritzburg 3200
Tel: 033 – 846 7246 Fax: 033 – 846 7273 Email:sthembiso.blose@kznhealth.gov.za
www.kzhealth.gov.za

Reference: Ms. Margaux d'Hangest d'Yvoy: Research Masters Student

Date: 09 October 2017

TO WHOM IT MAY CONCERN

LETTER OF SUPPORT FOR KZN DOH OCCUPATIONAL THERAPISTS TO PARTICIPATE IN THE RESEARCH STUDY – MS M d'HANGEST d'YVOY

Dear Sir/Madam,

The Disability and Rehabilitation Programme in the Department of Health KZN supports the proposed study which Ms. M. d'Yvoy will undertake in her studies for her masters.

The research proposal titled 'Developing a Family Quality of Life tool directing occupational therapy for mental health care users and their families in a South African forensic psychiatric setting' by the postgraduate Masters student, Ms. Margaux d'Hangest d'Yvoy, has been considered to conduct research with occupational therapists form various psychiatric facilities across Kwa-Zulu Natal.

The researcher has received a letter of support from Fort Napier Hospital to conduct research on patients who are on Leave of Absence, family members and some members of the clinical staff.
I hereby recommend that the researcher also be granted permission to conduct the study recruiting Occupational Therapists working for Department of Health at various psychiatric hospitals/ units within Kwa-Zulu Natal

Thank you;

MR. SB BLOSE
DEPUTY MANGER:
DISABILITY AND REHABILITATION

Fighting Disease, Fighting Poverty, Giving Hope

Appendix H: Permission to conduct research at Fort Napier Hospital

health
Department:
Health
PROVINCE OF KWAZULU-NATAL

DIRECTORATE:
Fort Napier Hospital

Physical Address: 1 Devonshire Road, Napierville, Pietermaritzburg
Postal Address: Fort Napier Hospital, P O Box 370, Pietermaritzburg 3200
Tel: 033 2604361 ; Fax: 086 7510974 ; Email: anthony.pillay@kznhealth.gov.za
www.kznhealth.gov.za

31 August 2017

The CEO
Fort Napier Hospital

Dear Mrs Nxaba

Ms M d'Hangest d'Yvoy: Research Ethics Application
Permission to conduct research towards a Masters in Occupational Therapy (UKZN)

The Fort Napier Hospital Research Ethics Committee has considered the application from Ms M d'Hangest d'Yvoy to conduct the abovementioned research on Fort Napier Hospital patients who are on Leave of Absence (LOA), their family members and some members of the clinical staff. The Committee also had a meeting with Ms M d'Hangest d'Yvoy on 31 August 2017 to clarify certain issues pertaining to the proposed research.

The Committee has no objection to this research being conducted, provided that:

(1) Informed consent is obtained from all patients, family members and staff who are recruited into the study.
(2) The capacity to consent must be carefully monitored since some patients, even though they are on LOA, may not have the cognitive capacity to consent in an informed manner. These patients cannot be included in the study. Similarly care must be taken with recruiting family members to ensure they have the capacity to provide informed consent.
(3) The researcher should make it very clear to patients and their families that this is independent research that is not connected in any way to the patients' treatment and that it is not related to the patients' LOA. It is important that patients and their families do not view the researcher as part of the treatment team because that would mislead the patients and families into believing that they are obliged to participate in the study.
(4) Patients, family members or others brought onto the Fort Napier Hospital premises must sign indemnity forms against injury or any other adverse event that may occur. The researcher must formally advise them on matters of safety and confidentiality.

We, therefore, recommend that the researcher be granted permission to conduct the study, subject to the above.

Sincerely,

Professor Anthony L Pillay
Chair: Research Ethics Committee

Fighting Disease, Fighting Poverty, Giving Hope

Appendix I: Invitation to participate (Family members' example)

COLLEGE OF HEALTH SCIENCES

Date: 26.06.2018

Student: Ms Margaux d'Hangest d'Yvoy (c) 076 148 7036; (e-mail) margaux.dhdy@gmail.com

Supervisors: Prof K Uys (w) 031 260 7953; (e-mail) kitty.uys@up.ac.za

Mrs D Fewster (w) 031 260 7953; (e-mail) fewster@ukzn.ac.za

Biomedical Research Ethics Administration, Westville Campus, Govan Mbeki Building, Private Bag X 54001, Durban, 4000, KwaZulu-Natal, South Africa; Tel: +27 31 2602486; Fax: +27 31 2604609;
Email: BREC@ukzn.ac.za

RE: INVITATION TO PARTICIPATE IN RESEARCH – Family Members

I am a Masters in Occupational Therapy student from the University of KwaZulu-Natal, and would greatly appreciate you to consider participating in my research project. You have been approached as a potential participant because of your experience as family member living with a mental health care user.

The results of this study could improve occupational therapy services and help occupational therapists to address family support needs with specific occupational therapy skills. It is known that family life is important and the gaps in support, challenges and joys are not understood well by therapists.

Purpose and aim:

The purpose and aim of this study is to create a Family Quality of Life measurement tool that could help in setting Occupational Therapy goals for therapy with MHCUs and their families in a forensic psychiatric setting. This study will use the life experience and expertise of three key participant groups (mental health care professionals, mental health care users on LOA, and their family members) to explore aspects of family life to be included in this tool.

This research will help not only with improved service delivery at the hospital, but it may help the Department of Health in changing therapy for MHCUs to strengthen families, and improve the quality of life for all. Families often are left unsupported and this can change.

If you agree to take part, you will participate in 1 discussion group in Pietermaritzburg. This group will take place on a Saturday that offers convenience to the participants.

Risks:

There are no particular risks of participation in this study. However, if there are any overwhelming emotions that you may experience by participating in this study, referrals will be made for psychotherapy.

Incentives:

Tea and a light lunch will be provided on the day. The researcher will also reimburse you for your transportation costs.

Ethical considerations:

Please know that participating in this research is completely your choice. You are not being forced to take part. You are also able to withdraw or leave the study at any stage without fear of negative consequences.

If you agree to participating, you will need to fill in a consent form before the discussion group happens.

All information shared in the group will not be shared outside of the group. Information shared in the MHCU group and the family members' group will not be shared with each other. This means that all discussion will happen in a safe space respecting your confidentiality.

Your identity will be kept confidential at all times. People participating in the groups will agree through the confidentiality forms, not to share each other's identities with people outside the groups.

Results of the study may be shared in scientific journals and could be presented at research congresses/ conferences. This may mean that the hospital will be identified, but it is important to know that the identities of all participants will be protected.

Participants will also need to fill in a "Biographical Form" to gather information of age, gender, profession etc. This will be shared in the results of the study without sharing your name.

Remuneration of transport fees will take place. This is not a payment for participation in the study but to make sure that there is no inconvenience caused to you by participating.

This study has been ethically reviewed and approved by the UKZN Humanities and Social Science Research Ethics Committee. (Approval number: BE 297/17). Please note BREC contact details above.

Kindly direct any concerns, comments or queries to myself on 0761487036, or the UKZN Humanities and Social Science Research Ethics Committee on 031 260 4557.

Your participation in the study would greatly be appreciated.

Yours Sincerely,

Ms Margaux d'Hangest d'Yvoy

Department of Occupational Therapy

University of KwaZulu-Natal

Appendix J: Informed consent form (Pilot study example)

UNIVERSITY OF KWAZULU-NATAL
INYUVESI YAKWAZULU-NATALI

COLLEGE OF HEALTH SCIENCES

INFORMATION SHEET AND CONSENT TO PARTICIPATE IN RESEARCH: PILOT STUDY:

Date: 09.12.2017

Dear potential participant,

My name is Margaux d'Hangest d'Yvoy and I am a Masters in Occupational Therapy student at the University of KwaZulu-Natal.

Invitation, Aim and Purpose:

You are being invited to consider participating in a study that involves research aimed at developing a Family Quality of Life measurement tool for Occupational Therapists to provide family centered support to MHCUs and their families in a forensic psychiatric setting. The study will explore which domains (aspects of family life) and measurable indicators should be included to help OTs in goal setting in their therapy, followed by confirmation of these aspects through a validation process.

Participants:

The study is expected to enroll 3-4 participants in the initial piloting/ interview schedule evaluation phase, and 6-12 participants in each of the 4 initial focus groups (mental health care professionals, mental health care users, and their family members). The initial focus groups will take place at Fort Napier Hospital in the Lecture Hall Building.

Procedures:

If you consent to participate you will be involved in the evaluation of the interview schedules developed for the one (1) of the initial three (3) focus groups. You would participate in a pilot group discussion simulating the process of the focus group with the completion of an evaluation addressing areas of clarity, semantics, and whether the overall outcome of the interview schedules was achieved. There is also an opportunity to make any other additional recommendations.

Duration of Involvement:

Participants will attend a face to face discussion for a duration of approximately 2 hours. This will include introduction to the topic, completion of documentation, participation in discussion (individual interview/ group session), and evaluation of interview schedule.

Risks, Discomforts or Inconveniences:

There are no known apparent risks to participation in this study.

Benefits:

Your participation in this study will benefit the profession as we expand the knowledge base through an unexplored area of mental health care.

Voluntary Participation:

Participation in this study is completely voluntary. You will be able to withdraw from this study at any moment. You are in your full right to refuse participation or to withdraw from the study with no concern of negative consequences.

Privacy and Confidentiality:

We will take strict precautions to safeguard your personal information throughout the study. Your information will be kept without your name or other personal identifiers. The group interview will take place in a private room. Any reports or publications about the study will not identify you or any other study participant.

Ethical Review:

This study has been ethically reviewed and approved by the UKZN Biomedical Research Ethics Committee (Approval number: BE 297/17).

Questions:

In the event of any problems or concerns/ questions, you may contact –

1. The researcher, Margaux d'Hangest d'Yvoy, at (c) 076 148 7036; (e-mail) margaux.dhdy@gmail.com
2. Her supervisors, Professor Kitty Uys, ((w) 031 260 7953, (e-mail) uysk@ukzn.ac.za), and Mrs Debbie Fewster ((w) 031 260 7953, (e-mail) fewster@ukzn.ac.za)
3. Or the UKZN Biomedical Research Ethics Committee, contact details as follows: Biomedical Research Ethics Administration, Research Office, Westville Campus, Govan Mbeki Building, Private Bag X 54001,

Durban, 4000, KwaZulu-Natal, South Africa; Tel: +27 31 2602486/ +27 31 2604769; Fax: +27 31 2604609; Email: BREC@ukzn.ac.za

If you have any other further comments, questions or concerns about the study, do make contact with the Department of Occupational Therapy at UKZN (031 260 8218)

Signatures:

I, the researcher, have explained the above verbally and given the potential research participant time to ask any questions they may have. They have been given a copy of this consent form.

_____ _____

Researcher's Signature Date

I, _____ have been informed about this research study and understand its purpose, possible benefits, risks and discomforts. I agree to take part in this research as a subject. I know that I am free to withdraw this consent and leave this project at any time, and that doing so will not cause me any penalty or loss of benefits that I would otherwise be entitled to enjoy. I have been given time to ask any questions and these questions have been answered to the best of the investigator's ability.

_____ _____

Participant's Signature Date

I understand that the focus group discussion will be audio-recorded and then transcribed for pilot study purposes. I understand that only the researchers will have access to the tape and to the transcriptions. I agree to the recording of the group's discussion.

_____ _____

Participant's Signature Date

Appendix K: Informed consent form (Family member focus group example)

INFORMATION SHEET AND CONSENT TO PARTICIPATE IN RESEARCH:

FOCUS GROUP 4 – FAMILY MEMBERS:

Date: _____

Dear potential participant,

My name is Margaux d'Hangest d'Yvoy and I am a Masters in Occupational Therapy student at the University of KwaZulu-Natal.

Invitation, Aim and Purpose:

You are being invited to consider participating in a study that involves research aimed at developing a Family Quality of Life measurement tool for Occupational Therapists to provide family centered support to MHCUs and their families in a forensic psychiatric setting. The study will explore which areas of family life should be included to help OTs in setting goals for therapy.

Participants:

The study will include three (3) different groups (mental health care professionals, mental health care users, and their family members) with 6-12 participants in each discussion group.

Procedures:

If you agree to participate in the study, you will participate in 1 traditional focus/ discussion group with other family members of mental health care users. The session will be audio-recorded, with information being written up afterwards. All information will be kept confidential, and all members are asked to respect each other's confidentiality.

Duration of Involvement:

As a participant, you will be required to attend one focus group with a duration of 1 – 2 hours taking place on one Saturday on a specified date.

Risks, Discomforts or Inconveniences:

There are no known apparent risks to participation in this study. If you experience any negative emotions and require psychotherapy, discuss with the researcher who will assist with a referral. By consenting to participate you agree to participate within the focus group, and agree to communicate openly and honestly. You also

agree to respect the anonymity of the group members not sharing personal information with others outside the group. Your work/ income or finances should not be affected as groups will take place on a Saturday, and you will be reimbursed for transport.

Benefits:

The researcher hopes that the study will create the following benefits – Treatment will be more family centered, funding would be provided for family centered programs, and that occupational therapists will be recognized as valuable members supporting the family and mental health care users well allowing for successful community reintegration. The development of this tool will provide evidence for therapy intervention.

Voluntary Participation:

Participation in this study is completely voluntary. You will be able to withdraw from this study at any moment. You can refuse participation or withdraw from the study with no concern of negative consequences (stigma, refusal of treatment, or intimidation). You can refuse to answer any question. Kindly, notify the researcher by phone or email if you wish to withdraw from the study. You will stop participating immediately. The researcher can stop a participant's involvement if the participant shows negative behavior that is harmful to others.

Privacy and Confidentiality:

The researcher will take strict precautions to keep your personal information safe throughout the study. Your information will be kept without your name or other personal identifiers. The group interview will take place in a private room. Any reports or publications about the study will not identify you or any other study participant. Participants are also responsible to maintain confidentiality of members of the group.

Ethical Review:

This study has been ethically reviewed and approved by the UKZN Biomedical Research Ethics Committee (Approval number BE 297/17.

Questions:

In the event of any problems or concerns/ questions, you may contact –

1. The researcher, Margaux d'Hangest d'Yvoy, at (c) 076 148 7036; (e-mail) margaux.dhdy@gmail.com

2. Her supervisors, Professor Kitty Uys, ((w) 031 260 7953, (e-mail) kitty.uys@up.ac.za), and Mrs Debbie Fewster ((w) 031 260 7953, (e-mail) fewster@ukzn.ac.za)

3. Or the UKZN Biomedical Research Ethics Committee, contact details as follows: Biomedical Research Ethics Administration, Research Office, Westville Campus, Govan Mbeki Building, Private Bag X 54001, Durban, 4000, KwaZulu-Natal, South Africa; Tel: +27 31 2602486/ +27 31 2604769; Fax: +27 31 2604609; Email: BREC@ukzn.ac.za

If you have any other further comments, questions or concerns about the study, do make contact with the Department of Occupational Therapy at UKZN (031 260 8218)

Signatures: I, the researcher, have explained the above verbally and given the potential research participant time to ask any questions they may have. They have been given a copy of this consent form.

_____ _____

Researcher's Signature Date

I, _____ have been informed about this research study and understand its purpose, possible benefits, risks and discomforts. I agree to take part in this research as a subject. I know that I am free to withdraw this consent and leave this project at any time, and that doing so will not cause me any penalty or loss of benefits that I would otherwise be entitled to enjoy. I understand that participating in this study will have no implications on MHCU treatment or the status of LOAs. I have been given time to ask any questions and these questions have been answered to the best of the investigator's ability.

_____ _____

Participant's Signature Date

I understand that the focus group discussion will be audio-recorded and then transcribed. I understand that only the researchers will have access to the tape and to the transcriptions. I agree to the recording of the group's discussion.

_____ _____

Participant's Signature Date

Appendix L: Assent form

UNIVERSITY OF KWAZULU-NATAL
INYUVESI YAKWAZULU-NATALI

COLLEGE OF HEALTH SCIENCES

Date: _____

Dear Sir/ Ma'am

INVITATION TO PARTICIPATE IN RESEARCH – Mental Health Care Users/ Family Members

Hello! My name is Margaux d'Hangest d'Yvoy

UNIVERSITY OF KWAZULU-NATAL
INYUVESI YAKWAZULU-NATALI

I am a student Occupational Therapy at UKZN

My lecturers are Prof Kitty Uys and Mrs Debbie Fewster.

Our CONTACT DETAILS are:

margaux.dhdy@gmail.com

(c) 076 148 7036

uysk@ukzn.ac.za

(w) 031 260 7953

fewster@ukzn.ac.za

(w) 031 260 7953

BREC@ukzn.ac.za

+27 31 2602486; Fax: +27 31 2604609

Biomedical Research Ethics Administration, Westville Campus, Govan Mbeki Building, Private Bag X 54001, Durban, 4000, KwaZulu-Natal, South Africa

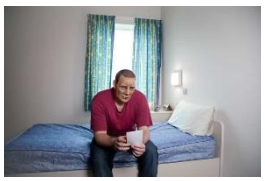
Invitation:

You are

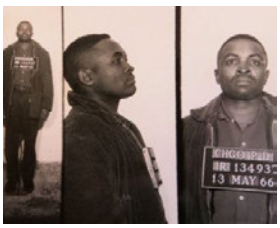
invited to take part

in my research study

because of your experience living in a family



with a person who is a mental health care user



with a charge

at a forensic psychiatric hospital

Why:

OCCUPATIONAL THERAPY

We will be creating an assessment to plan treatment to help families.

OCCUPATIONAL THERAPY

health Department: Health PROVINCE OF KWAZULU-NATAL

To help OTs in DoH to work towards improving families' quality of life.

When?:

Date: Saturday morning

What:

For ONE (1) group discussion

RISKS:

There are no risks.

But if any severely negative emotions are experienced, you can be referred to psychotherapy at Fort Napier Hospital.

INCENTIVES:

Tea and a light lunch will be provided.

You will also be reimbursed for your transport costs

ETHICAL CONSIDERATIONS:			
Do you want to help?			
You can leave the group at any stage		☑	☒
You need to complete the consent form		☑	☒
All personal information shared in the group needs to be kept confidential.		☑	☒
Your identity will be protected and will not be shared.		☑	☒
No sharing of names/ identities will occur outside this group.		☑	☒
Do you understand that I will be using a video camera/ voice recorder today?		☑	☒

Do you have any questions?			

This form will be completed together with the researcher during the individual administration sessions.

Name: _____

Date: _____

Signature: _____

Appendix M: Generic biographical questionnaire

Biographical Questionnaire (Generic)

FG no. ☐
Participant no. ☐

Kindly, complete the following questionnaire with your personal details. All information will be treated with strict confidentiality, and will only be reported on collectively or as a group, e.g. 55% of the participants were female.

Office Use

Preferred Pseudonym: _____

PART A: GENERIC FORM

Please answer the questions below by placing an X in the appropriate box.

1. Gender: Male ☐ Female ☐ ☐

2. Age: _____ ☐

3. Race: African ☐ Indian ☐ White ☐ ☐
Coloured ☐ Other ☐

4. Marital status: Single ☐ Married ☐ Widowed ☐ ☐
Divorced ☐ Separated ☐ Other ☐

5. Home language: English ☐ isiZulu ☐ isiXhosa ☐ ☐
Other (specify): _____

6. English proficiency: Very good ☐ Good ☐ Average ☐ ☐
Bad ☐ Very bad ☐

7. What level of schooling did you complete? If more apply, select the **highest** one. ☐

No schooling ☐
Primary school (Gr 1 to 7) ☐
Secondary school (Gr 8 to 10) ☐
High school (Gr 11 and 12) ☐
Tertiary education ☐
Not graduated yet ☐
Post graduate studies ☐

8. Which of the following statements about occupational status apply to you?

Not working at the moment	
Part-time or hourly work (< 15 hours per week)	
Part-time work (15 to 34 hours per week)	
Full-time work	
In training (apprentice or internship)	
Currently studying	

9. If yes to working on the above, what is your **present** occupational position or (if no longer working) was your **last** position?

Unskilled Labourer		Trained on the job		
Skilled		Professional		
Self-employed		Other (specify)		

Appendix N: Biographical form - population specific: MHCPs

PART B1: POPULATION SPECIFIC - Mental Health Care Professionals:

Office Use

1. What is your profession?

Psychiatrist		
Nurse		
Psychologist		
Social Worker		
Other (Specify)		

2. What is your designation/ level of responsibility?

3. Indicate what type of environment (facility) you practice in?

Special hospital (high security)		Regional (Medium security)	
Low secure unit		Psychiatric intensive care unit	
Community		Prison	
Other			

4.1. How many years have you worked in a mental health context?

1 – 2 years		2 – 3 years		
3 – 5 years		6 – 10 years		
11 – 15 years		> 15 years		

4.2 How many years have you worked in a Forensic Specialist Psychiatric Setting?

[ ] years

5. Please answer the following questions by circling the correct answer

Completed my Masters Postgraduate studies	Yes	No	
Completed my Ph.D. degree	Yes	No	
Completed any other studies pertaining to mental health	Yes	No	
Specify:			
Have you published in the field of Mental Health	Yes	No	
Do you participate in Mental Health Care research	Yes	No	
Have you previously participated in measurement tool development	Yes	No	

6. Are you familiar with the following concepts

- Family Quality of Life	Yes	No	
- Outcomes measures	Yes	No	
- Have you incorporated the concept of Family Quality of Life as an outcome in your work	Yes	No	

Appendix O: Biographical form - population specific: MHCUs

PART B2: POPULATION SPECIFIC - Mental Health Care Users:

Office use

1. What is your diagnosis?

Diagnosis	Tick if Yes	Specify Type	
Neurodevelopmental disorders - Intellectual or developmental disability			
Neurocognitive disorder - Organic disorders including dementia, amnesia d/o			
Substance abuse and Addictive Disorders - abuse of alcohol, cannabis, intoxication, withdrawal, psychosis			
Schizophrenia spectrum and other Psychotic disorders - SAD, Delusional disorder, Psychosis unspecified etc.			
Bipolar mood disorder and related disorders			
Depressive disorders - eg. Major Depression			
Anxiety disorders			
Obsessive compulsive and related disorders			
Trauma and stressor related disorders (PTSD)			
Other Neurotic Disorders – Dissociative/ Somatoform			
Behaviour – Feeding/eating disorder/ sleeping disorder			
Personality disorders – Borderline, Antisocial, Narcissistic, Schizoid etc.			

2. How many LOAs have you experienced to date?

1 to 3		4 to 6		
7 to 9		>10		

3. What is the longest successful Leave of Absence you have completed to date?

1 month		3 months		6 months		

1 year ☐ > 1 year ☐

4. How many people are living in your household, including yourself?

1 (yourself) ☐ 2 ☐ 3 ☐ ☐

4 ☐ 5 ☐ 6 ☐

More (specify): _____

Appendix P: Biographical form – population specific: family members

PART B3: POPULATION SPECIFIC - Family Members of Mental Health Care Users:

Office Use

1. What is your relationship to your family member(s) with mental illness?

Mother		Father		Sister	
Grandmother		Grandfather		Brother	
Child		Other (specify)			

2. Which family member acts as the custodian for the mental health care user

Mother		Father		Sibling	
Grandmother		Grandfather		Child	

Other (specify) _____

3. When your family member is on LOA, how many hours per week does the custodian spend him/her

Specify: _____

4. When your family member is on LOA, how many hours per week do you spend with him/ her?

Specify: _____

5. How many people are living in your household, including yourself?

1 (yourself)		2		3	
4		5		6	

More (specify): _____

6. Persons with Mental Illness in the family:

Kindly, indicate the gender and age of all family members with mental illness in your family.

Person	Male	Female	Does this person live at home with you	Diagnoses Give the number as indicated below
1				
2				
3				
4				
5				

Below are some of the diagnoses of mental illness? Kindly tick in the appropriate box of which mental illness(s) may be appropriate to your family members?

Diagnosis	**Number**
Neurodevelopmental disorders - Intellectual or developmental disability	1
Neurocognitive disorder - Organic disorders including dementia, amnesia d/o	2

Substance abuse and Addictive Disorders - abuse of alcohol, cannabis, intoxication, withdrawal, psychosis	3
Schizophrenia spectrum and other Psychotic disorders - SAD, Delusional disorder, Psychosis unspecified etc.	4
Bipolar mood disorder and related disorders	5
Depressive disorders - eg. Major Depression	6
Anxiety disorders	7
Obsessive compulsive and related disorders	8
Trauma and stressor related disorders (PTSD)	9
Other Neurotic Disorders – Dissociative/ Somatoform	10
Behaviour – Feeding/eating disorder/ sleeping disorder	11
Personality disorders – Borderline, Antisocial, Narcissistic, Schizoid etc.	12

7. What physical conditions do your family members with mental illness experience? Tick in the appropriate box.

Diagnosis	**MHCU/ Participant in the Study**	**Person 2**	**Person 3**	**Person 4**	
Nutritional and metabolic diseases (eg. Diabetes)					
Cardiovascular disease (eg. Hypertension)					
Viral diseases (eg. HIV/AIDS)					
Respiratory Tract Diseases (eg. Asthma, TB Lungs)					
Musculoskeletal diseases					
Sexual dysfunction					
Pregnancy complications					
Stomatognathic diseases (diseases of the mouth and jaw)					
Cancers (eg. Obesity-related)					

8. What level of disability – related support is needed for your family member(s) with mental illness?

Level of disability – related support:	**MHCU/ Participant in the Study**	**Person 2**	**Person 3**	**Person 4**	
Does not require disability-related support					
Requires disability- related support for only a few aspects of life					
Requires disability- related support for some aspects of life					
Requires disability- related support for most, but not all, aspects of life					
Requires disability- related support for almost all aspects of life					

9. Which family member(s) are most involved in the day to day life of your family member(s) with mental illness?

Custodian		
Mother		
Father		
Grandparents		
Siblings		
Other (Specify)		

Appendix Q: Indemnity form

INDEMNITY FORM:

I, _____, hereby state that I enter the premises of Fort Napier Hospital of my own free will. I do not hold the hospital or the University of KwaZulu-Natal liable for any incident/ adverse event (injury/death or loss/damage of property) that may occur to my person or property whilst on the premises.

I acknowledge responsibility to ensure my own personal safety.

Signed _____ on this _____ day of _____ (month) 20___ (year).

Witness Signature: _____

Witness Name: _____

Appendix R: Study feedback request form

Study Feedback Request Form I hereby request that feedback on the study, "Developing a FQOL tool directing Occupational Therapy for Mental Health Care Users and their families in a South African forensic psychiatric setting", be made available to me on completion of the study.		
Participant Name	**E-mail Address**	**Contact Number**

Appendix S: Transportation reimbursement register

Transportation Reimbursement Register Date: _____ Focus Group: _____			
Participant Name	**Reimbursement Amount (Rands)**	**Received (Participant's Signature)**	**Co-signed (Researcher)**

Appendix T: Turnitin Similarity Report