# Mental health literacy and information sources of hospitalised mental healthcare users with mood disorders.


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This research is dedicated to my mother, L Coetzee, who spent most of her life as my role model, exercising patience and perseverance through all of life’s challenges.

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## DECLARATION

I, Celente Nisha Rhodè French, student number 21532265, declare that:

The research *"Mental health literacy and information sources of hospitalised mental healthcare users with mood disorders"* is my own work and all the sources used are acknowledged in the reference list.

The research complies with the research ethical standards of the North-West University (Potchefstroom Campus).

Signature: _____

Date: _____

# ABSTRACT

Mood disorders, specifically depression and bipolar mood disorder have taken the world by storm and can be regarded as a leading cause of deaths amongst diagnosed persons. Although treatable, mood disorders are often misdiagnosed and individuals stigmatised by family, friends and members of the community avoid seeking professional help due to fear of rejection. Mental health information and enhancing mental health literacy amongst individuals and communities are an international priority but there lacks research in this field. The objective of enhanced mental health literacy is to develop a society where mental healthcare users are able to recognise symptoms, take rapid action to obtain professional evidence-based treatment and receive public and social support. Enhancing mental health literacy as an outcome of information sharing should be applied on various levels in order to create awareness and change in individuals, families and communities.

The aim of this research was to investigate the information sources as well as perceptions on mental health literacy of hospitalised mental healthcare users with mood disorders regarding their own mood disorder and mental health. Research was conducted from a qualitative, interpretive descriptive, contextual design. Purposive quota sample lead to 12 (N) participants with bipolar mood disorder. Data was collected by means of semi-structured, individual interviews. Data saturation occurred at the tenth interview but two more interviews were done as confirmation. Due to the high ethical risk of the target group; the researcher used the MacArthur competence assessment tool for clinical research (MacCAT-CR) to establish cognitive competence and capacity to consent twice prior to data collection. Participants completed a checklist of information sources during or after the semi-structured interviews. Voice-recorded interviews were transcribed. Thematic analysis was conducted and consensus reached with a co-coder. Field notes were kept.

The information sources checklist revealed that although individuals make use of traditional sources such as seminars, brochures and newspapers, a trend towards family guidance and self-help methods has developed. Ultimately the leading information sources selected are seeking information from professionals, followed by the Internet. Eight main themes were formulated. Although denial hinders mental health literacy, acceptance facilitates it. Mental health literacy is a positive enabler and an impetus towards health-seeking action. Mental health literacy is influenced by existing knowledge and views of self, family and significant others; and the information sources used and the interpretation thereof vary amongst individuals. Recommendations were formulated to inform psychiatric nursing education, - research and psychiatric nursing practice to enhance mental health literacy. Recommendations are also aimed

at enhancing individual, family, public and national mental health literacy through the distribution of appropriate information through a variety of information sources and methods.

Word count: 447

**Key words:** Health literacy, mental health literacy, mental healthcare users, mental healthcare practitioners, information sources, information communication technologies, hospitalised mental healthcare users, mood disorders, lifetime disorders

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## ABBREVIATIONS

| | |
|---|---|
| ADHD | Attention deficit hyperactive disorder |
| APA | American Psychiatric Association |
| APMS | Adult psychiatric morbidity survey |
| App | Application |
| CMHA | Canadian Mental Health Association |
| DBSA | Depression and Bipolar Support Alliance |
| DVD | Digital versatile disc |
| DSM | Diagnostic and statistical manual of mental disorders |
| eHealth | Electronic health |
| e-mental health | Electronic mental health |
| HHS | Health and human services |
| HREC | Health research ethics committee |
| ICT | Information communication technologies |
| MacCAT-CR | MacArthur competence assessment tool for clinical research |
| MARS | Medication adherence rating scale |
| MEC | Member of executive council |
| mHealth | Mobile health |
| MHFA | Mental health first aid |
| MHF | Mental health foundation |
| NAMI | National alliance on mental illness |
| NHREC | National research ethical council |

| | |
|---|---|
| NIMH | National institute of mental health |
| NMHA | National mental health association |
| NWU | North-West University |
| PHC | Primary health care |
| PMB | Prescribed minimum benefits |
| SADAG | South African depression and anxiety group |
| SAMHSA | Substance abuse and mental health services administration |
| SASH | South African stress and health |
| SIM | Subscriber identity module |
| SCID-I/P | Structures clinical interview for DSM-IV-TR patient version |
| TIP | Treatment improvement protocol |
| UCT | University of Cape Town |
| UNESCO | United Nations Educational Scientific and Cultural Organisation |
| USA | United Sates of America |
| WHO | World health organisation |
| *WMH* | *World mental health* |

# CHAPTER 1: INTRODUCTION TO THE RESEARCH

## 1.1 INTRODUCTION

Although treatable, mood disorders often go misdiagnosed and stigmatised. Poor mental health literacy and negativity towards mental healthcare users influence mental healthcare users' health seeking behaviour negatively (Swami, 2012:1). Depression is a known mental health disease with suicide the second leading cause of death amongst 15 to 29 years old individuals (World Health Organisation [WHO], 2016:1). Information about mood disorders are available; although mass media as a prominent source of information portrays mental health disorders in general as negative and unstable (Canadian Mental Health Association [CMHA], 2004:3). In this research, it is argued that despite the high prevalence of mood disorders in South Africa, there is insufficient evidence of mental health literacy among adult mental healthcare users with mood disorders.

## 1.2 BACKGROUND AND PROBLEM STATEMENT

Mood disorders (also formally known as affective disorders) are the dysregulation of mood and psychomotor activity and are associated with biorhythmic and cognitive disturbances (Kaplan *et al.*, 2004:55). The diagnosis and classification thereof can be complex. The international classification of diseases' 10$^{th}$ version (ICD10) by the WHO (1993), confirmed mood disorders as being difficult to classify as practitioners are limited to emotions and behaviours in the absence of biochemical and physiological measurement. The Diagnostic and Statistical Manual of Mental disorders (version 5) (DSM-5™, 2013), categorised mood disorders broadly into depressive and bipolar mood disorders. The distribution of mood disorders varies over cultural and racial groups (Uys & Middleton, 2014:158). Both males and females are affected by bipolar mood disorder and low socioeconomic status could possibly be linked to a higher prevalence of bipolar mood disorder (Bressert, 2016).

An estimated 30 million people worldwide live with bipolar mood disorder (Swartz, 2015:1) and depressive disorder affects over 350 million people globally (WHO, 2016:1). By 2004 mental health disorders compiled 11% of the total global burden of disease (WHO, 2012f:6). It presents in more than a million South Africans although poor help-seeking behaviour can lead to underdiagnoses (Miric *in* Collins, 2015). According to the South African Depression and Anxiety Group (SADAG), bipolar mood disorder is the sixth leading cause of incapability in individuals (*cited by* Brits, 2013:1). The prevalence of bipolar mood disorder increased drastically in South Africa due to misdiagnosis (Human, 2015a:11). Since medical schemes cover prescribed minimum benefits (PMB's), claims for bipolar mood disorder (one of the 27 listed disorders to be covered by medical schemes) increased drastically (Human, 2015a:11). Mood disorders hold an

inherent risk to suicide and cause intense suffering in affected persons and their significant others (Uys & Middleton, 2014:358). Up to 30% of individuals suffering from bipolar mood disorder will attempt suicide at least once during their lifetime; yet receiving adequate medication and medical assistance can decrease the risk with up to 3% (Brits, 2013:1). Considering, more than 6% of the people with bipolar mood disorder will commit suicide; suicide can be regarded as a cause of premature death amongst individuals living with bipolar mood disorder (Swartz, 2015:1).

The South African Medical Aid Council determined that from 2007 to 2012, the prevalence of bipolar mood disorder increased with about 173% (*cited by* Watson, 2015:1); between the year 2013 and 2014, bipolar mood disorders increased from 6.6 per 1000 medical aid beneficiaries to 7.4 medical aid beneficiaries (Human, 2015a:11; Watson, 2015:1). Yet, according to SADAG, since 2013, 69% of individuals diagnosed with bipolar mood disorder are misdiagnosed and when misdiagnosed and incorrectly treated, the condition can worsen (Brits, 2013:1). Approximately 75% of South Africans diagnosed with a mental illness do not receive their required treatment (Tromp *et al*., 2014). This is because the South African government only allocates 4% of its budget to mental health. Underfunding of mental health together with insufficient mental health services and the migration of patients towards an outpatient treatment basis; will eventually have a negative impact on the mental healthcare user, the family and the communities (Tromp *et al*., 2014). According to the MEC (member of the executive council) of Health in Gauteng, the Department of Health can no longer afford the treatment of mental healthcare users in government institutions (Human, 2015b:11). Planned mass deinstitutionalisation of mental healthcare users in general can have drastic implications. There are insufficient hospital beds or psychiatric medicine available in community clinics, risking strain of mental healthcare users and their significant others (Human, 2015b:11).

Mental healthcare in South Africa is deinstitutionalised and based on primary healthcare whilst 85% of psychologists in private practice are available to only 14% of the population (Tromp *et al.,* 2014). Yet, the WHO (2004c:11) stated that mental health is ‘everybody’s business’, considering the high prevalence and devastating outcomes thereof in modern societies. This is even more applicable in vulnerable communities (WHO, 2004c:11). Since 2007 the WHO (2007:6) stipulated that all healthcare practitioners must have the necessary knowledge and skills integrated into their training curricula to ensure sufficient mental health education. Health education is a dominant modus for the five action strategies in the Ottawa Charter for Health Promotion (WHO, 1986). The five action strategies include: developing personal skills, building healthy public policy, creating supportive environments, reorientation of health services and strengthening community action. In fact, part of developing personal skills entails provision of information and dissemination thereof for individuals to understand mental health. Health

literacy, or in this research, mental health literacy, guides health education in mental health promotion (WHO, 2004c:55).

Within this information age, an abundance of mental health information sources are accessible to the general public. Research publications, mental healthcare organisations and communities, blogs and other online resources such as social interactive sites are accessible (LoFrisco, 2015). Over one hundred leading electronic sites providing information on bipolar mood disorder and depression are available to the public (LoFrisco, 2015). It is generally acceptable for the public to gain health knowledge while seeking treatment for physical illnesses and the public has become more attentive to the early signs and detection, prevention and treatment of physical diseases. Yet, this is not the case with mental health (Jorm, 2011b:1).

A decade ago an Australian study by Burns and Rapee (2006:226) concluded that although the Australian youth were in relative good physical health; there was a pandemic profile of increased mental healthcare needs that could be alleviated through increased knowledge regarding risk factors, self-management and prevention of diseases (Burns & Rapee, 2006:226). During the Burns and Rapee research period health literacy was a fairly new term (*cited by* Ross & Deverell, 2004:286). The Canadian Council on Learning (2007:3) defined health literacy as the ability of individuals to use information appropriately as part of health-related decisions in order to maintain health. Health literacy is viewed as the outcome of effective health education (WHO, 2012f:7). In addition, mental health literacy refers to having knowledge that can benefit the mental health of oneself and/or that of others (Jorm, 2011c:1). It also entails "*knowledge and beliefs about mental disorders which aid in their recognition, management or prevention thereof*" (Jorm *et al*., 1997:182 *as cited by* Jorm, 2011b:1). Health literacy is not simply possessing knowledge, it is having the knowledge combined with possibilities of action aimed at enhancing the mental health of oneself or that of others (Jorm, 2011c:1).

According to Jorm (2011c:10), mental health literacy entails developing a society where mental healthcare users take rapid action to seek professional assistance, obtain and adhere to evidence-based treatment. It also involves receiving social support, taking precautionary measures and a society where mental health services and facilities are seen as contributing and valuable services that encourage public support and acceptance (Kutcher *et al*., 2015:233; Reavley & Jorm, 2011:14). Mechanisms to improve mental health literacy include: providing adequate health education, training for professionals, evidence-based practice, web-based interventions, media-use and support to mental health services (Jorm, 2011c:8). Health promotion programs and supportive public policies are as well indispensable in improving mental health literacy (WHO, 2012f:10).

Mental health literacy presents on a continuum stretching from lay beliefs to professional knowledge (Jorm, 2000a:398). Healthcare professionals possess scientifically-based knowledge, while the public rely on experiences, anecdotes, media, and more informal sources to obtain health information. Mental health literacy can assist in early recognition and help-seeking behaviour of mental health disorders (Wei *et al*., 2015:1-2). Mentally ill patients will therefore become more accepting and knowledgeable of the available treatments and resources available (Jorm, 2011b:1-10). In addition early detection and treatment of mental disorders in adolescents and their support systems can enhance long term positive outcomes (Kelly *et al.,* 2007:26). Improved mental health literacy can teach mental healthcare users more effective self-help techniques and strategies; even more so, it provides the skills and techniques necessary for mental health support to others, and knowledge in the prevention of mental health disorders (Jorm, 2011c:1-10). Health education as a health promotion tool is not always used effectively and lacks the attention of healthcare professionals (WHO, 2012f).

The efficiency of health education and its effect is difficult to assess. Health educators are expected to divide their time between their work and health promotion projects, have limited training and often lack the understanding of health education foundations and application of theories (WHO, 2012f). According to Jerzembek (2014:ii), health education aims at influencing individuals' perspectives of health and their health status and providing support for sustainable behavioural change. Health education aims to broaden individuals' knowledge and skills through motivational skills development and raising awareness (WHO, 2012f). Reciprocally, Clark (2008:260) concluded that empowerment creates beneficial changes in health and health literacy in general.

Various types of technologies and media have been considered for mental health education to enhance mental health literacy. Padhy *et al.* (2014:164) states that mass media can fill gaps in knowledge of the general public about mental illness, but whether these gaps are filled by accurate information or by imprecise exaggerated reports remains to be contemplated. Padhy *et al*. (2014:165-166) recently conducted a study in India which assessed whether media posed as a risk factor for mental illness. It was found that media can impact on eating disorders, substance abuse, Internet addiction, sexual behaviour, mood disorders, aggression, post-traumatic stress disorder and even suicide. Media has two faces of influence (Boydstun *et al*., 2014:509). On the one hand media could lead to various imitative suicides globally, on the other hand media is an opportunistic tool to clarify and avoid speculation and myths related to mental health and education of the population (Padhy *et al.,* 2014:165). Television broadcasts of suicides can lead to a marked increase in suicide attempts (Della Vigna & La Ferrara, 2015:22) referred to as the "Werther effect" or copycat suicide (Kumar *et al.,* 2015:1). Social media

containing information on celebrity suicide has led to increased amounts of expression of suicidal ideation in online media posts (Kumar *et al.,* 2015:3).

The negative aspects of media are confirmed by Holland (2012:217) who states that media impacts negatively on mental health as it contributes to stigmatisation, stereotyping and portraying mental illness in general as violent with undesirable traits. Maier *et al.* (2014:239) claimed that movies and television present audiences with mental health-related programs with the focus on entertainment, which increased self-stigma and decreased professional help-seeking as it is viewed as a weakness. Leo and Lacasse (2015:8) recently published information related to attention deficit hyperactive disorder (ADHD) in children leading to increased over-diagnosis of ADHD and negatively affected treatment adherence.

Although mental health can be strained under media (Leo & Lacasse, 2015:8), mass media can fill knowledge gaps for the general public about mental illnesses (Padhy *et al.*, 2014:164). According to Goldney and Fisher (2008:129) mental health literacy is presumed to be a facilitative factor in suicide prevention. Again on the contrary, poor health literacy of the general public also leads to recurrent hospital admissions with negative cost implications (Baker *et al.,* 2002:1278). This is supported by Vigod *et al.* (2013:187) who stated that 13% of discharged mental healthcare users are readmitted shortly after discharge. Pinto-Foltz *et al.* (2011:2011) states that enhanced mental health literacy can also empower members of the community to take action and improve their mental health. During the mid-1990s, the dominant view on measures to improve health literacy was focused on the training of health professionals to better manage and identify mental health disorders; the public was disregarded (Pinto-Foltz *et al.*, 2011:2011).

Despite literature claiming the critical role of mental health literacy in mental health promotion, insufficient research is available related to mental health literacy (Pinto-Foltz *et al.,* 2011:2012) in general. Stein (2012:427) agreed to a tremendous lack of knowledge and research regarding mental health literacy, not only in South Africa, but also in other low and middle income countries. There seems to be even less literature about mental health literacy related to mood disorders. Mendenhall and Frauenholtz (2013:1) explored mental health literacy of mood disorders and reiterated the need for public mental health efforts to raise the mental health literacy. Furthermore Pelletier *et al.* (2016:11) emphasised the importance of mental health literacy, help-seeking behaviours and efficient diagnosis of mood disorders in light of the global prevalence of mood disorders and their intense impact on life.

This background argued the progressive increase of mood disorders in South Africa against the insufficient access to appropriate healthcare. Mental health literacy was presented as one critical aspect to promote mental health through improving mental healthcare users' understanding of

their mood disorders and the treatment thereof. Mental healthcare users can access health-related information from various sources such as the media and the Internet and the risks and benefits of mass media information sources are reiterated. There is insufficient research related to mental health literacy of mood disorders and the sources of information accessed by mental healthcare users to inform mental health education significantly.

## 1.3 RESEARCH QUESTION

Expounded from the background and problem statement, the following research question was formulated: *What are adult mental healthcare users' diagnosed with mood disorders' perceptions on mental health literacy of their mood disorders and their information sources about mood disorders?*

## 1.4 AIM AND OBJECTIVE

The aim of this research was to inform mental health practitioners on appropriate mental health education strategies according to perceptions on mental health literacy of hospitalised patients with mood disorders; and to list where patients acquire their mental health information. This aim was obtained by means of the following objective:

To explore and describe adult mental healthcare users', diagnosed with mood disorders, perceptions on mental health literacy of mood disorders and the information sources they access about mood disorders by means of a qualitative, interpretive description design.

## 1.5 DEFINITIONS OF KEY CONCEPTS

The following concepts are central to this research:

**Mental health literacy** is the ability to recognise mental health disorders, knowing when and how to seek mental health information, knowledge of various probable causes, treatments, self-care, the availability of professional assistance and promoting appropriate help-seeking behaviour (Burns & Rapee, 2006:226).

**Information communication technologies (ICTs)** are relevant, effective media used to strengthen communication with groups that are traditionally hard to reach; it includes technological devices such as computers, laptops and mobile phones, and technologically enabled communication methods for example e-mail, social networking and gaming (Stephens-Recher et al., 2011:59). ICTs are within modern society, viewed as a definite mechanism for health education and to obtain information that can impact on health and mental health literacy.

**Information sources** are any information that might contribute to a person's knowledge. In this research information sources referred to printed media, word of mouth, digital information, Internet and social media, conversations, formal - and informal health education and magazines or newspapers (McInnis & Merajver, 2011:168; Jorm, 2012d:398; Norris *et al.,* 2013:1; Clifton *et al.,* 2013:23; Tsai *et al.,* 2014:126).

**Lifetime disorders** refer to the prevalence of any disorder during one's life span (Herman *et al.,* 2009:340). In this research mood disorders are also viewed as potential lifetime disorders.

**Mood disorders** entail a variety of categories of mental disorders that influence a person's mood from being elevated or feeling depressed. The following typical mood disorders are classified (APA, 2013:20):

- Major depressive episode and major depressive disorder.
- Dysthymic disorder.
- Bipolar episode and bipolar mood disorder.
- Substance-induced mood disorder.
- Mood disorder due to a general medical condition.
- Adjustment disorder with depressed mood.

In this research, the focus was on adult mental healthcare users diagnosed with a mood disorder such as bipolar manic or depressive episode.

**Mental healthcare user** is an individual with a syndrome characterised by disturbance of cognition, emotional regulation, or dysfunctional behaviour of psychological, biological or developmental processes of mental functioning that impairs social, occupational, and other functioning according to the (APA, 2013:20). In this research the mental healthcare user refers to adults, aged 18 years and older.

**Mental healthcare practitioners** are trained, educated professionals with the ability to work as part of a multidisciplinary team with ethical practices and professional tasks. Mental healthcare practitioners can enhance community development using primary care models (Walker & Sonn in Purdie et al., 2010:157). These practitioners include nurses, psychologists, psychiatrists, and other trained professionals.

## 1.6 METHODOLOGY

The research methodology followed was divided into the research design and research method.

### 1.6.1 Research design

A qualitative research design was used that was interpretive descriptive and contextual. It produced data from feelings, thoughts, behaviours and understanding of a specific phenomenon, as well as an in-depth insight by converting experiences to dense description (Botma *et al*., 2010:182). Interpretive description brought an alternative method to obtain grounded knowledge pertaining to the clinical nursing contexts. Interpretive description is an inductive analytic approach that contributes towards methods of understanding through analysis and expansion through interpretation (Thorne *et al*., 1997:172; Thorne *et al*., 2004:2). In this research interpretive description provides the researcher with the opportunity to use subjective observations emerging in semi-structured interviews as a part of data collection. Subjective experiences are converted to form part of the overall collected data, this reflects in the field notes (***see*** Annexure J:Field notes, p.167). The context of this research was a private psychiatric hospital in the Matlosana Municipality in the Dr. Kenneth Kaunda District, North West Province.

### 1.6.2 Context and research setting

The hospital was a voluntary, private, in-patient hospital offering a wide range of treatment programs that augments healing through the provision of high quality and compassionate care. The aim of the hospital was to provide a safe and supportive environment for mental healthcare users to start with treatment and to facilitate personal growth and development and social skills. Staff of the hospital included a multi-disciplinary team of psychiatrists, psychologists, professional nurses, physiotherapists, dieticians and occupational therapists. These team members were all trained in delivering specialised treatment, care and rehabilitation of various psychiatric conditions including:

- Mood disorders such as depressive disorder and bipolar mood disorder, including manic episodes.
- Anxiety-related disorders.
- Work-related issues such as stress and burnout.
- Eating and sleeping disorders.
- Suicidal ideation and suicidal attempts.

- Substance abuse and other addictions.

- Psychotic episodes.

The hospital included consultation and therapy rooms, a recreation room, swimming pool and gardens to facilitate a therapeutic milieu. All admitted mental healthcare users participated in a program of private consultations with psychiatrists and psychologists and group work. Although the hospital was private, it did admit public mental healthcare users through a public-private agreement. This hospital admitted up to 44 mental healthcare users, generally admitted for up to 21 days. This hospital was selected because it provided access to a variety of adult mental healthcare users with mood disorders.

The research setting was a neutral, accessible and comfortable office within the selected psychiatric hospital. The office had sufficient ventilation, minimal distraction, and comfortable seating for the researcher, as well as for the participating mental healthcare user. This setting was an office used for counselling and therapy. Interviews were scheduled in a manner that did not inconvenience the patient or the hospital, thus no interviews were scheduled during therapy or group sessions, lunch times, or ward routine hours. Interviews were scheduled only during the participating mental healthcare user's "off/self" time.

The selection of this hospital was not based on convenience as the following motivation describes:

- The hospital was a preferred mental healthcare hospital within the North West Province. Since the inception of this hospital in 1994, many previously treated mental healthcare users returned to this hospital for treatment. This was due to insufficient amount of acute mental healthcare facilities in the North West Province. Even though this hospital is a private hospital, in agreement with the North West Provincial Department of Health, the hospital admitted mental healthcare users with acute mental disorders without medical insurance.

- The selected hospital held a long term ongoing service and mental healthcare expertise in dealing with mood disorders.

- The researcher visited this hospital in 2015 and discussed the proposed research problem during which time this hospital's management confirmed interest and support in a verbatim manner, which was confirmed in writing after ethical clearance was obtained.

### 1.6.3 Research method

The research method is depicted in figure 1.1 (*see* p.11) and described in the following paragraphs.

#### 1.6.3.1 Population

The population was adult, hospitalised, mental healthcare users diagnosed with a mood disorder by a psychiatrist. The following rationale was presented for accessing hospitalised mental healthcare users:

- A confirmed diagnosis of a specific type of mood disorder made by a psychiatrist enhanced accurate sampling.
- Mental healthcare users were declared as being stable by a multi-disciplinary team. The term “stable” referred to mental healthcare users who were not severely depressed or excessively manic.
- Mental healthcare users were aware of their diagnosis as part of the hospital program and this limited the risk of denial.

Immediate support was available to participating mental healthcare users and the researcher, should the need arise.

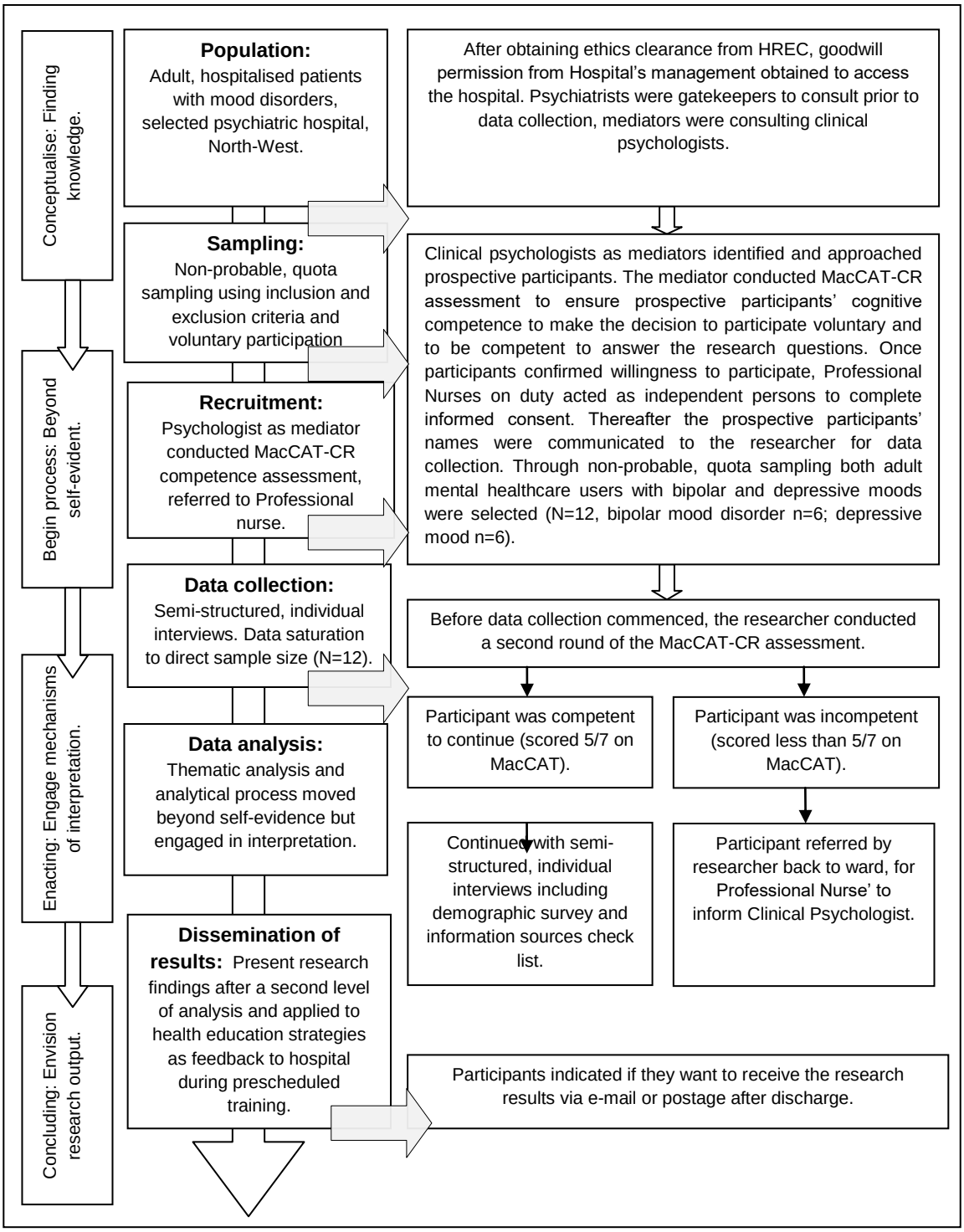


**Figure 1-1: Conceptual depiction of research method aligned with the analytical process of interpretive description**

#### 1.6.3.2 Sample and sampling

In line with the interpretive descriptive design (Thorne *et al*., 1997:172; Thorne *et al*., 2004:2) sampling was conducted in the following way: gatekeepers and mediators identified suitable participants that contributed towards purposive, quota sampling according to inclusion criteria (Brink *et al*., 2010:132). To ensure that mood disorders were represented in the sample, equal representation of the two main groups in mood disorders directed the sampling process, as follows:

- Adult, hospitalised mental healthcare users with either depressive disorder or bipolar mood disorder with manic or hypomanic episodes (severe episodes were excluded).

To enhance fairness and justice, four psychiatrists that supervised the mental health services within the selected hospital acted as gatekeepers. The clinical psychologist tending to participating mental healthcare users during their hospital stay was initially the mediator responsible to identify, recruit and refer all prospective participating mental healthcare users. Eventually, the clinical psychologists acted as mediators in support with the professional nurses. The following inclusion criteria demarcated the selection process:

- Participating mental healthcare users that were hospitalised and formally diagnosed by a psychiatrist with a mood disorder according to DSM-5™ guidelines.

- Stabilised and treated mental healthcare users who were a-suicidal, a-homicidal, not severely depressed, excessively manic, and not psychotic and did not experience any form of hallucinations. Mental healthcare users were fully orientated and not aggressive in any way as confirmed by the treating psychologist who acted as mediator.

- The participating mental healthcare user was fully orientated towards time, place and person and was able to comprehend the aim of the research in order to ensure factual capacity. The participating mental healthcare user was able to retain and weigh the information provided during the recruitment and data collection. Participants were able to communicate a decision after weighing the possible risks and benefits of this research.

- Was willing and able to make decisions and signed informed consent to participate. The participating mental healthcare users were excluded from the research if they presented with cognitive incompetence to make decisions. Therefore a mental healthcare user wanting to participate had to score a minimum of five (5) marks on the MacArthur competence assessment tool for clinical research (MacCAT-CR) (refer to 1.6.3.2.1, p.14 for a discussion of the MacCAT-CR applied to this research also *see* Annexure F, p.156).

- Both males and females could partake in this research, neither gender were excluded.

- Participating mental healthcare users had to be able to comprehend and speak English or Afrikaans as the researcher used these languages as language of instruction during data collection. The official language of the selected hospital was English and all therapeutic groups were presented in English although the majority of participating mental healthcare users spoke Afrikaans.

- Participating mental healthcare users were aged between 18 and 65 years as the focus was on adult mental healthcare users with low risk of age-related cognitive impairment. To ensure competency and capacity to participate and consent, the MacCAT-CR assessment was done twice before conducting interviews; once by the mediator when recruiting prospective participating mental healthcare users, and once by the researcher before conducting data collection interviews.

- Participating mental healthcare users with comorbid diagnoses (specifically axis 2/ personality disorders), as well as substance-induced mood disorder and mood disorder due to medical conditions were excluded.

- Participating mental healthcare users that were willing to participate within 24 hours of obtaining consent to minimise fluctuation in cognitive disability.

1.6.3.2.1 Competence to make informed decisions

As indicated in the inclusion criteria, participating mental healthcare users must have had the mental and cognitive capacity to make informed decisions and comprehend the aim of the research. According to the British Department of Constitutional Affairs (2005:1), possible causes for incapacity or incompetence include conditions such as dementia, acute confusion or psychosis, distress or emotional disturbance; yet lack of capacity cannot be established merely by age, appearance and diagnosis and was tested in order to ensure fairness and justness. The researcher used the MacArthur competence assessment tool for clinical research (MacCAT-CR) to establish cognitive competence (Wang *et al*., 2016:165). The MacCAT-CR entailed asking seven questions during a semi-structured interview (Morán-Sánchez et al., 2015:4; Wang et al., 2016:165) aimed to explore the participating mental healthcare users' understanding, appreciation, reasoning and expression of choice.

The following questions were presented:

- **Understanding** referred to the ability to understand and comprehend relevant information and was asked as follows: 'Please explain to me what the research I have explained to you is about?' and 'what do you understand of what is expected of you?'

- **Appreciation and retaining of information** as the ability to appreciate and recognise a situation and consequences of actions and applying it to one's own situation. Examples of questions were: 'How will participating in this research affect you?'; 'Will taking part in this research affect your hospital stay or hospital program?'

- **Reasoning** entailed the ability to reason information in a rational manner. An example of a question was 'Please explain to me what will happen if you decide to withdraw from this research?'

- **Expressing a choice** was communicating a choice clearly and consistently asked as follows: 'What do you think are the effects of you taking part in this research?' and 'Why would you like to take part in this research?'

All the competence abilities were assessed by specific questions as listed above (Morán-Sánchez et al., 2015:4). An appropriate answer equalled a YES or NO mark. A score of five or more on the MacCAT-CR indicated the capability to consent to research. Sturman (2005:961) confirmed the MacCAT-CR as a valid and reliable tool, flexible and adaptable towards research with any diagnostic group. Please refer to Annexure F (p.157) for an example of this tool. During the recruitment and selection process the clinical psychologist (mediator) conducted the MacCAT-CR assessment. This assessment was repeated by the researcher before data collection started.

#### 1.6.3.3 Sample size

Sample size was established once data saturation occurred (Brink *et al.,* 2010:135) and no more new themes emerged from the interviews, N=12.

#### 1.6.3.4 Method of data collection

Digitally voice-recorded semi-structured individual interviews (Botma *et al*., 2010:208, 214; Grove *et al*., 2013:271) were conducted, interviews were appropriate as the researcher aimed to explore participants' perceived mental health literacy and the information sources accessed. The following four phases were followed during the interviews (Welman *et al.,* 2012:167-169):

**Phase 1: Preparation**

During the preparation phase, the researcher compiled a demographic survey (Annexure H, p.167) and an information source checklist (Annexure I, p.168). The demographic survey and information source checklist enabled the researcher to describe the participants in the research report according to diagnosis, gender, age, language and level of education and socio-ecological status. The survey also enabled the researcher to determine what/which types of information sources are used by mental healthcare users in order to obtain information on mood disorders. Literature concluded that there were determinants to mood disorders such as socio-ecological status, gender and literacy levels (WHO, 2012:6-7), these were assessed during the preparation phase.

**Phase 2: Pre-interview**

Following hospital permission and informing the multi-professional team of the research being conducted, the researcher did weekly telephonic or courtesy follow up visits to monitor both the recruitment and informed consent processes. The following aspects were covered during the information session to the multi-disciplinary team members that were functional in the recruitment and selection process of this research (*see* annexure D, p.150 & annexure E, p.153):

- Aim and objectives of the research.
- The roles of the gatekeepers, mediators and persons responsible for obtaining the informed consent.
- Inclusion criteria and how to conduct the MacCAT-CR assessment.
- The process and associated document for informed consent.
- Confidentiality agreements
- The process of data collection and the management of probable risks during the research, and
- The planned dissemination of the research results.

Clinical psychologists of the hospitalised mental healthcare users were asked to approach and recruit prospective participating mental healthcare users that met the requirements to the strict set of inclusion criteria (*see* 1.6.3.1, p.10)

The time frame from recruitment to participation was within 24 hours to minimise possible fluctuation in cognitive disability. Once a participant met the requirements of competency as assessed by the psychologist and the MacCAT-CR assessment, the participant's name was reported by the mediator to the professional nurse on duty who acted as the person obtaining informed consent. During phase two the researcher obtained the names of the prospective participating mental healthcare users who signed informed consent and contacted participants in person or telephonically to schedule the interview.

**Phase 3: The interview**

The researcher introduced herself to the participant, explained the aim of the research, confirmed informed consent and briefly outlined the interview process. The researcher then reassessed the MacCAT-CR standard of competence (*see* Annexure F, p.156) before conducting the semi-structured interviews (*see* p.17). A deliberate focus to use understandable language, to manage time wisely and grant sufficient time to participants to answer questions was maintained. The following communication skills (Mather *et al.*, 2002:15) were used during the interviews, the researcher:

- Established a good rapport through clarifying the research purpose, aims, and objectives with the participant. The researcher allowed the participants the opportunity to ask questions in a relaxed informal manner and the interviewer maintained a non-threatening environment through effective use of body language and encouragement.

- Reassured that participation was confidential and that no identity would be revealed.

- Explained to participating mental healthcare users that recordings would be transcribed, coded and stored after completion of this research and recordings will be destroyed after a five-year storage period.

- Probed gently when the answer to a question was unclear or incomplete or answered in a manner that directs away from the research topic.

- Didn't interrupt unless when the participant was not focused on the question, but rather tried to let the participants finish their thoughts.

- Tried not to give personal opinions.

- Remained sensitive and avoided being over sympathetic /empathising. Focus was aimed at research questions.

- The researcher included the checklist as part of interviews in cases where participating mental healthcare users had difficulty in determining sources on their own, this served as examples to create clarity for the participant.

- Was aware of body language, remained relaxed and read the participant's non-verbal ques.

- Some verbal communication skills were summarising, paraphrasing and minimal verbal response, as well as minimal verbal response, clarification and silence.

#### 1.6.3.5 Interview schedule

The following interview schedule was followed:

**Table 1-1: Interview schedule**

| | |
|---|---|
| Opening sentence and question: | "As you remember when we were discussing my research, I was talking about mental health literacy – and what people actually know about their own condition and treatment. Today I want to ask you to tell me what do you know about mood disorders and where do you get your information from?" |
| Open-ended questions asked during the interview. | • *"What do you understand about your mood disorder?"*<br>• *"What do you think are the causes of this illness?"*<br>• *"Tell me more about the treatment/medication you are using for your mood disorder?"*<br>• *"Describe to me where do you get your information about this illness?"*<br>• *"How can more knowledge regarding your mood disorder affect you?"*<br>• *"Where else do you think you can learn more about your mood disorder? / What other resources can help you to learn more about your mood disorder?*<br>• *"To which of these sources do you have access and do you trust information from these sources?"* |
| Information sources checklist | During or immediately after the semi-structured interview, the researcher and participant completed the information check list (*see* Annexure I p.167). |

#### 1.6.3.6 Data analysis

Data analysis was aligned with the analytical process of interpretive description. Interpretive description as a more recent generation from traditional qualitative approaches emphasises

integrity, accountability and coherence within the research. It acknowledges the contextual significance of naturalistic enquiry and human experiences to be critically analysed within the methodological guidelines consistent to the nursing discipline (Thorne *et al*., 2004:3). Analysis within the clinical context strengthens conceptual creativity, proper engagement, resourcefulness and superiority in qualitative analysis (Thorne *et al.,* 2004:9).

In the analytical process the researcher moved beyond mere investigation towards interpretation. Thorne's interpretive description was used as it entails an enhanced qualitative investigation of a clinical phenomenon (mental health literacy and information sources of hospitalised adult mental healthcare users with mood disorders). It involved the analyses of perceptions of themes and patterns directed to formulate findings within existing knowledge and locating explanatory features arising from the analysis to a wide-ranging perspective (Berterö, 2015:1). The researcher moved beyond investigation towards interpretation implying that the researcher was actively engaged in the analytical process throughout the research process (Thorne, 2000:68). The process of data analysis was combined with thematic analysis by Creswell (*in* Botma *et al.,* 2010:223) and raw data were organised with the method of Thorne *et al.* (2004:4), whereby the researcher conducted a second level analysis towards a rich and coherent interpretation. The data analysis processes followed are described hereafter.

**Initiating the analytic process by moving beyond the self-evident**

In line with the interpretive descriptive research method described by Thorne et al. (2004:2) an inductive analytical approach was followed. The researcher initiated the first part of data analysis even before data was collected. Therefore, the researcher reviewed existing literature regarding mental health literacy, information sources about mood disorders; mood disorders within adults and current health education and information strategies as the basis for an analytic framework. This was conducted as part of a comprehensive literature review before the activation of data collection and it is discussed in chapter two. Throughout data analysis, the researcher applied inductive logic by continuously re-evaluating the interpretations of data in order to enhance the coherence, integrity and accountability of the research findings. The researcher actively engaged in the reciprocal process of linking raw data to existing theory as a rational means of data interpretation. The process of moving beyond the self-evident referred to a second level of analysis whereby the researcher used scaffolding, coding and organising of the raw data to assess how this data linked to the primary theory. The researcher identified and examined themes with similar characteristics and re-examined data for alternatives by gradually departing from the data as new concepts emerged new themes. This continuous reciprocal analysis required a maintained disciplined reflexivity from the researcher. Therefore the researcher contested earliest conceptualisations, strived to avoid pre-existing assumptions and questioned immediate, superficial concepts.

**Organised raw data into a manageable format through thematic analysis**

During interview transcription, the theoretical analysis framework was established and the researcher actively engaged into the reciprocal process of data analysis towards data interpretation; the researcher transformed raw data in an organised and manageable format. The researcher verified and organised the transcripts and field notes in preparation of data analysis, all data was frequently reassessed and grouped according to main themes. Thereafter the researcher assessed the interviews and field notes in order to obtain a general sense of the data corpus as a whole. Finally, transcripts were reduced according to recurrent ideas, thoughts and themes; then themes and sub-themes were categorised and simplified by using similar terms as used by the participants.

**Engaged in the mechanisms of interpretation**

The process of active reciprocal engagement with the data towards interpretation entailed that the researcher applied different mechanisms towards interpretation of the data, namely:

- Re-contextualised data into interpreted findings by truly understanding the data, synthesising the meanings of data and analysing the relationships and characteristics of the data. The researcher continuously assessed data through reading and grouping similar themes together.

- Used creative coding and constant comparative analysis as forms of inductive imagining. Main themes and sub-themes were identified in transcripts and field notes and then grouped through colour coding and recorded onto a comparative table. This assisted the researcher to reason and logically conceptualise loose associations into coherent relational themes.

- Continuously explored and analysed data by questioning own interpretations, by asking oneself “what is happening here in this data analysis?”; “what am I really learning about these results?”; “what is the meaning of these themes?” and “why are these themes here and not somewhere else?”. The researcher recorded field notes (***see*** Annexure J, p.167) after conducting semi-structured interviews as part of data collection and integrated field note observations and experiences into the data exploration. All findings were discussed with the study leader to ensure validity of findings and reduce the possibility of researcher bias.

Furthermore, as guided by Berterö (2015:1), themes, patterns and field note recordings were grouped into subjective perceptions to facilitate understanding and interpretation of data.

**Concluded the analytical process by envisioning the research product**

The conclusion of the analytical process was aimed at presenting a research product in a narrative format. After determining the inherent relevant assumptions, themes and patterns were organised and the researcher conveyed the deeper sense of meaning, the logical argumentation, data interpretation and the description of the findings. The researcher aimed to present the research product as part of a manuscript that has been fortified with graphic depictions from the theoretical analysis framework towards the final results.

The researcher approached an advanced psychiatric nurse with data analysis experience to train her with additional skills needed in order to accurately interpret and code data and report the research findings accordingly. The data was co-coded by a senior lecturer at the School of Nursing Science, North-West University. Final results were only recorded after a consensus discussion was concluded.

### 1.6.3.7 Field notes

Field notes (see annexure J, p.168) were recorded after conducting each semi-structured interview and transcribed as a written account of all the observations, thoughts and experiences of the researcher. It included an analytical interpretation of what the researcher observed, heard, felt, experienced and thought about during the course of the data collection process (Botma *et al.,* 2010:191). Field notes were grouped into descriptive, personal, methodological and theoretical notes (Corsaro *in* Botma *et al.,* 2010:191) that briefly described the following:

- **Descriptive field notes:** observations that the researcher directly perceived with her senses such as “the participant was laughing”. Descriptive notes didn’t include interpretations or meaning but remained purely descriptive.

- **Personal field notes:** the researcher’s interpretations of the participants’ observed reactions, as well as interpretations of the researcher’s personal thoughts, feelings and experiences during the research process, specifically focused on data collection and analysis.

- **Methodological field notes:** referred to the recording of the sampling process and selection choices, challenges that were experienced during data collection and how these challenges were managed.

- **Theoretical field notes:** noted the researcher’s perceived premonitions and links that the researcher made between this research and the existing literature and theory.

## 1.7 ROLE OF THE RESEARCHER

Guided by Botma *et al.* (2010:203-204) and Maree (2013:41), the role of the researcher was listed as:

- Conceptualising and identifying a problem statement.
- Conducted a literature review and compiled a research proposal.
- Obtained ethical clearance and goodwill permission.
- Maintained a trusting relationship with staff and management of the selected hospital.
- Orientated the mediators and independent persons to assist in the recruitment process and measures of obtaining informed consent.
- Scheduled appointments with participants aligned with the participants' and the hospital's programs and conducted the semi-structured interviews with participants.
- Managed the data collection and analysis processes.

## 1.8 MEASURES USED TO ENSURE TRUSTWORTHINESS

Trustworthiness implies a deliberate attempt to ensure valid and reliable results and was reflected throughout the research (Botma *et al*., 2010:292). According to Brink (2010:118) qualitative research rejects the terms 'validity' and 'reliability' in favour of trustworthiness and credibility. Credibility introduced the reader to trustworthiness in congruence with interpretive descriptive design (Padgett *in* Given, 2008:9).

### 1.8.1 Credibility

Bias was a realistic threat and measures to ensure truth value were deployed throughout the research process (Thorne *et al*., 1997:175). Credibility implied to demonstrate the truthfulness of the process by declaring the clear methodological link between participants' expression and the emerging codes identified during data analysis (Jensen *in* Given, 2008:138). Although interpretive description used a critical review from a broad range of literature to guide data analysis, it remained dependent on the researcher to comprehend, synthesise, theorise and contextualise data into findings. The researcher remained the ultimate determinant of relevant constituting data, structuring conceptualisations and dissemination of findings (Thorne, 2004:6). The risk of researcher bias risked credibility of the research results; the manner in which the researcher sought conceptualisations as a critical element that affected credibility of the findings was reported (McPherson & Thorne, 2006:3) and credibility was captured in 'interpretive

authority'. The following strategies were used to increase the credibility of the research results (McPherson & Thorne, 2006:3; Thorne *et al*., 1997a:175; Thorne *et al*., 2004:6):

- Began with conceptualisations that represented the entire sample rather than individual participants. This facilitated the formulation of more insight and perspectives on individuals' perspectives, refined theoretical links and represented grounded data of shared realities.

- Engaged into continuous observations, reflections and challenged conceptualisations to enable a deeper analysis. Observations challenged the researcher's subjective thinking to shift the analysis towards the complexity of mental health literacy and information sources of mood disorders perceived by diagnosed adult hospitalised mental healthcare users with mood disorders, this activated a cascade toward uncovering assumptions and reviewing core understanding.

- The research report directed the reader by distinguishing whether concepts had been derived from a majority of cases, an influential case, or the researcher's interpretation based on obtainable evidence. Demography and topography were applied to present the outlining credibility amidst individual interpretation.

### 1.8.2 Truth value

Truth value was assured in the correctness of the research findings (Jooste, 2010:31). The fundamental principles to ensure truth value were credibility and internal validity (Jooste, 2010:21). It is suggested by Maree (2013:38) that validity of qualitative designs included the extent to which concepts and interpretations have joint meaning for the researcher as well as the participant. Truth value determined the researcher's confidence in the truth of the research findings (Botma *et al.*, 2010:233) that were obtained through credibility, reflexivity, researcher authority and peer review. Strategies to enhance truth value were:

- *Rich, dense descriptions:* the researcher provided an insiders' perspective of dynamics and behaviour as it occurred during contact with the participants, this was captured in the field notes.

- *Clarification of researcher bias:* The researcher steered clear of bias by means of recurrent self-reflection and respect towards the views and opinions of the participant.

- *Managing information discrepancies:* The researcher conducted a consensus discussion with the co-coder and integrated a literature discussion of the research results.

- *Prolonged time:* The researcher spent extended time in the field to ensure accurate, in-depth understanding of the research phenomenon.

- *Peer debriefing:* Throughout the research process the researcher included her supervisors in all areas and ensured that the research objectives were adequately met.

### 1.8.3 Applicability

Applicability referred to the extent to which findings could be applied in various contexts. The strategies that were used to enhance applicability were the generalisation of findings through transferability (Botma *et al.,* 2010:233). Generalisation was obtained through the provision of an in-depth description of the context and documentation that proved a rigorous audit trail of the followed methodology.

### 1.8.4 Consistency

Consistency considers if the findings would be consistent if the inquiry were to be replicated in a similar context by using the same participants. The researcher ensured consistency through dependability and conformability. Dependability was enhanced because the researcher provided a report of all aspects of the research process that supported a stepwise replication (Botma *et al.,* 2010:229).

### 1.8.5 Neutrality

Neutrality referred to freedom of bias during the research process and the extent to which findings were the only informants of the researcher (Botma *et al.,* 2010:233). The researcher ensured neutrality through conformity and eliminated bias through recurrent self-reflection and respecting the views and opinions of the participants.

## 1.9 ETHICAL CONSIDERATIONS

As mandated by Section 72 of the National Health Act (Act no. 61 of 2003), the National Research Ethical Council (NHREC) directs ethical and responsible health research in South-Africa (Department of Health, 2015:3). Therefore the ethical considerations in this research were based on the South African Department of Health's health research ethics guidelines (Department of Health, 2015:2). The main expectations of these guidelines are that:

- The proposal for this research which involved human participants underwent an ethical review.

- This research promoted health and contributed towards the prevention of disease.

- This proposal was evaluated by a scientific panel and was submitted to the Health Research Ethics Committee (HREC) of the North-West University.

- The researcher minimised any possible harm to the participants and promoted the wellbeing and safety of the participants.

- The researcher acknowledged her accountability for all the research activities.

- The researcher promoted the social and ethical values captured within civil society and within the nursing profession during the comprehensive execution of this research.

- In light of the listed expectations, the following ethical considerations directed the realisation of this research:

### 1.9.1 Risk and benefit analysis of a vulnerable population

According to the South African good clinical guidelines (Department of Health, 2006:19) individuals with mental disabilities (such as mood disorders) are placed in a vulnerable situation when participating in research related to their capacity to reason and comprehend. Therefore, the researcher approached this research from the perspective that the participants are a vulnerable group. This research's population was vulnerable because as adult hospitalised mental healthcare users with mood disorders, participants may have felt coerced and might have lacked the competence to make voluntary and informed decision to participate. Therefore, a risk and benefit analysis was conducted to establish areas of risk and to ensure the management thereof to minimise risk and discomfort.

Participating mental healthcare users gained only indirect benefits from the research; they became more aware of their own predicament and obtained new insights into information seeking alternatives in future care and treatment after being discharged from the hospital. The indirect benefit of this research was to inform the body of knowledge in psychiatric nursing and possibly influence the health education strategies of adult mental healthcare users with mood disorders in a positive manner. This research enabled a description of adult mental healthcare users' mental health literacy about mood disorders and listed their information sources. An indirect benefit was to give feedback to the hospital that could lead to implementation of recommendations for health education methods.

While considering the risks of this research, the following types of harm were discussed (Botma *et al.,* 2010:22):

- *Physical harm:* No physical harm could come to a participant for taking part in this research, however boredom may have occurred. Physical harm was minimised by interviews being performed by a competent interviewer who was well-prepared and took place in a comfortable office.

- *Psychological harm:* Self-disclosure, introspection or sharing personal information might have caused embarrassment or emotional response to the participant. Participants were also at risk of experiencing emotional discomfort related to their mood disorder, and it was possible but unlikely that interviews could trigger emotional experiences. The researcher remained objective, avoided personal or irrelevant data and focused on the objective of the research. The researcher was able to observe signs of participant discomfort, emotional or vulnerable behaviour, thus the researcher planned to refer the participant to the attending psychologist if necessary. The research questions in no way expected of participants to share the details and emotional connections of their mood disorder, the focus was placed on their mental health literacy and the sources they use to obtain their knowledge. In the case where a participant was to become emotional, they were allowed a five-minute break, received counselling if deemed necessary, and in cases where this was ineffective the participant was to be accompanied back to the ward and handed over to the registered nurse on duty; the tending psychologist was then contacted to see the patient as soon as possible.

- *Social harm:* All participants were hospitalised mental healthcare users in the selected hospital. It was assumed that patients/participants already know one another through group therapy sessions as part of their hospital program. During admission to the hospital patients signed a form of confidentiality that minimised the risk of social harm, discrimination and stigmatisation. The participants' identity was kept anonymous and confidential throughout the research process and interviews for this research were conducted individually in order to enhance privacy and confidentiality.

- *Economic harm:* There were no financial risks involved as the participant was already hospitalised on the premises during the time of research data collection.

- *Legal harm:* The researcher was legally bound to report illegal actions by the participant that she might become aware of during data collection. In this event the researcher was to explain that she is legally bound to share this information with the treating psychiatrist for further management and the research interview was to be terminated immediately if it were the case.

- *Dignity harm:* All participants were treated respectfully as individuals with values, preferences and commitments at all times. The researcher minimised risk to dignity by means of an appropriate research methodology and showed competence during the conduction of this research.

### 1.9.2 The right to self-determination

Self-determination was adhered to when acknowledging that the participating mental healthcare user had the right to decide to participate and were made aware that they could, without any discrimination choose to withdraw from participation without discrimination. The researcher was able to re-assess and evaluate the ability of the mental healthcare users to make cognitively competent decisions, for this the MacCAT-CR competency assessment tool was utilised. Thus, the MacCAT-CR assessment was conducted twice before conducting interviews; it was first assessed by the clinical psychologist and re-assessed by the researcher. In cases where the competency assessment results were unsuccessful, the prospective participating mental healthcare users were to be counselled and referred back to their clinical psychologist.

### 1.9.3 Recruitment and monitoring

In the hospital setting each adult mental healthcare user was treated and tended to by one specific clinical psychologist; these psychologists were familiar with the mental healthcare users' condition, emotional state, and behavioural functioning and thus were included as mediators. The role of the mediators was to approach prospective participating mental healthcare users that adhered to the strict set of inclusion and exclusion criteria. The selected mental healthcare user was also to score a minimum of five (5) marks on the MacCAT-CR competence assessment that was performed by the psychologist (mediator). Participating mental healthcare users were granted at least 24 hours to consider participation during which time they had the opportunity to inquire more information regarding the research from the mediator. After mental healthcare users were deemed competent by the Psychologist, as well as the MacCAT-CR assessment to decide upon participation and indicating their willingness to participate; their names were reported by the mediator to the Professional Nurse on duty who acted as the independent person obtaining the informed consent. After consent was obtained by the Professional Nurse, the names of participating mental healthcare users were issued to the researcher during telephonic follow up calls. The researcher then contacted each participating mental healthcare user and scheduled appointments within 24 hours after informed consent was obtained; this was done to monitor for fluctuation possibilities in prospective participants' emotional and psychological ability. Prior to data collection, the researcher repeated the MacCAT-CR assessment and confirmed each participating mental healthcare user's emotional and psychological competence. In the event where the participating mental healthcare user scored less than five (5) marks from the MacCAT-CR, the participant was referred back to the ward, and the Professional Nurse on duty was to contact the applicable clinical psychologist. Prior to the recruitment process the researcher had a briefing session with the mediators and Professional Nurses in order to clearly discuss their roles and functions in the research process and to establish rapport and a clear line of communication between the researcher and professionals.

Throughout the research, progress was monitored by the research supervisors who frequently received reports of the researcher's progress, especially during data collection. Two monthly monitoring reports were submitted to the HREC. In the event of an incident or occurrence of adverse effects of the data collection process, the researcher was to report this immediately to the supervisor who would have then reported to the HREC. In the likelihood that an incident was to occur while the researcher was present, she was to inform the Professional Nurse on duty first to see if this could possibly be resolved in the ward, if not, the Psychologist and Psychiatrist were to be telephonically informed. In the event where an incident was of managerial concern, it was to be reported to the unit manager on duty.

### 1.9.4 The right to privacy

The researcher protected the participating mental healthcare users' right to privacy by conducting interviews in a private, secluded room with good ventilation within the hospital. This room was pre-booked for interviews and limited disturbances were ensured. Voice recordings were only available to the researcher, supervisors, co-coder and transcriber who have signed an agreement of non-disclosure in order to ensure privacy of the participants' information. Recordings were transcribed and stored securely for five years and will be destroyed thereafter as also explained to participating mental healthcare users' in phase three of interviews.

### 1.9.5 The right to anonymity and confidentiality

The researcher ensured that anonymity and confidentiality were maintained throughout the research; data was coded instead of using names and surnames and was regulated to a limited number of viewers who formed part of the research and signed a non-disclosure agreement in order to maintain confidentiality. Code numbers were used during analysis and interpretation of data and the original demographic data of participating mental healthcare users' were kept in a locked office, separate from data and the list was destroyed following the completion of this research. Any individual who accepted information in confidence was held liable to maintaining confidentiality. The content of data included essential demographic information, in the event that it was necessary to follow up with mental healthcare users.

### 1.9.6 Right to fair treatment

The researcher ensured that participating mental healthcare user's right to fair treatment was maintained by treating all mental healthcare users equally, non-judgmentally and by deploying a justified inclusion and exclusion criteria list for selection.

### 1.9.7 Respect for people

Participating mental healthcare users were respected and treated equally, they were allowed freedom of speech and the researcher maintained a non-judgmental approach, treated mental healthcare users with dignity, and ensured confidentiality. Furthermore the researcher ensured diligent preparation and competence during the data collection phase and acknowledged that participants' private time was occupied.

### 1.9.8 Justice

Justice was adhered to by following a justifiable sampling process. Sufficient time was granted for data collection to ensure that all mental healthcare users who adhered to the inclusion criteria had a fair opportunity to do so. Mental healthcare users who declined participation were treated fairly.

### 1.9.9 Competence of the researcher

The researcher completed 960 hours clinical practice in Community Psychiatric Nursing Science in 2015 and passed a research methodology module in 2014. Yet, the researcher did not conduct interviews before the supervisors declared her capable through role play and supervision. Both supervisors were advanced psychiatric nurses with ample experience in postgraduate supervision.

### 1.9.10 Dissemination of data

The research results were disseminated by means of a presentation to the health practitioners of the selected hospital according to a prescheduled training session. Participating mental healthcare users were also granted the opportunity to indicate on their demographic questionnaire if they would prefer feedback and whether they would like to receive the results via e-mail or sent via postage after the completion of the research. This meant that even though the mental healthcare users were discharged from the hospital, they still received feedback and recommendations of the research results upon request. The researcher completed the mini-dissertation and will submit a manuscript for publication after success examination.

### 1.9.11 Storage, archiving and research data management

Saved data included proof of the MacCAT-CR assessment, demographic survey, voice recordings of semi-structured interviews, and the completed information source checklist. All raw data was coded to ensure confidentiality and only the supervisors, the researcher, co-coder and transcriber had access to the data and/or voice recordings. The co-coder and transcriber completed confidentiality agreements prior to inclusion in this research. Data sharing was

minimised to the furthest possible degree and members who have access to the data signed confidentiality non-disclosure agreements to ensure protection of data, all information that was sent via e-mail was be deleted upon completion of the research. Data possessed by the co-coder and transcriber was kept on a password protected computer and was deleted upon completion of this research. Data saved on hard copy documents, memory sticks, or DVD's were kept in a fireproof, locked cabinet and data that was stored electronically was kept on a password protected computer with firewall and spyware protection. Thus all data was kept in the safe and secure office of the supervisor on the premises of the NWU; information will be kept safe for a total period of five years. Data will not be made available to other studies in the future as this is not what the mental healthcare users consented to.

## 1.10 MINI-DISSERTATION OUTLINE

The outline included the following chapter headings:

Chapter 1: Introduction to the research (p.1).

Chapter 2: Literature review: Information sources and mental health literacy related to mood disorders (p.31).

Chapter 3: Discussion of research findings and literature integration (p.74).

Chapter 4: Conclusions, limitations and recommendations of the researcher with specific reference to the formulation of approaches to enhance mental health literacy on all levels of society (p.109).

## 1.11 SUMMARY

The progression of this postmodern world is undeniably paralleled by an increased prevalence and incidence of mood disorders, globally and in South Africa. From these mood disorders there arise warnings of incorrect diagnosis and treatment. The adult mental healthcare user diagnosed with a mood disorder holds certain knowledge about mood disorders referred to as mental health literacy. The latter refers also to more than mere knowledge about mood disorders but serves also as impetus to search for and access mental healthcare and take up an active, participative role in the fight against mental illness. Mental health literacy is a fairly recent concept, presented as the internalisation of information by the mental healthcare user as recipients of health education. Health education is a deliberate intervention by health professionals and the use of media can be a positive and negative mechanism for health education. For example, mass media can inform society about mental illnesses but media can also stimulate suicides. The gap identified in the background was the absence of sufficient empirical evidence on mental health literacy about mood disorders in general in South Africa. There is also lack of understanding of

the types of information adult mental healthcare users with mood disorders access about their mental illness. Chapter 1 led to the realisation of a qualitative, interpretive descriptive methodology presented at a typical mental healthcare facility within the North West. Through the MacCAT-CR assessment, hospitalised adults diagnosed with a mental health disorder were screened for cognitive competence for informed, voluntary participation. After twelve (N=12) semi-structured, individual interviews conducted by the researcher on the premises of the selected mental healthcare facility, data saturation realised. The researcher remained congruent with the strategies to improve the trustworthiness of this qualitative design specifically applied to interpretive description. As the participants were vulnerable, a comprehensive process of ethics clearance and monitoring occurred throughout the research process. In chapter two follows a literature review on mental health literacy and mood disorders. The research results are declared in chapter three.

# CHAPTER 2: LITERATURE REVIEW

## INFORMATION SOURCES AND MENTAL HEALTH LITERACY RELATED TO MOOD DISORDERS

### 2.1 INTRODUCTION

In order to provide a comprehensive and contextualised theoretical base, a literature review was conducted. The aim of this chapter was to present existing literature related to current mental health literacy, information sources utilised to enhance an understanding of mental health literacy and the treatment of hospitalised adult mental healthcare users with mood disorders especially within the private sector. The most recent empirical findings and authoritative theories were synthesised. The motivation of this chapter is similar to the explanation provided by Thorne *et al.* (1997:175) in terms of acknowledging existing knowledge and developing an analytic framework to work towards further knowledge. Interpretive description requires a critical review from literature (Thorne, 2004:6) and the researcher determined relevant constituting data to structure, conceptualise and disseminate findings.

### 2.2 SEARCH STRATEGY

While compiling this literature review, the researcher utilised primary and secondary sources. Appropriate articles from search engines and databases provided by the North-West University were explored such as EbscoHost, Sabinet and Google Scholar. The researcher used recent literature published since 2000, yet a range of older articles published by Jorm were included as health literacy was coined by Jorm from as early as the mid-1990's. The literature review stretched from 2015 to 2016 during the completion of the research report. Through thorough referencing the researcher prevented plagiarism. Figure 2-1 (p.32) presents a mind map that directed the literature review. The three main themes reviewed were firstly mood disorders, secondly different information sources and thirdly mental health literacy as it evolved from health literacy.

### 2.3 MOOD DISORDERS

Mental health affects all areas of life for those affected both in developed and developing countries and is greatly influenced by factors such as poverty and low levels of education (WHO, 2004b). Mood disorders form a large part of mental health disorders and different types of mood disorders and their management may vary depending on the type of mood disorder. The following paragraphs provide an overview of mood disorders, types, management, prevalence and health education.

Major depressive disorder and bipolar mood disorder are both classified as mood disorders and are characterised by emotional and behavioural disturbance that influences various aspects in

life (Kneisl & Trigoboff, 2008:405). Bressert (2016:1) describes bipolar mood disorder as a mental disorder characterised by frequent mood changes: the American Psychiatric Association (APA, 2013:123) DSM-5™ states that bipolar mood disorders can be divided into various phases or episodes ranging from depressive to manic.

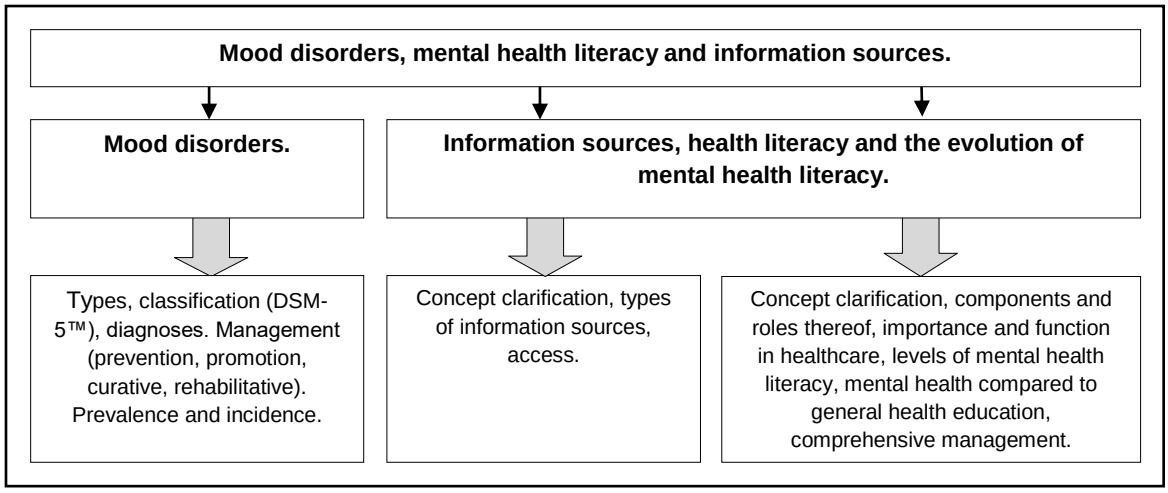


**Figure 2-1: Type of mood disorders, classification and diagnosis thereof**

Barlow and Durand (2009:215) suggest that major depressive disorder and bipolar mood disorder are parallel in fluctuating tendency of mood. Bipolar mood disorder is a chronic illness that requires long term multi-professional treatment (Yatham *et al.,* 2013:3). Yet, insufficient knowledge and fear of stigma has decreased professional help seeking (Depression and Bipolar Support Alliance [DBSA], 2016) leaving millions untreated. Weinstock *et al.* (2014:25) state that bipolar mood disorder can be regarded as a serious, disabling and highly prevalent illness that poses various treatment challenges; even with the development of various psychotropic medication, morbidity and mortality rates remain high. Bipolar mood disorder mainly involves mood episodes ranging from mania to depression. The DSM-5™ (APA, 2013:124-125) distinguishes clearly between a manic episode, a hypomanic episode and major depressive episodes. The Diagnostic and Statistical Manual of Mental Disorders (DSM-5™) clusters bipolar mood disorder into separate diagnosis including bipolar I disorder, bipolar II disorder, cyclothymic disorder, treatment induced bipolar and related disorder, bipolar mood disorder due to other medical conditions and other unspecified bipolar and related disorders (APA, 2013:123). Bipolar mood disorder can also be characterised by functional and psychosocial impairment and high rates of mortality related to suicide (Weinstock *et al.*, 2014:1). The DSM-5™ (APA, 2013:124) states that manic episodes in bipolar mood disorder is often associated with unusual changes in individual functioning; these changes do not always lead to marked impairment in functioning but can often be observed by others.

Major depressive disorder and bipolar mood disorder can affect memory, concentration, energy levels, confidence and decisional capability (Mental Health America, 2016; Kneisl & Trigoboff, 2008:405). Determining the most relevant classification of mood disorders is of utmost importance to ensure appropriate management and treatment. The DSM-5™ (APA, 2013:123) serves as strict diagnostic criteria tool that clearly differentiates between the various mood disorders and episodes.

In this research, the main focus will be placed on hospitalised mental healthcare users who have been formally diagnosed with bipolar mood disorder presenting with manic or depressive symptoms as specified by the DSM-5 (APA, 2013:123). Table 2-1 provides clarity related to the criteria of bipolar mood disorder. Once a confirmed diagnosis has been made based on this; treatment can be initiated.

**Table 2-1: Features of the respective phases or episodes of bipolar mood disorder (APA, 2013:124-125)**

| | **Bipolar mood disorder** | |
|---|---|---|
| | **Manic episode** | **Major depressive episode** |
| Duration of symptoms and characteristics | During this period of mood disturbance three or four of the following symptoms are present for at least one week and represent a notable differing behaviours including: grandiosity, decreased need for sleep, flight of ideas, pressured speech, distractibility, increased or excessive involvement in pleasurable activities (Colin, 2016:203). | Major depressive episodes can be characterised by symptoms of change in affect and cognition lasting for the duration of at least two – weeks. Individuals diagnosed with major depressive episodes tend to present with significant changes from previous performance with notable depressed mood or loss of interest in enjoyable or pleasurable activities (Lippi & Pretorius, 2016:179). |
| Vegetative features (hypothalamic dysfunction) | Colin (2016:203) states that during a manic episode, individuals may present with decreased need for sleep and often feel refreshed after only sleeping for a few hours; thus sleeping later or waking up earlier than usual. Appetite may be increased or decreased, usually decreased because “there is no time to eat”. Libido and sexual drive is also elevated. | Hypersomnia (excessive sleeping) or insomnia (difficulty sleeping) practically every day. Increased or decreased appetite and libido changes such as decreased or absent libido may also be present (Lippi & Pretorius, 2016:183). |

| | Bipolar mood disorder | |
|---|---|---|
| | **Manic episode** | **Major depressive episode** |
| Energy levels, involvement and motivation | Excessive involvement in activities that could have negatively impact outcomes such as compulsive decision making. Increased goal-focussed activities, constant increased goal directedness. Colin (2016:203) states that during manic episodes, individuals often perform activities including sexual, occupational, religious and political pursuits. | Lack of energy and fatigue almost daily. Loss of interest in all or nearly all activities for the majority of a day, almost every day. Diminished interest and decreased pleasure. Individuals generally spend less time on activities and hobbies due to listlessness and indecision and it takes effort to perform general activities (Lippi & Pretorius, 2016:183). |
| Mood or affect | Periods of unusually elevated irritability or even aggression. Grandiosity, delusions of grandeur or heightened self-esteem. Colin (2016:203) describes manic mood as inflated or overinflated self-value and states that individuals often embark on activities unrelated to their personal character, experience and ability during a manic episode. Labile mood with susceptible distraction by stimuli is also often noted (Jarvis & Middleton, 2014:397). | Experiencing feelings of worthlessness or inappropriate guilt nearly daily, depressed mood for most part of the day, almost every day. Individuals with depressed mood appear sad, down and they often report feeling sad, gloomy, and poorly interested or even emotionally absent saying that they are unable to feel grief, anger and pleasurable emotions (Lippi & Pretorius, 2016:183). |
| Observable | Pressured speech or the individual may be more talkative than usual. According to Colin (2016:203) speech can also be louder and more rapid than usual and it may be difficult to interrupt. Individuals with manic episodes may also frequently pun, joke, or make irrelevant comments with sudden complaints or anger outbursts during irritable mood (Colin, 2016:204). | Agitation or retardation of psychomotor responses that can be observed by others. Significant weight gain or loss. According to Lippi and Pretorius (2016:183) individuals with major depressive episodes may generally appear normal, yet some psychomotor agitation may be observed such as fidgeting, restlessness or playing with hands or hair. |

| | Bipolar mood disorder | |
|---|---|---|
| | **Manic episode** | **Major depressive episode** |
| Concentration and cognitive functioning | Colin (2016:204) explains that during manic episodes an individual may be easily distracted, unable to focus and "too busy" to perform general activities. During manic episodes the individual often makes unwise, abrupt decisions that can negatively influence them over the long term; due to their willingness to take risks, they often have poor insight (Colin, 2016:204). | Impaired ability to focus or difficulty making decisions on a frequent basis nearly every day. Some individuals with major depressive disorder may present with poor memory and although there might be an abrupt cognitive decline, insight generally remains preserved (Chiliza & Asmal, 2016:149). According to Lippi and Pretorius (2016:181) individuals with major depressive episodes may also complain of irritability, difficulty concentrating and they often have general pessimistic thoughts towards the world and the future. Negative self-perception, self-inferiority, failure and self-reproach is often reported by individuals with a major depressive episode (Lippi & Pretorius, 2016:183). |
| Thoughts | Distractibility, racing thoughts or flight of ideas. During manic episodes individuals often report that their thoughts are too rapid to verbalise; this is observable in rapid speech and an almost continuous flow of unrelated topics (Colin, 2016:204). | Frequent thoughts of death and suicidal ideation with no plan, or a specific plan of suicide method. Lippi and Pretorius (2016:183) state that major depressive episodes may lead individuals to feeling that suicide or death is the solution to their situation; although this may not always be the case they may also have no intention of harming themselves (Lippi & Pretorius: 2016:183). |
| Other probable causes | The mood disturbance is severe enough to lead to a notable impairment in functioning. The episode is not related to the effects of substances or another medical condition. | Symptoms may cause clinically significant distress and impairment in functioning. The episode is not attributable to the effects of substances or another medical condition. |

### 2.3.1 Management of mood disorders (prevention, promotion, curative, rehabilitative)

Various treatments are effective in managing mood disorders, including pharmacological treatments, psychosocial therapy, and in certain cases also electroconvulsive therapy (Barlow & Durand, 2009:255). Yatham *et al.* (2013:4) concluded that medication alone is insufficient in treating persons with bipolar mood disorder and suggest that combining pharmacotherapy, psycho-education, cognitive-, group-, and interpersonal therapy has been effective in treating acute and long term depressive disorders. Combining these interventions has led to decreased

relapse, defaulting, readmission and it has shown increased adherence to treatment (Yatham *et al.*, 2013:4). Weinstock *et al.* (2014:25) are concerned that persons living with bipolar mood disorder are strained by the risk of side effects, drug interactions, medication error, non-adherence, co-morbidities and more and are thus at risk of poor adherence or defaulting of treatment. In addition, Javelot *et al.* (2014:1) agreed that it is impossible to predict responses of individuals to treatment and there is always a risk of poor compliance or relapse.

In developing countries such as South-Africa the need of mental health resources and access to services is rising (Hanlon *et al.,* 2014:10), yet, the mental health budget is insufficient (Ganasen *et al.,* 2008:23). About 75% of mentally ill South-Africans remain untreated due to decentralisation that decreases the availability of mental health resources. In contrast to the provision of mental healthcare in developed countries, shortage of professionals, poor availability of medication and poor integration of mental health into primary healthcare has left developing countries behind (Ganasen *et al.,* 2008:24).

A recent comparative study between low- and middle- income countries namely Ethiopia, India, Nepal, South Africa and Uganda was done in order to inform integration of mental health and primary healthcare. These countries generally lacked mental health resource availability, specialist mental health professionals and reliable medication supply. In South Africa there was moderate treatment coverage in the form of psychotropic medication for severe mental disorders. Community mental health literacy was low in all sites of selected countries and a severe lack in multi-sectored collaboration with community healers was noted; although mental health is highly prevalent internationally, the focus of existing models and outreach program initiatives were only placed on non-communicable disorders, tuberculosis and HIV. The University of Cape Town's (UCT) compared the staff/population ratios of 2006 and 2010 and found that South Africa was short of 464 psychiatrists and 466 psychologists, thus emphasising the gap of availability of professionals (*in* Bateman, 2015:7). Outreach programs, networking and application of community healthcare workers are available in low- and middle- incomes countries including South-Africa; these programs integrated with primary healthcare could provide opportunity for the expansion of mental healthcare (Hanlon *et al.,* 2014:1).

According to Lund, a professor at UCT, training of more general workers to identify and manage mental illness within the community with specialist support could narrow the mental health treatment gap in South Africa (*in* Bateman, 2015:7).

### 2.3.2 Prevalence and incidence

With a global lifetime risk of above 25%, mental health disorders directly and indirectly impact developed and developing countries globally (Ganasen *et al.,* 2008:23). According to the London

Mental Health Foundation (MHF, 2016) mental health disorders account for 21.2% of years lived with disability internationally. The MHF (2016) recently published fundamental facts of mental health based on the findings of the Adult Psychiatric Morbidity Survey (APMS) that was published in 2014 and highlighted that one in six adults experience mental health symptoms on a weekly basis, and one in five adults have considered committing suicide at some stage in their life (MHF, 2016), the National Alliance on Mental Illness (NAMI, 2016) also revealed that an average of one in five adults in the United States of America (USA) experiences mental illness annually.

With the high prevalence and incidence, it is shocking to read that only a third of individuals who have experienced mental health symptoms in the past sought help and were formally diagnosed with a mental disorder (MHF, 2016). The MHF (2016) place emphasis on risk factors associated with mental health disorders; women aged 16-24 are 26% more likely to experience mental health symptoms than the 9% risk of their male counterparts, in comparison mid-life between the ages of 55 and 64 symptoms are equally prevalent among both males and females (MHF, 2016).

Depressive disorder is one of the leading causes of disease burden globally (Ferrari *et al.*, 2016). The MHF (2016) found that in 2007, 2.3% of adults above 16 were diagnosed with depression and this has dramatically increased to 3.3% in the APMS findings of 2014. In 2014 a popular South African newspaper, Sunday Times published an article on 6 July 2014 titled "*SA's sick state of mental health*". The article suggested that 17 million (a third) of the South African population are affected by mental illness. Due to questioning of these statistics the researcher referred to the results of the South-African Stress and Health (SASH) study conducted in 2009 that was aimed to determine twelve month and lifetime prevalence of common mental disorders in South Africa that formed part of the World Mental Health (WMH) survey initiative (Herman *et al.,* 2009:339). The first epidemiological mental health survey conducted in South Africa was in 2009, it included 4351 South African adults; it was found that 11, 2% of participants had two or more lifetime disorders and these disorders were further classified according to prevalence. According to the SASH (2009) study the most prevalent lifetime disorders amongst South Africans were anxiety disorders (15,8%) followed by substance use (11.4%). Mood disorders accounted for 9.8% of lifetime disorders while major depressive disorder, also 9.8% was one of the most prevalent individual lifetime disorders in South Africa (Herman *et al.,* 2009:339). Bateman (2015:7) wrote that Discovery Health, the largest medical aid provider in South Africa, showed that between 2008 and 2012 there was 41% increase of mental health disorder claims and a review of all medical schemes showed that hospital admissions for mental health disorders increased by 51% during this period; these figures exclude the remaining 80% of the

population treated within the public sector. These findings give a clear confirmation of how the various mental health disorders have taken a toll on South Africans.

Amongst a variety of mental disorders and their different presentations, depression and bipolar mood disorder are classified as two of the leading mood disorders affecting about 60 million individuals worldwide and in South-Africa more than four million individuals have bipolar mood disorder, thus 3-4% of the population (WHO, 2016). Bipolar mood disorder is recurrent and more than 90% of individuals who have experienced a single episode will have recurring episodes in the future, thus it can be classified as a lifetime prevalent disorder (Bressert, 2016:1; Weinstock *et al.*, 2014:1; Kessing *et al.*, 2013:212). The Depression and Bipolar Support Alliance [DBSA] (2016) states that bipolar mood disorder can affect individuals of all ages and onset of symptoms mainly occur during adolescence or early adulthood. Rickwood *et al.* (2015:1) agree by stating that three-quarters of mental disorders are frequently diagnosed by the age of 24 i.e. during young adulthood. Barlow and Durand (2009:215) likewise agree that mood disorder recurrence is common and thus treatment should be aimed not only on medication and therapy but also on its prevention through education.

## 2.4 INFORMATION SOURCES, HEALTH LITERACY AND THE EVOLUTION OF MENTAL HEALTH LITERACY

We live in a world where information is everywhere and receiving, collecting, interpreting and producing information has led to increased knowledge in all fields and societies. Burgin (2011:348) states that an infological (information integration) system discerns various types of information such as social, chemical, biological, genetic or cognitive and adds that these aspects grouped together, refers to the overall concept “information”. Information can be found in a variety of sources and methods and forms a critical part of enhancing health literacy.

Potential information sources traditionally include self-help books, radio, television, telephonic help-lines, pamphlets, brochures, word of mouth and newspapers (Reavley *et al*., 2011:1267). In contrast to traditional sources, the Internet has evolved into a much more digitalised and technological field that includes websites such as Wikipedia, Encyclopaedia Britannica etc. The internet is a rapidly growing information source in which medical and psychiatric problems, symptoms and treatment are often accessed by mental healthcare users and their carers (Reavley *et al.,* 2012:1753).

Although traditional and digitalised information sources are available, their use and interpretation in different communities or groups vary due to factors such as age, culture, educational level, access to information, personal experiences; family and friends who are most likely the main sources of mental health information (Jorm, 2011c:398). In addition, Ganasen *et al.* (2008:26)

state that economic inequality is also a major contributing factor that influences mental health literacy, especially in developing countries. In order to identify factors and challenges that influence the utilisation of information sources negatively, the WHO (2008:10) suggested that utilising and integrating information with stakeholders could contribute to the development of overall health literacy. Stakeholders in this reference include members of the general public, community-based facilities, healthcare professionals, communicators of health and educators, academic and business communities, healthcare facilities, faith-based organisations, news and electronic media, and also healthcare practitioners. It is also recommended that social departments and health authorities join forces to develop health promotion programs. Such programs may include: computer games, pocket books, visual and audio discs and mobile phone applications to assist in health information provision and aimed to enhance the knowledge of illiterate populations (Tsai *et al.,* 2014:126). Various studies (Sykes *et al*., 2013:150; Sarkar *et al*., 2010:183; Volandes & Paasche-Orlow, 2007:5) have investigated literacy from the view of the healthcare users' interaction in decision making, disenfranchisement of groups related to poor literacy skill, lack of communication between healthcare user and professional healthcare provider including cultural barriers, and finally the health outcomes of poor literacy. Different types of information sources are used for health education as described in the following paragraphs.

### 2.4.1 Types of information sources

As society has transformed, so has information sources and methods used to communicate and convey information to the public. Already in 1997, the National Mental Health Association in the USA (*in* CMHA*,* 2004:4*)* determined the most popular sources for obtaining mental health information were television news magazine shows, newspapers, television news, news-related magazines, television talk shows, radio news, magazines, Internet, non-fiction books, radio talk shows and women's magazines. In figure 2-2 (p.40) the researcher depicted findings of the type of information sources that are available that could be used to enhance health literacy.

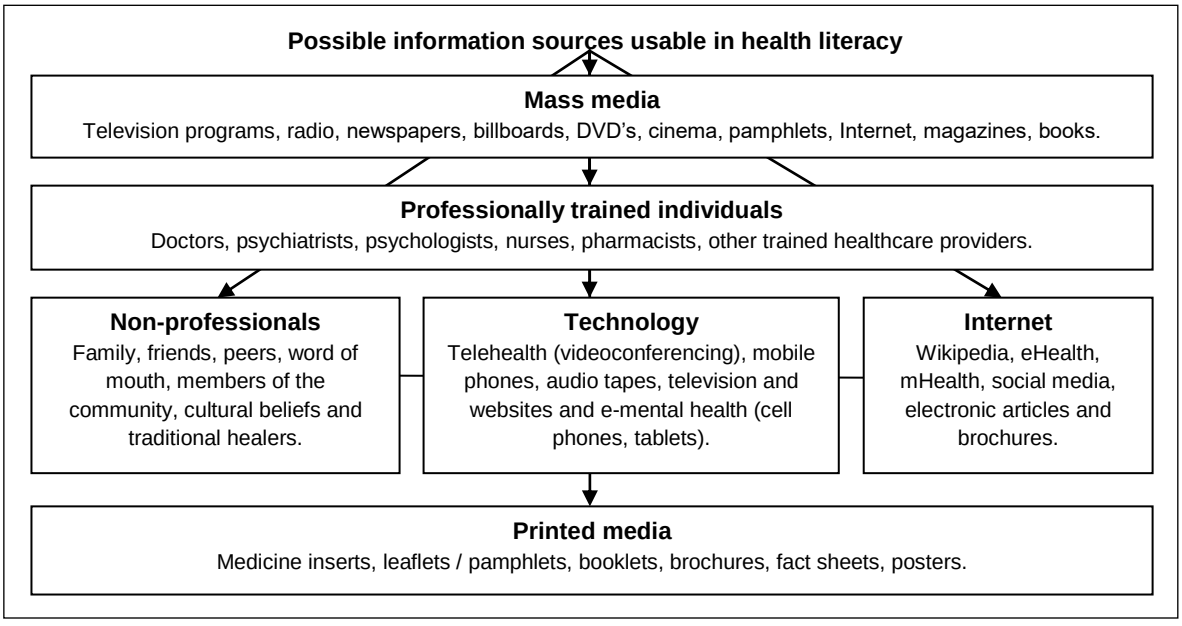

**Figure 2-2: Types of possible information sources usable in health literacy**

Figure 2-2 serves as an example of the transition of information sources over the last decade and shows the evolution of information from the production of paper towards a global technologically driven society through the Internet and electronic applications. Traditionally, the most accessible and popular information sources were informal sources such as magazines, pamphlets, brochures and leaflets. Regardless of the quality and validity of the information provided it seems that members of the community deemed these sources as trustworthy to enhance their mental health literacy. One recently published example in a popular South-African magazine states that a patient was diagnosed with Stephens-Johnson syndrome and toxic epidermal necrolysis syndrome shortly after being treated with mood stabilising medication; the affected patient urged the public to become aware of medication side effects by reading medicine inserts. Another article reported that medication such as antidepressants could possibly lead to weight changes (Van der Spuy, 2015a:24). How are these articles interpreted by the reader if they are illiterate? Literate individuals tend to have better mental health when compared to their illiterate counterparts because of their ability to utilise and interpret printed media (Tsai *et al.,* 2014:126).

Although printed media provides more in-depth and factual information, it is not the preferred information source for individuals who are poorly literate/illiterate (Norris *et al.,* 2013:1). Poor literacy skills such as reading, writing and interpreting information is a significant contributor to the disease burden of the poorer communities and illiterate individuals are forced to rely more on mass media such as television and radio (Ganasen *et al.,* 2008:24). For the illiterate, mass media is often regarded as a valid source of information due to its availability and accessibility. It is the most comprehensive information source, yet the true impact of mass media can potentially create mixed outcomes. The evolution of technology has led to a shift in research where the impact of information provided by technologies such as the Internet has been widely investigated for its influence on health outcomes (McCray, 2005:153).

Regardless of the negative correlations made about mass media, if used correctly, it has great potential to create positive outcomes. However, Kutcher *et al.* (2016:156) suggest that no mental health research intervention should be allowed to be published without acknowledgement and transparent conflict of interest endorsements. Jorm (2011c:398) suggested that consulting and including professionals' views, knowledge and perspectives can convey information in a less stigmatising and sensational manner. Media as a source of mental health information can potentially enhance mental health literacy (Kelly *et al.,* 2007:29) related to recognition, causes and variety of treatment, challenges of stigma related to public attitudes, stereotypes and social acceptance of mental illness (Fennel & Boyd, 2014:670). Often viewed as the primary source of

information available to the public, mass media's portrayals of mental illness could potentially lead towards enhanced mental health literacy as individuals conceptualise, construct, and practice different identities and perceptions from obtained information (Fennel & Boyd, 2014:670). An example of a specific event in which mass media was used effectively as a part of disease control was during a recent Ebola outbreak where there was an urgent need to inform the public of risk factors associated with Ebola. Kott and Limaye (2016:42) found that mass media is an efficient primary transmitter of information to the public and that it influences behaviour and perception of risk; due to its accessibility in modern society, however, individual interpretation may vary.

From Table 2-2 (p.42) it becomes clear that access to health education to higher coverage of end users might be stronger through digital mass media. Yet, the responsibility remains strongly with the reader to interpret health education information, irrespective of the medium used to communicate. In the following paragraphs various types of information sources are discussed.

**Table 2-2: Examples of typical content provided by different mass media as information sources to describe the evolution of mental health literacy and the access thereof from traditional sources to higher technological sources**

| Author | Type of mass media used | Summary of health information provided through the identified mass media source | A reflection from the researcher regarding the semantic clarity and how the health information can typically be interpreted |
|---|---|---|---|
| **A popular South African magazine as a very traditional mass media source** | | | |
| Van der Spuy (2015a:12). | Local South African magazine titled "When medication becomes catastrophic". | Patient was diagnosed with Stephens-Johnson syndrome, a toxic epidermal necrolysis syndrome shortly after being treated with mood stabilising medication. The affected patient now urges the public to become aware of the side effects of medication by reading pamphlets attached to their medication. The interpretation of this article may vary among different individuals. | Enhanced mental health literacy could possibly have provided the knowledge of the affected patient in order to be aware of the side effects from the beginning of the treatment and recognise symptoms earlier and thus this type of article teaches members of community to be aware of whether they have been correctly diagnosed, if they are using the appropriate treatment and if they are taking medication as per prescription. On the other hand such an article could also be interpreted in a manner whereby individuals might avoid taking mood stabilising medication due to fear of developing the same side effects as noted in the article. |
| Van der Spuy (2015b:24). | Local South African magazine titled "Antidepressants make me fat! Can these medicines really cause fluctuating body weight? The opinion of some experts". | Reports that medication such as antidepressants could possibly lead to weight increase or decrease. | Interpretation could lead to inappropriate use of treatment in order to lose / gain weight. Adherence and positive results can enhance mental health and motivate further recovery (Parker *et al.,* 2012:511). When a mental healthcare user does take their treatment correctly, they will feel better, eat better and thus gain weight. |

| Author | Type of mass media used | Summary of health information provided through the identified mass media source | A reflection from the researcher regarding the semantic clarity and how the health information can typically be interpreted |
|---|---|---|---|
| **The transition from basic television, radio and newspapers to high-tech mass media** | | | |
| Clement *et al.* (2013:1-15). | Television, Radio, newspapers, billboards, DVD's, cinema, pamphlets, Internet | Investigated the possibility of using mass media interventions as a method to reduce stigmatisation towards mental health. | Prejudice and stigma can be reduced by using mass media as a form of "social marketing" that enhances knowledge and change. The media can impact individuals, as well as communities and often use techniques of communication and persuasion intertwined with theories of change. Often the use of personal narratives from celebrities or members of the public who have been affected by mental health problems; telling individual stories creates awareness, tolerance and "mediated associations" with presented themes or individuals. The use of mass media thus has the ability to directly or indirectly influence mental health stigmatisation. |

| Author | Type of mass media used | Summary of health information provided through the identified mass media source | A reflection from the researcher regarding the semantic clarity and how the health information can typically be interpreted |
|---|---|---|---|
| **The transition of health education information towards digital mass media available any place, anytime and anywhere.** | | | |
| Hoolahan *et al.* (2007:145-155). | Telehealth | Delivering mental health information through the use of technology. Technological sources such as videoconferencing, telephonic conferencing and Internet used to enhance mental health literacy amongst healthcare workers, mental healthcare users, caregivers and members of the community. | Videoconferencing enhanced participation of community members that led to enhanced access to healthcare information, decrease in costs related to travelling in order to obtain health information, and also served as a supportive network for community members. This could be regarded as a possible source of information to enhance mental health literacy for some communities, but cannot be generalised to all communities due to lack of technology, poverty, illiteracy and demography. |
| Faurholt-Jepsen *et al.* (2014:2). | e-mental health using cell phones | Recent information sources such as e-mental health technologies and self-monitoring systems using cell-phones as communication medium between professionals and patients with bipolar mood disorder has been suggested as an accessible and affordable manner to continuously monitor and identifying symptoms of mania and depression. | Patients with bipolar mood disorder often present with poor adherence to mood stabilisers. Obtaining treatment for depressive or manic episodes are thus often delayed. This self-monitoring system resulted in prompt symptoms recognition, professional intervention and appropriate treatment. |

#### 2.4.1.1 Printed media

Impact Information Plain Language Services (2016) recently published a newsletter stating that individuals seeking information on medication mainly use health professionals, medication labels and inserts, video clips and mobile apps as preferred information sources. Although printed media can be a helpful source of information for some, literacy entails social aspects intertwined with cognitive ability, being literate means that one has the ability to combine components meaningfully. The following competency skills imply the capability to function efficiently in the health related environment (Mancuso, 2008:248).

- *Operational competence:* Ability to utilise techniques for handling language proficiently such as the functional literacy skills (Nutbeam, 2000:262). Including the ability to communicate through reading, writing, and skill in numeracy. This also includes the skill of understanding and acting upon information given by health professionals (Kickbusch & Maag, 2008:203).

- *Interactive competence:* Self-management and cognitive skills such as problem solving and decision making aimed at enhancing self-care and collaborating with others. Mancuso (2008:249) here also refers to Nutbeam's interactive competence (2000:263) as the ability to derive meaning from information in various forms and to respond to changing needs.

- *Autonomous competence:* Self-empowerment through the ability to judge information and to apply it to one's one circumstance, this corresponds with the views of Nutbeam's critical health literacy (2000:263).

- *Informational competence:* Ability to determine the currency and authority of health information and to identify relevant sources and type of information.

- *Contextual competence:* It is suggested that familiar environments in which individuals are comfortable can enhance interactive and interpretive learning.

- *Cultural competence:* Includes a pattern of human actions, communications, beliefs, racial and religious aspects and customs influencing the interpretation of health information.

MaineHealth (2010), a central role player that guides health education principles to improve the adoption thereof compiled a guide to assist in creation and evaluation of printed communication materials in order to promote understanding and adherence to care plans. Due to limited literacy skills, adults prefer easy to understand information and the following key elements in printed communication (MaineHealth, 2010) are suggested:

- Limiting content: Information in printed form should highlight main aspects in an action-forced manner; should provide the reader with the 'what to do's' or 'need to know' in three to five

points. Printed information must be accurate, evidenced-based and recent with a clear call to action and a direct targeted audience.

- Organising and structuring: A broad content should be divided and main aspects emphasised followed by subtitles to guide further reading. Key points placed from most to least importance and relevance.

- Writing style: Personal or conversational with appropriate and consistent use of pronouns, use short words and lay language to explain difficult terminology. Keep paragraphs short and use bullets appropriately, three to five sequenced.

- Appeal and design: The piece should appear attractive and make scanning of the document easy, the design must reflect plain language standards for font, size, print, contrast, line length and justification. Images, lists or charts must be appropriate and provide a clear supportive message.

- Cultural sensitivity and appropriateness: The information piece should reflect the needs and values of the cultural groups defined disability, gender, orientation, race, ethnicity and economic status. Respectful terms must be used in a manner that considers ease of potential translation. The role of medical care, understanding of health and the possibility of complimentary medicines or practices should be considered. Printed information must reflect the expected roles of the individual, family and professionals.

Printed media, as the best known medium for communication of health information pathed the way towards mass media of various communication formats as discussed hereafter.

#### 2.4.1.2 Mass media: Newspapers, pamphlets, radio, television programs, billboards, cinema, digital versatile discs (DVD's)

The term "*mass media"* refers to media that is intended to communicate messages to a large group of individuals in the absence of face-to-face contact, such as listed above (Clement, 2013:2). Mass media has a tremendous influence on communities worldwide and has the ability to affect the entire population, the most vulnerable target being young adults due to their interest and exposure to this source (Cunningham *et al.,* 2014:415). The Canadian Mental Health Association (CMHA) agrees by stating that mass media could affect belief systems and perceptions of society, mainly due to availability and accessibility to even the smallest communities (CMHA, 2004:1). Mass media has driven its focus and aim purely towards entertainment and creating sensational programming (Fennel & Boyd, 2014:670) regardless of facts. This created negative correlations and portrayals of mental disorders becoming deviant, stereotypical, inaccurate and stigmatising (Fennel & Boyd, 2014:670). Journalist reports,

television, and cinema dramas (Jorm, 2011c:398) can potentially change world views and beliefs and the overall impact of mass media portrayals of mental health remains unknown. In order to limit these negative impacts, multimedia sources need to be controlled for quality and standards in order to enhance accuracy and trustworthiness of the information it broadcasts (Jorm, 2011c:398). In 2004, the CMHA investigated various mass media sources and its influence toward mental health and determined that this popular source was associated with negative portrayals of mental health that impeded positive public attitudes and perceptions towards mental illness (CMHA, 2004:1). Regardless of the accuracy in mass media, illiterate individuals who lack the ability to read and write tend to regard television and radio as trustworthy information sources and rely on mass media for mental health information (Ganasen *et al.,* 2008:24).

#### 2.4.1.3 Technologic and digitalised sources, eHealth and mHealth

Technologic and digitalised sources are growing rapidly, especially the Internet. The latter has evolved into a widely accessible source of health information worldwide and it is rapidly becoming a method that could potentially enhance mental health information and service delivery in the future (Cleary *et al.,* 2008:42). Electronic-health (eHealth) existed from the platform of evolutionalised technologies and digitalisation and has had a tremendous effect on health (Srivastava *et al.,* 2015:1). According to WHO (2017m) eHealth is the use of information and communication technologies (ICT) at global, regional and country level in order to promote health. eHealth is growing in healthcare, paving its way for researchers to develop technologies assisting with health-related issues and translating health-related knowledge and creating health-related interest (Srivastava *et al.,* 2015:1). The United States National Institute of Mental Health (NIMH, 2016) states that technology opened new frontiers in mental health by providing new methods of accessing help, progress monitoring, provision of support and increasing mental health and wellbeing. Technology is regarded as a valuable source of communication and information translation that could largely impact societies all over the world, and is highly assistive for researchers and medical practitioners (NIMH, 2016).

The aim of ICT is to create applications that can disseminate relevant health information to diverse groups of users that could assist in preventative management of health disorders (Clough & Casey, 2015:429). Technologies such as satellite, mobile devices, Internet and cloud services can enhance quality, safety and efficiency of services, and assist in delivering affordable and timely healthcare; contributing towards mental health literacy (Srivastava *et al.*, 2015:2).

Clough and Casey (2015:429) define Mobile health (mHealth) as a subsection of eHealth that is aimed at expanding potential engagement of healthcare users through communication

technologies such as mobile phones. One example of mHealth named by Clough and Casey (2015:430) is PsychAssist, a smartphone application designed to assist in self-management of anxiety through the implementation of exercises and activities. This application provided psycho education, motivation, monitoring and exposure to adults with anxiety. Amongst its users it was reported that adults with anxiety had a positive attitude towards using their smartphones in combination with their psychological treatment.

Stephens-Reicher *et al.* (2011:58) state that ICTs are relevant and effective and can expand literacy related to accessing and engaging in health services; especially for individuals who normally find themselves in communities with insufficient resources and access to healthcare. According to Coulter *et al.* (2008) ICT's present many beneficial properties related to enhancing mental health literacy if applied correctly, ethically and through electronic sources such as mobile phone messages, audio tapes, television and websites. This may have positive effects on improving behaviour when combined with technology (Coulter *et al.,* 2008). Norris *et al.* (2013:1) claimed that little evidence supports the notion that technology and electronic media are truly effective in delivering accurate health information. Technology could potentially enhance access to mental health interventions and self-management, yet Norris *et al.* (2013:385) warns of the ethical risks associated. Although there is a definite need of mental healthcare users to access e-mental health and mHealth, Clough and Casey (2015:429) also warn that there is a moderate risk that this method could expose consumers to untested interventions. Based on a literature review conducted on 21 published papers from Europe, North-America and Australia, Clifton *et al.* (2013:19) identified the impact of digital technology on the mental health and well-being of "young people and children" of school/college/university age. This review determined some implications for practice and highlighted risks and benefits of technology use as an information source.

Amongst the most harmful risks of digital technology use in young adults and children, Clifton *et al.* (2013:23) specifically warns against cyber bullying, sexual exploitation, Facebook depression, loneliness and social anxiety but on the other hand state clear benefits such as enhanced communication, technical and social skills. Using the Internet to obtain health information is accessible, affordable and anonymous, thus it has become one of the most frequent "health seeking tools", specifically amongst adolescents (Clifton *et al.,* 2013:22). The affordability and widespread mobile service coverage worldwide made mobile phone technology more available to rural communities; its use provides new potential and opportunities towards enhanced access to care, monitoring of health outcomes, supervision and self-management (Norris *et al.,* 2013:379).

The WHO (2017m) states that 58% of member states have an eHealth strategy, 55% of countries have legislation in place to protect the data of patients, and 87% of countries report

having one or more national mHealth initiative in place. In 2012 an eHealth Strategy was published in South Africa, the mission of this strategy reads “To establish eHealth as an integral part of the transformation and improvement of healthcare services in South Africa, especially enabling delivery on the health sector’s Negotiated Service Delivery Agreement 2010-2014” (Department of Health, 2012/13-2016/17).

The efficiency of eHealth and mobile health (mHealth) to enhance mental healthcare was recently investigated in South-Africa (Norris *et al.,* 2013:1). Benefits of mHealth (Norris *et al.,* 2013:1) suggest that mobile phones can enhance cognitive behavioural therapy; improve medication adherence; allow monitoring the progress of mental healthcare users; enhance therapeutic relationships and provide mental healthcare users and therapists with mental health-related information. Buhi *et al.* (2012) (*as cited by* Norris *et al.,* 2013:1) reported that Subscriber Identity Module (SIM) cards used globally exceeded six billion in 2012, thus the rapid increase of mobile phone users has created the opportunity to possibly enhance health conditions, alleviate financial burdens of understaffed healthcare services, and potentially support individuals in self-management of their health.

Norris *et al.* (2013:2) state that various health related fields have rapidly been utilising mobile technology to enhance healthcare, collect data in research, and monitor adherence to medication; but no known research has been applied in the specific field of mobile technology usage in the mental health field. Hoolahan *et al.* (2007:146) evaluated mental health information sessions to health workers, consumers, carers, and community members in small rural towns within Australia and found that technology such as video conferencing and web-forums or ‘teleHealth’ is extensively being used as a method to deliver health services, diagnosis, and treatment to various communities. Hoolahan *et al.* (2007:148) aimed to educate small rural communities, enhance mental health literacy among health workers and community members and enhance discussion and development of local networks and to allow communities to establish educational content through consultation with stakeholders. Six interactive mental health sessions were provided to health workers and community members through video-conferencing and web-discussions, each session provided opportunity for community members to discuss issues with peers, health workers, and mental health specialists. Amongst 257 participants involved in one or more information sessions, 82% consisted of healthcare workers, and 18% of participants were members of the community. It was found that 39% of participants appreciated just having access to mental health information, 27% valued being able to access mental health information locally and 14% appreciated not having to travel to obtain information.

Although there is a need to enhance mental health literacy and research proved accessible, convenient and contributed to mental health literacy, 7% of respondents felt that the method of videoconferencing was impersonal (Hoolahan, 2007:151). However, 68% of respondents valued

the sessions and welcomed video-conferencing as an effective alternative to face-to-face consultation. Hoolahan *et al.* (2007:153) concluded that video-conferencing could enhance the provision of information to small rural areas as it is also deemed cost effective and convenient. Electronic methods of health provision may seem like a fully positive approach, yet when applied to e-mental health various limitations and challenges create difficulties in combining clinical practice and technological research (Clough & Casey, 2015).

According to the national eHealth Strategy of South Africa, eHealth is an investment in ICT in healthcare that has the potential to enable health improvement if applied in a feasible manner matching time and affordability (Department of Health, 2012). The South African Department of Health (2012) state that the rapid growth of eHealth requires strong leaders to identify and leverage opportunities in order to make eHealth a national reality in South Africa.

#### 2.4.1.4 Internet, Wikipedia, electronic applications (apps) and social media

The Internet has become more accessible for the majority of the population, with an increased number of web-based interventions developed specifically related towards mental disorders (Reavley *et al.,* 2011:1268). Although little research has been done related to the true influence of the Internet on mental health (Rickwood *et al*., 2015:2); it has a wide range of communicative modes that could have vast potential for the provision of "information, misinformation and even disinformation" (Mercer, 2007:88). Broadly, the Internet is used as a tool of information for health information seekers; it is anonymous and cost effective. Ganasen *et al.* (2008:26) state that promoting the use of the Internet could possibly maximize mental health literacy in developing countries. According to Clifton *et al.* (2013:22), the use of Internet and social media can contribute positively towards the identification, prevention and treatment of mental health problems but its use is not risk free.

Wikipedia is known as one of the largest Internet websites that involves users in information sharing rather than providing information published by professionals; this online encyclopaedia can be edited and changed by anyone thus information is not necessarily evidenced and literature based facts (Reavley *et al.,* 2012:1753). Wikipedia is widely used as a source of mental health information as persons who identify symptoms in change of mood, behaviour or anxiety levels tend to avoid immediate help seeking and preferably turn to the most available source of information first. The risk with the Internet is that it could also be a root cause of psychological problems in young people due to the risk of victimisation and isolation. This is because young people tend to turn to the Internet to avoid the stigma accompanying mental health problems (Clifton *et al.,* 2013:22).

The NIMH (2016) recently wrote that the trend of technology and digitalised media has moved beyond simple information provision into the development of a very sophisticated range of applications for smart phones and tablets. These applications can track changes in the user's behavioural patterns, detect behavioural changes and even connect the user to peer counsellors or healthcare professionals when necessary (NIMH, 2016). Flaherty (2014:418) states that a mobile application (app) is a piece of information-access software that is specifically designed to run on mobile devices; apps are available to browse and download on online stores such as the Google™ Play Android™ store or the Apple™ App Store. The development of mobile applications has led to a burst of mental healthcare applications developed by various industries and research related to their efficiency has increased.

Flaherty (2014:418) investigated the regulation and privacy of mental health applications in America and states that there are various benefits and risks associated with the use of applications. Healthcare applications have not only increased access to healthcare and communication channels with professionals but has also led to enhanced general well-being of users through tracking, self-management and the provision of encouraging health information (Flaherty, 2014:418). One example of a digital application developed to assist in mental wellbeing is Headspace®; a digital service that provides guided meditation and mindfulness training that is said to relieve anxiety and reduce stress through teaching basic relaxation techniques (Feloni, 2016). There are about 8.5 million active users of this application and it is free to download, thus the cost efficiency and availability of this application is clear (Feloni, 2016).

Although there are numerous benefits associated with healthcare applications, application regulations are limited thus creating uncertainty and doubt of the trustworthiness of information provided (Flaherty, 2014:421). In order to limit these concerns, the NIMH (2006) developed a set of guidelines to enhance the efficiency of mental health application in a manner that can be beneficial to individuals utilising mental healthcare applications including: i) providing electronic information based on scientific knowledge; ii) understanding of applications is effective for all individuals and for all mental health conditions, providing guidance related to standards in order to increase accuracy of information; iii) ensuring that electronic applications remain confidential, regulating data conveyed through mental health applications; and iv) prevention of overselling that could risk individuals from turning away from other, more effective methods.

With all the above-mentioned aspects taken into consideration, the NIMH (2016) suggests that the integration of technology into mental health could provide various benefits for mental healthcare users, as well as clinicians; as outlined in table 2.3 (p.52).

**Table 2-3: Advantages of electronic sources of mental health information (NIMH, 2016)**

| Advantage | Clarification |
|---|---|
| Convenience | Technology and applications available at any time or any place and could be ideal for individuals who are unable to attend in-person appointments. |
| Anonymity | Mental healthcare users can seek and obtain treatment in an anonymous manner and do not need external involvement. |
| Introduction to care | It is suggested that for those who have avoided seeking and obtaining mental healthcare in the past, the availability of electronic mental healthcare information could be effective as a first step introduction to mental healthcare. |
| Cost efficiency | Technological applications are low in cost and some applications are free of charge; this could be more cost effective than traditional methods of mental healthcare. |
| Accessibility | Even individuals in remote areas can be reached through technology; this could enhance the availability of care and strengthen communication, as mental healthcare providers are able to reach these individuals. |
| Interest | It is said that some traditional therapies and educational methods for mental health are generalised and disregarded due to lack of interest. The availability of mental healthcare information and treatments via technology could be more appealing to mental healthcare users and raised interest has the possibility of enhancing adherence to information and treatment seeking. |
| Availability | Technology is available 24 hours a day and can provide intervention support and monitoring at any time unlike traditional methods. |
| Consistency | Technology has the ability to provide the same program to mental healthcare users. |
| Support | The role of technology should not be to replace traditional methods of mental healthcare interventions, but can greatly contribute towards extending in-person sessions, reinforce new skills and tasks, and provide the monitoring and support needed in order to enhance overall mental health. |

Lately there has been an evolving trend of online help-seeking and support from peers through social media, or even interactive games to avoid family or peer involvement; individuals rather embrace digital systems for mental health promotion Clifton *et al.* (2013:23). Shepherd *et al.* (2015:15) explored the utilisation of social media as communication medium for mental health and proposed that electronic support networks and knowledge could be beneficial for users, yet positive interpretation is challenged. The authors assessed the role of social media in communication by individuals with mental disorders and as a source of feedback towards mental health service providers. Shepherd *et al.* (2015:2) stated that social media platforms such as

Facebook™ and Twitter™ have an increased influence in mental health practice as the amount of users are growing on a daily basis. It is hypothesised that social networking and Internet can provide valuable support for persons with mental distress; it can also be a valuable tool for health professionals to aid in collaborative relationships with service users (Shepherd *et al.,* 2015:6).

Although it seems as though access to social media has a wide array of positive influence, it also has risks and negative factors that need to be considered when determining its true worth as information source for mental health literacy. Livingstone *et al.* (2013:965) state that for those living with mental disorders, social media stigmatisation is a major contributing factor of adverse consequences such as hopelessness, reduced self-esteem, delayed help-seeking, diminished quality of life, and poorer clinical outcomes. Due to this, stigmatisation elimination is a global priority to improve the lives of those living with mental health disorders and government and non-government organisations worldwide are mobilising resources to address this problem mostly through anti-stigma campaigns (Livingstone *et al.,* 2013:966).

Although media campaigns do not provide successful long-term outcomes; the popularity of media campaigns to address mental healthcare self-awareness and public attitudes towards persons with mental health disorders continue to grow. In response to this, Livingstone *et al.* (2013:966) performed the *In One Voice* social media campaign intervention focused on emphasising public education with the aim of addressing mental health literacy among youth and young adults in British Columbia. *In One Voice* included celebrities in collaboration with authorities and charities to work towards a broad goal of enhancing activity on an interactive, educational and youth-focused website (*see* www.mindcheck.ca as an ideal example). This website was a measure of enhancing mental health awareness and knowledge that can improve behaviour and attitudes towards mental health with a focus on youth mental health literacy.

The *In One Voice* campaign was specifically designed to reach individuals through all social media such as Facebook™, Twitter™ and YouTube™. The aim was to determine efficiency of a brief social media campaign to raise mental health awareness and enhance mental health literacy of the public. In this research it was found that awareness among youth and young adults did not dramatically increase and the initial outcome of the campaign towards mental health issues was not achieved. Livingstone *et al.* (2013:971) thus agree with conclusions drawn by experts on stigma, that education and awareness alone are unlikely to achieve reduction in personal stigma and social distance. Unfortunately, Internet health information is of variable quality and it has raised concerns that self-help interventions over the Internet have resulted in decreased help-seeking from professionals who have been reported as protectors against risk factors and emotional problems (Reavley *et al.,* 2011:1268). There is a great need for research

related to the efficiency of the diverse information sources and the effect of media on help-seeking behaviour (Reavley *et al.,* 2011:1268).

#### 2.4.1.5 Academic journals

Beliefs and attitudes towards mental health literacy differ widely between public and professionals, and it was found that mental health literacy can be placed on a continuum running from lay beliefs to professional knowledge (Jorm, 2000a:396). Professionals learn their knowledge from academic journals containing scientifically-based information and empiric research where in contrast the public largely relies on beliefs based on experiences and views, anecdotes, media reports and other informal sources of information.

#### 2.4.1.6 Non-health professionals: Knowledgeable friends or family

Although health professionals are important providers of information, limited numbers, insufficient training and poor accessibility has increased the need for alternative information sources (Reavley *et al.,* 2011:1267). Due to poor access to care and poor literacy related to mental health and resources, many individuals tend to turn to other individuals for advice and assistance related to their health and mental health. McInnis and Merajver (2011:166) state that persons of all ages most commonly rely on “ambassadors” in order to obtain mental health information; these include parents, family, teachers, health professionals, community leaders and colleagues at work.

Relatives specifically play a major role in the functioning of mental healthcare users with bipolar mood disorder. According to Chatzidamianos *et al.* (2015:9), relatives perceived that key barriers to their inclusive care is poor access to support opportunities and it seems that structural impediment, communication among stakeholders and pre-existing world views are negatively impacting relative support (Chatzidamianos *et al.,* 2015:9*).* Not only is there a need to enhance mental health literacy of mental healthcare users, it would also be beneficial to determine sources that could be used to enhance the mental health literacy of family members, friends, and other members of the community. This is supported by Ross *et al.* (2012:229), stating that the majority of adolescents seek informal help from peers rather than formal help from professionals. In 2012, Wu *et al.* (2014:35) conducted a study in Taiwan where medical help seeking preference, mental health literacy and attitudes towards mental illness were investigated. The authors assessed help-seeking preferences of persons with mental disorders by providing participants with a multi-choice questionnaire in which they were able to select from options such as formal help-seeking and informal help-seeking. It was found by Wu *et al.* (2014:38) that mental health help-seeking is influenced by attitudes towards mental illness, as well as the health-literacy level of participants. Persons who attributed mental health symptoms

to physical cause were more likely to seek medical support, whereas individuals who view symptoms of depression etc. as both physical and mentally induced, rather sought facilitation from informal sources such as family and friends (Wu *et al.,* 2014:38).

According to Rickwood *et al.* (2015:2), help-seeking literature acknowledges the role of informal support by family and friends as a first preference when seeking help related to mental health; thus family and friends form a critical part of the help-seeking process. Simmons *et al.* (2015:3) assessed the general and mental health information sources used by rural women in Western Kentucky (USA) and found that out of one thousand women all participants reported that they had access to at least one source of general health information; in contrast 20.8% of participants admitted that they do not seek or do not know where to seek information related to mental health (Simmons *et al.,* 2015:3).

In the above mentioned research regarding help-seeking preferences and the help-seeking process it is clear that mental healthcare users globally need to be supported by family or friends, yet there is a growing concern that the current measure to enhance mental health help-seeking in Africa will be insufficient if the help-seeking behaviour of South Africans are not addressed (Cooper, 2016:696). Research conducted in South Africa mainly focus on the barriers of mental health help- and support- seeking behaviour.

#### 2.4.1.7 Specialised programs and campaigns such as 'Mental health first aid', 'Individual psycho education program' and 'post discharge programs'

It is suggested that literacy programs could have a great impact for mental healthcare users, yet this specific group is underserved and remain at high risk for preventable chronic diseases due to poor mental health literacy (Clausen *et al.,* 2015:1). Ross *et al.* (2012:293) suggest Mental Health First Aid (MHFA) as a method to enhance mental health literacy; this program teaches adult community members about initial recognition and treatment seeking for mental health symptoms until professional treatment can be obtained (Ross *et al.,* 2012:293). Ross *et al.* (2012:237) furthermore state that current research does not offer direct proof that adolescents employing endorsed messages will enhance the outcome for peers with mental health problems. The efficacy of MHFA as a measure to enhance mental health literacy was investigated by Kitchener and Jorm (2002:3). Participants took part in a three weekly course that focused on mental health related topics such as: depressive disorder, psychotic episodes, anxiety, panic attacks, suicide and substance abuse. In this research, it was concluded that the training course effectively contributed to the mental health literacy of the public (Kitchener & Jorm, 2002:3).

The imperative need to develop mental health perspectives of the community is supported by Kermode *et al.* (2009:476), stating that mental health is a neglected field of interest, especially in

areas where access to resources is limited. Various methods of enhancing mental health literacy have been researched and a literacy survey was conducted in the rural areas of Maharashtra, India. This study aimed at developing a mental health training program; it was noted that community awareness and literacy related to the recognition of mental disorders, efficacy of interventions, actions to take in cases of mental disorders, and stigmatising attitudes towards the mentally ill was poor (Kermode *et al.,* 2009:477). Thus, the community recognised mental disorders, but had limited knowledge related to its treatment.

According to Sturgeon (2007:38) the implementation of mental health promotion programs is a realistic option to enhance the health literacy of various target groups, especially in settings such as schools, workplaces, and local community based facilities., This is supported by the statement; stakeholders need to be included in order to promote health literacy (WHO, 2008:10). The main outcome of referring patients with bipolar episodes to standard out-patient departments in comparison to specialised post-discharge programs is psychiatric readmission due to relapsing manic and depressive episodes. In response, recurrence prevention programs such as specialised post-discharge treatment and psycho education is focused on key attributes of mental health literacy through teaching recognition, management and prevention of early signs and symptoms of mental health disorders (Gumus *et al.,* 2015:174; Kessing *et al.,* 2013:216).

It was recently determined that specialised post-discharge treatment led to a 40% decrease in readmission rates and extended periods before readmission in comparison to groups that only received standard follow up care; a comprehensive mood disorder clinic program combining pharmacological treatment and group psycho-education also enhanced adherence of treatment (Kessing *et al.,* 2013:218). Post-discharge programs could decrease readmission to a psychiatric hospital and could positively affect long-term improvement of the course of illness in bipolar mood disorder due to its positive relationship towards mental health literacy (Kessing *et al.,* 2013:218). According to Galynker *et al.* (2015:4) suicide is the tenth leading cause of morbidity in the United States and ascribes 11.3 deaths per 100 000 individuals; suicidal ideation over a life span is a predictor of suicide, yet the majority of suicides occur mainly in persons with pre-existing mental health conditions following discharge from a psychiatric hospital (Galynker *et al.,* 2015:1, 4). Early out-patient interventions among patients with severe mood disorders following discharge from a psychiatric hospital should be enhanced in order to enhance mental health literacy that can lead to decreased readmission rates, and extended periods before readmission (Kessing *et al.,* 2013:218).

### 2.4.2 Access to information sources

As indicated in Table 2.3 (p.52), accessibility is an important factor in health education information. Access to information has a profound effect on health, yet it is one of the most challenged aspects in the provision of mental healthcare and information, regardless of literacy, background or educational level (McCray, 2005:152). In spite of various developed interventions and initiatives aimed at enhancing mental health outcomes; access-related issues still leave mental healthcare users and vulnerable groups disadvantaged, due to: i) poor awareness or expression of mental health needs; ii) poor knowledge of available resources; iii) unavailability of care and professionals at the right time or place; iv) deterring or diversion of methods of care due to poor interaction with professionals (Dowrick *et al.,* 2016:2). Incorporating information into individual and community cultures and beliefs can potentially enhance mental health literacy in a manner that addresses the challenges and impediments related to access of information (McInnis & Merajver, 2011:168).

Vulnerable populations are most often at risk of having limited access to care. Dowrick *et al.* (2016:2) refer to an example where South Asian females in the UK suffering from symptoms of depression and self-mutilation that could affect their society. Yet, these difficulties only became visible during times of crisis. Another vulnerable group experiencing difficulties related to access is elders; even though they are prone to depression they are frequently misdiagnosed or inadequately treated (Dowrick *et al.,* 2016:2). In the rural communities of the Northwest Wyoming (USA) elders generally accept mental health treatment but due to easier access they initially prefer care from trusted community members and primary care providers (Kitchen Andren *et al.,* 2013:252). Many healthcare systems aim to develop access to mental healthcare policies but interventions focus on provision factors rather than the needs of individuals, communities and societies affected by mental health related difficulties. In response, Dowrick *et al.* (2016:2) developed the *Improving Access to Mental Health in Primary Care* model (AMP); a needs-based program aimed at enhancing access to high quality care and mental healthcare for vulnerable populations.

#### 2.4.2.1 Access to mental health in primary care model

One model of note is the Access to Mental Health in primary care model which is strongly applicable also to the South African healthcare context. This model assessed the specific needs, evidence-based facilitating and impeding factors related to access to care of vulnerable under-served elders and South Asian or Somali minority ethnic groups. It also in turn designed a three-component model to enhance access to mental health in primary care (Dowrick *et al.,* 2016:2). At the core focus of the AMP lays community engagement, primary care quality and psychosocial interventions; members of the communities were identified to participate through

presenting local community interests in joint action plan focus groups with local individuals of the community, agencies and stakeholders. The primary care and psychological intervention element composed of interactive needs based training by trained professionals; analysis of systems to identify impeding or promoting factors related to access and raising awareness of relevant local resources on individual level, group level or sign-posting to other services (Dowrick *et al.,* 2016:1). Using this model and its element as a part of mental health literacy awareness campaigns could possibly enhance mental health literacy as it not only confronts individuals but also includes community and stakeholder involvement. In the following part of the literature review the researcher focuses on health literacy and mental health literacy.

## 2.5 HEALTH LITERACY

As indicated in Chapter 1 (p.1), health literacy can also be adapted towards mental health literacy. In the following paragraphs the researcher aims to explain the evolution of the concept 'literacy' towards health literacy and thereafter to mental health literacy. Both health and mental health literacy are two progressive concepts with varying comprehension in literature. It is aimed to present health and mental health literacy to the reader as two separate concepts. However, there remain blurred boundaries and the necessity of a proper concept analysis for future research is needed, which is beyond the scope of this research.

### 2.5.1 Literacy

"Literacy" in general, is multifaceted and interpreted in numerous ways due to influences from research, cultures, communities, institutional agendas and individual experiences (United Nations Educational Scientific and Cultural Organisation [UNESCO], 2006). The original English term "literacy" referred to literature familiarity' or 'well educated', later it evolved into a phrase also describing the ability to read and write and being 'educated or knowledgeable' in a specific field of interest. Literacy theories originally focused on processes of basic cognitive skills and individual change and evolved into a multifaceted framework encouraging and enabling socio-economic awareness and critical reflection within a wide range of disciplines including psychology, economics, sociology and philosophy (UNESCO, 2006). Since literacy is a contested concept, four broad clusters (UNESCO, 2006) of literacy provide a functional typology, including: i) *an autonomous set of skills* including reading, writing, to communicate, numeracy skills and skills enabling access to knowledge and information; ii) *applied, practiced or situated* as a technical skill and socially situated; iii) *a process of learning enabling access to knowledge and information* when learning creates literacy as a learning process and not merely the product of educational intervention; and iv) *literacy as text*. Ganasen *et al.* (2008:24) adds that numeric, reading and understanding skills may be an important contributor towards health literacy and could be a more valuable predictor of individual health status than other factors such as age,

ethnicity, economic status and level of education. Literacy forms a broadened context of competencies and skills entails 'information literacy', 'media literacy' and 'visual literacy'. These concepts shift towards literacy not only as skills, but also '*ways of reading the world*'; applying knowledge and skill in order to enhance social change allowing individuals to interpret, express, investigate, query and comprehend change among society.

### 2.5.2 Health literacy

Whilst literacy is on the one hand broadened to education and knowledge in general, it presents a specific meaning in the context of *health literacy (*McInnis & Merajver, 2011:166). Sørensen *et al.* (2012:1) performed a systematic review and content analysis of 17 definitions and 12 conceptual models of health literacy and determined that the majority of available definitions focused on individual skills development related to obtaining, processing and comprehending health information as well as resources and making appropriate health related decisions. In addition, the importance of health literacy as a population goal and interactive chain between health system demands and individual skills are highlighted in literature (Sørensen *et al.,* 2012:1). A variety of perspectives focus on using information appropriately in order to enhance health; these perspectives include dimensions, scope, methods, qualities to enhance knowledge, skills and understanding (Ílgün *et al.,* 2015:2630).

#### 2.5.2.1 Conceptual models and approaches to health literacy

Although various conceptual models of health literacy are available, these are not specifically related to health literacy definitions. Sørensen *et al.* (2012:8) reviewed twelve existing models developed to enhance health literacy and found that the existing models are ineffective as they do not integrate existing theoretical knowledge related to health literacy as part of their approach and secondly, few models integrated medical and public health aspects into developed models. These models are described in table 2-4 (p.62) and the variety of components, dimensions and views are outlined and discussed.

#### 2.5.2.2 Levels of health literacy

The WHO (2004a) stated that health promotion policies in environmental, economic and social sectors could positively influence the determinants of health. Therefore, as health is managed in a comprehensive manner on different levels, so follows health literacy. The Ottawa Charter of Health Promotion (*in* WHO, 2004a) classified levels of health literacy from local individuals to national populations and policy development. Therefore, various methods and models of health literacy have been investigated and different approaches towards levels of literacy became evident. In the view of Nutbeam (2000:259), health literacy is the preferred outcome of effective health education, communication and health promotion.

Nutbeam (2000:260) suggested an outcome-focused model integrating the levels of literacy emphasising improved health outcomes, promotion and the prevention of mental illness through enhanced educational and communication strategies on three distinct literacy levels (Nutbeam, 2000:265), namely:

- *Level 1, Functional health literacy* referred to outcomes of traditional health education and knowledge related to utilising health systems; resulted in individual benefit that can be applied towards benefit of the population. This approach lacked interactive communication skills and development because it mostly included information such as leaflets or traditional health education.

- *Level 2, Interactive health literacy* reflected outcomes to health education focused on personal skills development within a supportive environment that enhances individual literacy. Individuals gain capacity, motivation and confidence to act on their knowledge. This approach is mostly individual-focused, including health education programs aimed to develop personal - and social skills.

- *Level 3, Critical health literacy* is focused on the development of cognitive skills that can enhance actions of change not only on individual - but also on socio-political levels. This type of health literacy is the most likely to lead to individual and population benefit because it includes communication of information and also integrates the development of skills investigating feasibility of health promotion activities. Critical literacy methods are directed towards enhancing individual and community health literacy that enables healthier choices and the efficient use of resources and treatment compliance. In addition, health literacy programs improve social action capacity that could influence public and organisational policies resulting in change in social, economic and environmental determinants of health for individuals and populations.

Lee *et al*. (2004:1312) suggest that poor health literacy enhances the likelihood of poor health behaviour, self-care, irregular follow up treatment, poor compliance and delayed help seeking that produces negative health outcomes. The models mentioned above are all associated with health benefits and suggest that enhancing health literacy on various levels through the inclusion of various domains and following an integrated approach to skills development could improve population health outcomes. Traditionally, health literacy objectives were individual-focused but Freedman *et al*. (2009:446) suggest that public health literacy is a rapidly growing concept that is targeted to enhance overall public health literacy, in turn creating positive health outcomes for the larger society; health literacy models developed over the past decade are focused on using health literacy as a tool to create societal change and positive health outcomes.

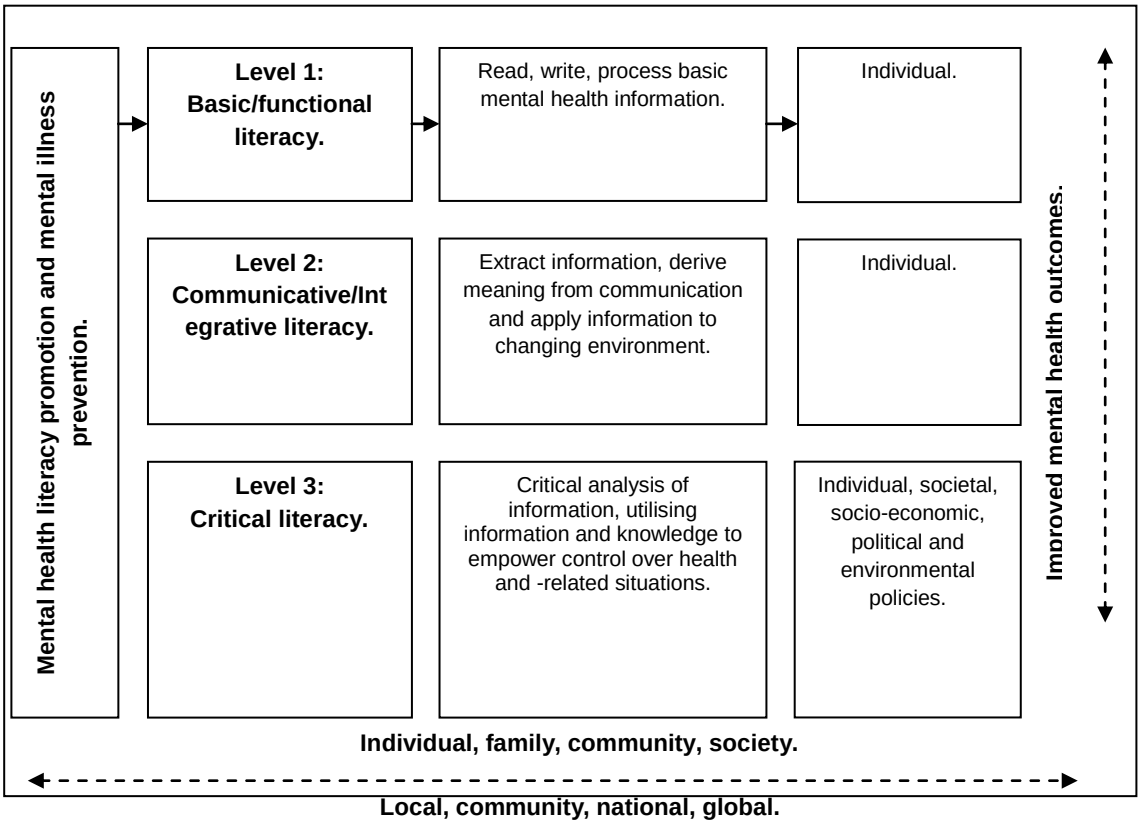


**Figure 2-3: Integrating levels of health literacy towards health promotion and prevention of disease – a mental health approach (*adapted from* Nutbeam, 2000:262 & WHO, 2004b)**

**Table 2-4: Conceptual models and approaches to health literacy (as guided by Sørensen *et al*., 2012:6-8)**

| | Author(s) | Focus / perspective | Descriptive summary |
|---|---|---|---|
| 1. | Nutbeam (2000:262). | Outcome model for health promotion. | The outcome model for health promotion distinguishes between levels of outcomes of interventions affecting literacy and places health education and communication as a broad perspective of health. Main dimensions of this model include *functional-, interactive-,* and critical *health literacy*. Literacy is highlighted as the key outcome of health education and the benefits of application of this model range from individual to community level (Nutbeam, 2000:263). |
| 2. | Lee *et al.* (2004:1309-1321). | Mechanisms linking health literacy to health outcomes. | The model assessed the link between poor health literacy, poor health status and utilisation of medical care and resources; and secondly investigates the impact that social support could have on the literacy and health resource utilisation relationship. A framework is proposed that links these aspects through the integration of four intermediate relative factors: *disease knowledge and self-care, health risk behaviour, preventative care and routine follow up, and medication adherence and compliance.* |
| 3. | Institute of medicine (2004). | Cultural and conceptual links to enhance health outcomes and costs. | The capacity of individuals to access, comprehend and process health related services and information in order to make appropriate decisions related to health. A model based on cultural and conceptual knowledge and the application of communication skills as a method of enhancing health outcomes and costs. |
| 4. | Zarcadoolas *et al.* (2005:195). | Expanded model | The model is characterised by four domains including *fundamental health literacy, science literacy, civic literacy and cultural literacy*. It was concluded that this model is useful as an instrument that analyses health communication, assists in developing more understandable communication methods and can guide towards new measures of assessing health literacy skills in individuals (Zarcadoolas *et al.,* 2005:195). It is suggested that application of this model could assist individuals/communities in application of knowledge and enhanced involvement in health related decisions on a public and private level. |
| 5. | Speros (2005:633-640). | Concept analysis of ‘health literacy’. | During a concept analysis aimed at clarifying the meaning of health literacy, Speros (2005:633) found that health literacy empowers individuals to adapt to health related |

| | Author(s) | Focus / perspective | Descriptive summary |
|---|---|---|---|
| | | | circumstances. Speros' view of health literacy defining attributes are reading and numeracy skill, comprehension, decision making capacity and successful health consumer functioning. In the view of Speros (2005:633) antecedents of health literacy are experience related to literacy and health literacy. |
| 6. | Baker (2006:878-879). | Conceptual model of the relationship between individual capacities, health related print and oral literacy, and health outcomes. | Baker presents a conceptual model of domains associated with health literacy and its relationship with health outcomes. The model is a supplementary aid for other models and could contribute towards a more specific discussion of health literacy. The model suggests that individual capacity of health-related print literacy and health-related oral literacy are influenced by culture, norms and barriers to change. It is suggested that a higher individual capacity leads to improved outcomes, acquiring of new information, development of positive attitudes and enhanced self-efficacy (Baker, 2006:879). |
| 7. | Paasche-Orlow and Wolf (2007:40). | Health literacy as a measure of enhancing health outcomes. | Paarsche-Orlow and Wolf (2007:19) suggest that poor health literacy is linked to poor health outcomes; methods most likely to influence access to health information and literacy are discussed in a model that highlights areas of systematic, interactional and self-care mechanisms. In addition to focus on individual capacity related to health activities, the proposed model includes a contextual approach towards access to health literacy not only individually; systems affecting access, medical encounters and self-care is also involved. Paarsche-Orlow and Wolf (2007:19) clearly distinguish influences of literacy on extrinsic, as well as intrinsic level and how it directly impacts access. In addition, Coles *et al.* (2011:7) indicated strong connotations between the recognition of problems; related beliefs and the likelihood of help-seeking and accessing services that are associated with mental health literacy. In the view of Paarsche-Orlow and Wolf (2007:19) enhanced health literacy can lead to enhanced outcomes. |
| 8. | Kickbusch and Maag (2008:204-211). | Implementation of functional, interactive and critical literacy as a process to enhance health outcomes and costs. | This model integrates functional, interactive and critical skills as a measure to enhance public health outcomes and costs. The focus of enhancing public health is through the inclusion of stakeholders such as educational and healthcare systems. Work, political and markets are also utilised as sources for information distribution within the community. |

| | Author(s) | Focus / perspective | Descriptive summary |
|---|---|---|---|
| 9. | Mancuso (2008:248-255). | Health literacy as a concept model. | According to this model, the outcome of health literacy depends on whether individuals possess skills and competencies to attain health literacy and whether one has sufficient or insufficient health literacy in order to potentially influence individuals and society. Literacy is viewed as a process that integrates attributes of capacity, comprehension and communication with the following multidimensional cognitive and social components: *operational-, interactive-, autonomous-, informational-, contextual-* and *cultural competence.* |
| 10. | Manganello (2008:840-847). | Enhancing health behaviour, costs and service usage. | The model describes how functional-, interactive-, and critical health literacy can enhance media literacy. It is said that mass media, the educational system and health systems could influence health behaviour, costs and the utilisation of health services. |
| 11. | Freedman *et al.* (2009:446-451). | Re-conceptualisation and integration of individual and public health literacy. | A new form of health literacy is needed; current aims of health literacy cannot be achieved without taking into account the broad range of influences on health. Current focus of health literacy is determined to influence individuals and their perspectives of health, thus a new approach is suggested – public health literacy. Public health literacy is aimed at approaching dimensions of conceptual foundations, critical skills and civic orientation in order to enhance literacy on a large public level through the use of media combined with community related initiatives. |
| 12. | Von Wagner *et al.* (2009:860-877). | Literacy and numeracy as a method of enhancing healthcare. | The outcome of this model is to enhance access to healthcare, professional-patient interaction and the overall management of illness and health. Dimensions of interest rely largely on the literacy and numeracy skills of individuals as part of health related decision making. Antecedents of this model include the influence of external elements, epidemiological determinants, and the influences of individual reading and arithmetic skills as a measure to enhance health outcomes (*in* Sørensen *et al.,* 2012:6). |

#### 2.5.2.3 Outcome objectives of health literacy

Health literacy research reached a peak from 2000 to 2009, when a variety of approaches and disciplines of health literacy were explored worldwide (Sørensen *et al.,* 2012:6-8). In contrast to traditional methods of enhancing health literacy, it seems that a drastic shift of focus has emerged in order to reach outcome objectives of mental health literacy. The most recent approaches move beyond individual factors and rather focus on integrating various dimensions, skills and attributes in order to obtain positive healthcare outcomes on various social levels. When referring to individual outcomes in contrast to society outcomes the term “pubic literacy” comes to mind, Freedman *et al.* (2009:447) views public health literacy as the ability of individuals and groups to obtain, process, understand, evaluate and act upon health related information as part of public health decisions to enhance community health, thus leading to positive outcomes in healthcare.

Although a public approach seems more feasible, it presents a wide array of challenges as mental disorders are prevalent in all populations. However, Kermode *et al.* (2009:476) state that they are more likely to be found amongst poorer communities and the course and outcome of mental disorders are negatively influenced by the socio-economic status of individuals and communities. Unfortunately, mental health remains a neglected field for diagnosed individuals especially those in developing countries and thus part of the outcome objectives of mental health literacy is to integrate mental healthcare into primary healthcare services where it can also assist poorer groups in obtaining appropriate treatment and care (Kermode *et al.,* 2009:476). Ganasen *et al.* (2007:23) agree by stating that one of the biggest barriers in providing positive mental health outcomes is poor mental health literacy, especially in low and middle income-countries. Ganasen *et al.* (2007:27) noted a gap in research regarding the relationship between improved health literacy and improved mental health outcomes although it is clear that poor mental health literacy generally hinders treatment of individuals and societies in need, yet improving health literacy can potentially impact health outcomes for this generally underserved population (Clausen, 2015:399).

There is a strong link between patients’ literacy skills and outcomes of health; it is suggested that enhancing skills of health literacy can facilitate patient involvement. In the view of Zarcadoolas *et al.* (2005:195), *fundamental-, scientific-, civic-, and cultural literacy* has the ability to create enhanced application of information and participation in health decisions. From another perspective, Baker (2006:878-879) refers to health-related print literacy and health related oral literacy as domains that influence health literacy and health decision making. Both of these approaches regardless of their difference are aimed at enhancing literacy and health outcomes through application of information, creating positive attitudes, and enhancing self-efficacy and

decision-making. Including individuals, populations, health professionals and health systems in health literacy enhancement is said to automatically enhance engagement and will thus create positive health outcomes. Five main strategies emerge from the social ecological health literacy model (Mc Cormack *et al.,* 2017:8): accumulation, amplification, facilitation, cascade and convergence. Increased patient engagement has the ability to enhance overall health literacy and lead towards positive health outcomes, therefore Mc Cormack *et al.* (2017:8) suggest that a social ecological approach gives rise to strategies to enhance both of these aspects.

### 2.5.3 Mental health literacy

Mental health literacy just as health literacy exceeds intellectual literacy as the skills to actively engage in decisions related to health management, treatment and care. By focusing on mental health promotion and development of mental health information may contribute to public knowledge and positive actions towards overall mental health (Jorm *et al.,* 2012d:1; McInnis & Merajver, 2011:166).

During the mid-1990 the term "*mental health literacy*" was conceptualised in Australia by Jorm and colleagues when the shift from health professions training towards mental health development in the public domain became evident (Jorm *et al.,* 2012d:1). Mental health literacy (Jorm *et al.,* 2012d:1) is the knowledge and beliefs about mental disorders that enable the recognition, prevention and management thereof. Since its original meaning, mental health literacy has broadened towards the knowledge related to the prevention and recognition of mental disorders including help-seeking, self-help strategies and supporting individuals with mental disorders. As literacy and health literacy are associated with broad definitions, mental health literacy also consists of various roles, functions and components that grounded its meaning.

#### 2.5.3.1 Integrating health literacy and mental health - the evolution of mental health literacy

Derived from the above-mentioned models of health literacy, Sørensen developed a model that integrates the qualities and core elements identified by different models (*see* table 2-4, p.62). The "all-inclusive" definition of Sørensen *et al.* (2012:7) describes four competencies related to mental health literacy process as: i) access, ii) understand, ii) appraise and iv) application of health-related information. *Access* refers to the ability to seek and obtain health information; to *understand* is the ability to comprehend the obtained information, and to *appraise* is regarded as the capability to interpret and evaluate findings; and finally to *apply* obtained knowledge as part of decision making, showing the ability to communicate information appropriately (Sørensen *et*

*al.,* 2012:9). Please refer to Table 2-5 (p.68) where Sørensen's (2012:10) matrix of the dimensions of health literacy and health domains are applied to mental health literacy.

#### 2.5.3.2 Components and roles of mental health literacy in healthcare

Derived from Jorm's (Jorm *et al.,* 2012d:1) definition of mental health literacy, key attributes constituting mental health literacy are i) knowledge and beliefs that aid in recognition; ii) management and prevention of mental disorders; and iii) knowledge of mental health related factors (O'Connor *et al.,* 2014:197). Ganasen *et al.* (2008:23) critiqued the Jorm definition, stating it failed to refer to the type of knowledge as evidence-based mental disorders and their available treatment. Therefore, Ganasen *et al.* (2008:23) stipulated a broader representation of components listed as: i) the ability to recognise symptoms and types of distress and disorders; ii) knowledge and beliefs related to causes, risks, self-help interventions; iii) professional resources and attitudes that aid in the recognition and appropriate help- and information-seeking. Furthermore, the focuses of mental health literacy components are grouped by O'Connor *et al.* (2014:198) as recognition; knowledge and attitudes. Mental health literacy in itself provides a firm structure for grasping individual mental health and help-seeking behaviour (O'Connor *et al.,* 2014:197).

#### 2.5.3.3 Importance and function of mental health literacy in healthcare

McCray (2005:152) scrutinised health literacy in relation to interactions in healthcare; deprived healthcare users due to a lack of health literacy; complex healthcare systems; quality of the professional-to-patient interaction; the overall cultural context and the effects of poor literacy on health. In the United States of America (USA) a national health assessment study performed in 2003 published that 26% adults of the general population had insufficient health and mental health literacy (*cited by* Clausen *et al.,* 2015:5).

#### 2.5.3.4 The implications of poor health and mental health literacy

Poor health literacy is associated with higher healthcare costs and increased demand for healthcare and hospitalisation that could possibly be related to insufficient understanding of disease processes, poor recall of education, health and cultural beliefs that interfere with care, and poor skills related to problem solving (McCray, 2005:152). The prevalence of poor health literacy among adults, specifically with a mental illness, is rapidly increasing and affects most, if not all areas of health globally (McInnis & Merajver, 2011:166). Self-reliant preferences, fear of stigma and overall poor mental health literacy account for 71% of mentally ill adolescents who avoid mental healthcare (Ross *et al.,* 2012:229).

**Table 2-5: The matrix of the dimensions of health literacy and health domains (Sørensen, 2012:10) applied to mental health literacy**

| | **Access to/obtain relevant mental health information** | **Understand relevant mental health information** | **Process/appraise relevant mental health information** | **Apply/use relevant mental health information** |
|---|---|---|---|---|
| Mental healthcare | Capacity to access mental health information. | Capacity to understand mental health information and acquire meaning. | Capacity to interpret and evaluate mental health information. | Capacity to make informed decisions on mental health information. |
| Prevention of mental illness | Capacity to access mental health information regarding the risk factors for mental illness. | Capacity to understand mental health information on the risk factors for mental illness and obtain meaning. | Capacity to interpret and evaluate mental health information on the risk factors for mental illness. | Ability to make informed decisions on the risk factors for mental illness. |
| Promotion of mental health | Capacity to update yourself on mental health determinants within one's bio-psychosocial environments. | Capacity to understand mental health information on mental health determinants within one's bio-psychosocial environments and to acquire meaning from this information. | Capacity to interpret and evaluate mental health information on mental health determinants within one's bio-psychosocial environments. | Capacity to make informed decisions on mental health determinants within one's bio-psychosocial environments. |

Mental health burdens and the implications associated with poor mental health literacy is a global health challenge that reaches deep into cultures and communities because a very large part of health related problems are associated with mental health (McInnis & Merajver, 2011:167). Mental illness increases the risk of suicide and mortally when compared to the general population, attributed to inadequate use of resources and poor adherence to treatment (Clausen *et al.,* 2015:1). Poverty, insecurity, homelessness, violence, physical illness and financial strain (Ganasen *et al.,* 2008:24) pose risks such as increased suicide prevalence, stigma, hospitalisation, mortality, and incidence of preventable chronic diseases including mental illness and the availability and provision of mental healthcare services. The abovementioned underlying factors are associated with greater vulnerability to mental illness which in turn leads to a vicious cycle as unemployment related to mental illness worsens financial conditions of the already poor. Although there is a significant relationship among poverty, poor mental health literacy and the prevalence of mental illness, Ganasen *et al.* (2008:24) acknowledged that it is yet to be determined whether mental health literacy could improve the mental health of low - and middle income countries.

#### 2.5.3.5 Factors influencing mental health literacy

- **Literacy skills:** Literacy skills are a stronger predictor of mental health literacy than age, employment status, ethnic group or educational level. Illiteracy affects more than 25% of the world population and impedes the provision of care, especially in developing and poor communities (Ganasen *et al.,* 2008:24). In 2003, a Taiwan-based study evaluated health literacy and health-promoting behaviours among multi-ethnic groups of women. The findings suggest poor health literacy as chief health-related concern globally; correlated directly with individual literacy levels. Furthermore, low health literacy clustered amongst younger participants who did not graduate from secondary school; used a second language and had little or no income (Tsai *et al.,* 2014:126). Poor mental health literacy is especially prevalent amid developing countries, because illiterate persons are more likely to avoid professional treatment for mental health due to communication difficulties, inability to read consent forms and medication inserts or directions (Ganasen *et al.,* 2008:24). South Africa, regarded as a developing country, faces challenges of poor mental health literacy (Health Systems Trust [HST], 2016); when considering in 2014, 5.2% of the South African population older than 20 years had no schooling; of which 7.4% unschooled citizens are within the North-West Province.

- **Poverty and culture:** Besides illiteracy in developing countries, there is a clear correlation between poverty and health literacy, one example is a prevalence study conducted across

eleven developing countries, among those included were: Lesotho, Zimbabwe, Indonesia, Pakistan, Chile and Brazil. It was found that mental disorders stood at a median rate of prevalence of 20%-30%, in ten of these countries there was a significant correlation between poverty and the prevalence of mental disorders (Ganasen, 2008:24). Mood disorders, being highly prevalent, are major cost drivers due to their early onset and recurrent nature (Javelot, 2014) and the need for mental health literacy is signified amid superstitions, cultural attitudes and personal beliefs portray stigmatising perceptions of mental health (Ganasen, 2008:24). South African citizens diagnosed with mental health disorders argued that the public is under the mistaken impression that mental health disorders are caused by drug abuse, the will of God, spiritual possession and other supernatural causes (Ganasen *et al.*, 2008:28). Furthermore, Ganasen *et al.* (2008:23) described how some Xhosa families believed schizophrenia is induced by witchcraft or possession by evil spirits. An Australia-based study by Pirkins and Dunt (2003) (*as cited by* Hoolahan *et al.,* 2007:147) reported that poor mental health literacy was a largely recognised problem and enhanced mental health literacy could aid the recognition of mental illness and reduce stigmatisation.

- **Attitudes:** In contrast to the positive role of mental health literacy, Lauber (2003:248) warned that mental health literacy could often be correlated with attitudes and associated behaviours toward mentally ill individuals that could give rise to stigmatisation. The realities of negative attitudes and related stigmatisation confirm the need to educate citizens regarding early recognition, awareness of treatment options and access to professional resources in mental healthcare. The role of mental health literacy from a societal perspective acknowledge attitudes and beliefs often portraying mental health as negative, especially in non-Western countries (Ganasen *et al.*, 2008:24).

#### 2.5.3.6 Benefits of mental health literacy

Mental health literacy as mechanism could possibly address mortality, treatment adherence, relapse prevention, decreased readmissions and the incidence of preventable chronic diseases (Ganasen *et al.,* 2008:23; McInnis & Merajver, 2011:167; Kessing *et al.,* 2013:216). According to the Mental Health Action Plan (WHO, 2013:9), mental health burdens can be decreased through strengthening of healthcare and information systems. McInnis and Merajver (2011:167) stated that mental health literacy is the core approach to addressing mental health as global research on mental health literacy has the ability to transform society over a generation. In addition, McInnis and Merajver (2011:167) warned that if mental health literacy is ignored, it may compromise economic

development, can increase suffering to those in structural poverty, violate human rights and increase health inequality.

The introduction of mental health literacy influenced the Australian mental health policy. The Australian National Mental Health Plan now includes aspects aimed at enhancing mental health literacy (Jorm, 2015e:1166). In the Fifth National Mental Health Plan 2009-2014, the Australian Government developed projects to enhance overall community mental health; including: training programs to enhance mental illness recognition; mental health first aid training aimed at improving mental health literacy; enhancing healthcare positions and infrastructure; mental health toolkits; expansion of textbooks and the development of culturally suitable mental health assessment tools (*in* Walker & Sonn*,* 2010:157). Ganasen *et al.* (2008:25) suggested the establishing of effective measures to enhance mental health literacy in the poorer developing countries; awareness campaigns; as well as workshops, training courses and mental health first aid programs, although these suggestions are ambitious and greatly challenged. A best known benefit of mental health literacy is the primary and secondary prevention of mental illness across the global and national society, amongst mental healthcare users, caregivers and families burdened by poor mental health (Dowrick *et al.,* 2016:2). Mental healthcare literacy becomes everybody's business considering that empowerment of society and strengthening of mental health literacy can be obtained by stakeholders such as families, students, medical professionals and traditional healers within communities (Kermode *et al.,* 2009:477; Kelly *et al.,* 2007:26; McInnis & Merajver, 2011:168).

### 2.5.4 Mental vs. general health education

The WHO (2004b:12) links mental health to general health with three concepts, namely i) mental health as integral part of health; ii) focusing beyond the absence of illness; iii) holding a strong connection with physical behaviour and health. Mental health is still viewed as residing outside the public health domain, where mental health enhancing opportunities are not fully exploited and society barricades the optimal functioning of the mentally ill (WHO, 2004b:13). Efforts aimed to reduce mental illness burdens are dependent on treatment and not focused on overall prevention, management and promotion strategies. As health education and literacy are essential in managing physical illness and empowering community participation in health, a mental health literate society will be better equipped at preventing, recognising and managing mental illness (Ganasen *et al.,* 2008:27; Jorm *et al.,* 2012d:1). Uys (2014:246) referred to the aims of mental health education to enhance understanding of the community and individuals and to empower self-sufficiency and responsible management of mental illness.

The core principles related to successful health education include active participation, planning, assessing the needs of the individual/community, creating long term behavioural change, altering norms and standards and research and evaluation (WHO, 2012:8). In addition to the core principles of health education by the WHO, Uys (2014:247) clustered five approaches to mental health education as presented in table 2-6. These approaches aim to provide individuals, groups and families with knowledge and insight into the prevention of mental illness and the promotion of mental health, thus utilising these approaches in health education provision will eventually lead to enhanced understanding and knowledge of the entire community (Uys, 2014:246-247).

**Table 2-6: Five approaches to mental health education (Uys, 2014:247)**

| Approach | Aim | Focus |
|---|---|---|
| **Total population approach** | Providing information through mass media to bring about behavioural change. | Entire community / population |
| **Milestone approach** | Instructed to determine alternative coping strategies as preparation for predictable situation or maturation crises. | Individual |
| **Gatekeeper approach** | Skills teaching to professionals and non-professionals to serve as 'gatekeepers' in enhancing early detection, insight promotion and positive attitudes. Groups involved usually have a caring or protective role in the community such as, teachers, community nurses, police and ministers. | Community |
| **Community / group approach** | Provision of general mental health education in a certain geographic group (such as mine workers). | Community |
| **High-risk approach** | Education provided based on specific individual risks succumbing to mental illness, such as the provision of stress management techniques to teachers. | Individual |

## 2.6 SUMMARY

Mental health has become a global health priority and the evolution of technology over time has had a tremendous impact on mental health literacy and attitudes towards mental health literacy. "*Mental health literacy"* not only refers to the knowledge and beliefs related to mental health. Literacy consists of various roles and components that play a significant role in healthcare; aims to address negative correlations towards mental health on local, international and political levels. In order to

create change, the focus should shift towards an active participation approach that includes individuals, families, community members and stakeholders respectively. Health education is one form of health promotion and prevention in mental and general health and has many resembling characteristics; yet mental health is viewed as residing outside the public health domain and mental health enhancing opportunities are neglected. In order to provide a clearer outlay of mental health literacy an integrated model approach is suggested for enhancing mental health literacy. Information is the key to enhancing knowledge, it is everywhere we go and is available in various forms. Mass media, technological sources, mobile, Internet, social media and journals, to name a few, unfortunately not all information sources are accessible, reliable, affordable and its interpretation also varies among mental healthcare users especially amongst vulnerable users such as the elderly or individuals living in rural communities who have limited access to sources. Mood disorders are highly prevalent and their diagnosis is rapidly increasing among individuals of all cultures, ages and communities; this research aimed to investigate adult, hospitalised, mental healthcare users', with mood disorders, perceived health literacy and information sources in order to inform mental health education strategies.

# CHAPTER 3: DISCUSSION OF RESEARCH FINDINGS AND LITERATURE INTEGRATION

## 3.1 INTRODUCTION

In chapter 1 a detailed description of the research methodology is discussed (*see* 1.6, p.8). Chapter 3 provides a comprehensive description of data collection, analysis and research findings are integrated with the literature review. Since the research methodology was discussed in phases, the realisation of data collection and analysis are consecutively discussed.

## 3.2 REALISATION OF RESEARCH

The following paragraphs provide a discussion of data realisation in accordance with data collection and analysis.

### 3.2.1 Realisation of data collection

Hospitalised adult mental healthcare users with a mood disorder were selected via non-probable, quota sampling according to the inclusion criteria set out in chapter 1 (*see* 1.6.3.2, p12). The selection of this hospital was not based on convenience as the motivation describes in 1.6.2 (p.8).

After obtaining written permission from the hospital (*see* Annexures B p.146 and C, p.149), the researcher attended an in hospital multi-professional team meeting where she provided psychologists and psychiatrists with an informative session of the research being conducted (*see* 1.6.3.4, p.14). During this session the researcher provided each mediator (psychologist) and gatekeeper (psychiatrist) with a folder containing a personal letter as request for assistance, participant information leaflets, and the MacCAT-CR standard of competency measure assessment questionnaire. The research was discussed with the team and the opportunity was given to ask questions and clarify discrepancies.

Clinical psychologists of the hospitalised mental healthcare users were asked to approach and recruit prospective participating mental healthcare users that met the requirements to the strict set of inclusion criteria (*see* 1.6.3.2, p.12). Once a participant met the requirements of competency as assessed by the psychologist and the MacCAT-CR assessment, the participant's name was reported by the mediator to the professional nurse on duty who acted as the person obtaining informed consent. The psychologists and professional nurses signed confidentiality agreements. During phase two the researcher obtained the names of the prospective participating mental

healthcare users who signed informed consent and contacted participants in person or telephonically to schedule the interview.

Written information leaflets were provided to potential participants to read through in order to ensure full understanding of the research (*see* Annexure G, p.157). Prior to consent, hospitalised mental healthcare users who were interested in taking part in the research were first assessed by their psychologist or psychiatrist to determine their competency to consent according to the MacArthur competence assessment tool for clinical research (MacCAT-CR) questionnaire (*see* Annexure F, p.156). This questionnaire was developed as per guidelines set out in the Competence to make informed decisions, *see* p.13.

Once the patient's psychologist of psychiatrist completed the assessment and found the mental healthcare user competent to consent, the mental healthcare user was referred to a registered nurse in the ward who confirmed understanding of the research and completed the declaration by professional nurse obtaining consent section on the consent form (*see* Annexure G, P.157). Upon the completion of the informed consent form and the MacCAT-CR, the researcher was provided with the names of selected participants during weekly telephonic or courtesy follow up visits. The researcher individually contacted participants in order to schedule appointments.

Upon meeting participants for interviews the researcher followed the planned schedule as provided in the discussion on the Interview schedule (*see* p.17). Introduction of the research was followed by a reassessment of the MacCAT-CR assessment and if appropriate, the check list for demographic data and information source checklist (*see* Annexure H, p.166 & Annexure I, p.167) was completed followed by semi-structured interviews were initiated. The researcher included the information source checklist as part of interviews in cases where participating mental healthcare users had difficulty in determining sources on their own, this served as examples to create clarity for the participant. Following semi-structured interviews the researcher formulated descriptive, personal, methodological and theoretical field notes as reflecting interpretations of what was observed during interviews (*see* Annexure J, p.168).

Table 3-1 (p.77) provides an outline of the demographic information of participating mental healthcare users. The following paragraphs will provide an explanatory description of the abovementioned findings. It is interesting to note that there were six participants between the ages of 40 and 49 years and only two participants each for the other age categories. The fact that so many of the participants were in their middle ages is in contrast to Chapter 2 section 2.3.3 (p.36, since most studies agreed that 75% of mental illnesses is diagnosed in a person's mid-twenties.

**Table 3-1: Demographic data (N12)**

| Criterion | N |
|---|---|
| Male | 6 |
| Female | 6 |
| **Age** | |
| 20-29 years | 2 |
| 30-39 years | 2 |
| 40-49 years | 6 |
| 50 years and older | 2 |
| **1st language** | |
| English | 3 |
| Afrikaans | 8 |
| Setswana | 1 |
| **Highest education** | |
| Grade 7 | 1 |
| Grade 12 | 6 |
| Diploma (nursing) | 1 |
| Diploma (other) | 0 |
| Degree (nursing) | 3 |
| Degree (other) | 1 |
| Depressive disorder | 6 |
| Manic episode | 6 |
| **Total days admitted** | |
| 6-10 days | 2 |
| 11-15 days | 10 |

The first languages for the candidates were mainly Afrikaans, English and Setswana. As this research was conducted in the North West Province, this split should be expected. It is however out of the norm for only one candidate to have Tswana for their first language. A general assumption is that individuals with less academic qualifications would be a higher risk of admission, but the findings determined that amongst participants, individuals with higher qualifications are more likely

to be admitted for a mood disorder. This could possibly be due to their ability to afford a medical aid but what may also be apparent is that candidates with a degree state that they also function under a high level of stress as their higher qualification may have opened doors to a more demanding career. In this research only one participant does not have grade 12 or a higher education, within the public sector drastic contrast in findings can be expected.

### 3.2.2 Realisation of data analysis

The first step of data analysis was to review existing literature related to mental health literacy, information sources used by mental healthcare users, information sources relevant to mood disorders, mood disorders within adults and finally current information sources and strategies used to reach mental healthcare users. The data analysis emphasised integrity, accountability and coherence with research, it acknowledged the contextual significance of naturalistic enquiry and data was critically analysed within methodological guidelines consistent to the nursing discipline (Thorne *et al.,* 2004:3).

The process of analysing semi-structured interviews was initiated through transcription and numbering of recorded semi-structured interviews accompanied by the transcription of comprehensive field notes (see Annexure J, p.167) of each interview, demographic data and checklist data. The researcher moved beyond investigation towards interpretation through thematic analysis and analytic processes that moved beyond the self-evident, as guided by the principles of Thorne *et al.* (2004:6). The researcher actively engaged in interpretation of findings though transcription coding and scaffolding of data, this brought about emerging themes and concepts that were independently assessed by the researcher and co-coder, respectively after which a consensus conversation took place. During the consensus conversation, topics of data corpus as a whole were colour coded and grouped according to themes, categories and sub-categories that were compiled in table format. On completion of the table, a second consensus discussion was conducted that lead to the overall theme categorization.

### 3.3 CHECKLIST OF INFORMATION SOURCES

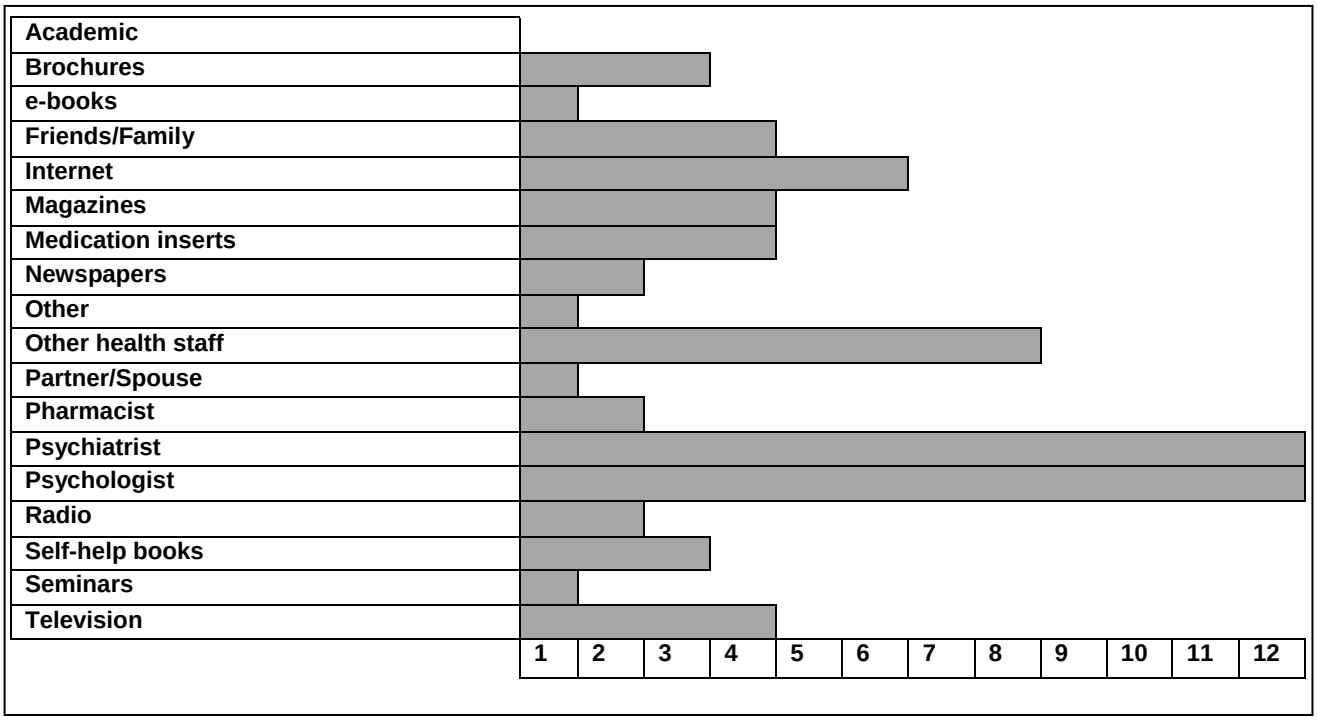


**Figure 3-1: Information sources (N12)**

Figure 3-1 illustrates the information sources that participants of this research trust and most frequently use in order to obtain information related to their mood disorder. In contrast to the high demand of psychiatrists, psychologists and other healthcare personnel, it became apparent during the semi-structured interviews that the traditional information sources that are generally available to the public remain less trustworthy to the participants than the word of trained professionals. Regardless of exposure to information on the internet, television, magazines and e-books, mental healthcare users still prefer information from a professional source. Participants are of the opinion that academic information sources are not readily accessible and thus not a generally utilised information source. It is also clear from Figure 3-1 that friends, family and spouses of mental healthcare users often play a role as information sources for mental healthcare users. Apart from professionals as the most preferred information source; the internet was the other preferred, dependable configurative information source.

## 3.4 RESULTS FROM INTERVIEWS

The end result present eight (8) main themes in relation to the perceptions of adult patients hospitalised with mood disorders about their mental health literacy and information sources on mood disorders namely:

- Denial hinders mental health literacy.
- Acceptance facilitates mental health literacy.
- Mental health literacy becomes an impetus towards health action.
- Mental health literacy is a positive enabler.
- Existing knowledge influences perceptions of mood disorders.
- The influence of family and significant others on health literacy.
- Various perceptions related to information sources.
- Specific types of information sources are more prevalent.

These themes will be discussed with literature integration. By reviewing the research results in comparison to available literature, the findings of this research and its unique contribution towards current gaps in research are presented.

### THEME 1: DENIAL HINDERS MENTAL HEALTH LITERACY

The first theme for discussion is that when participants denied their mood disorder, it hindered participants' awareness and development of their mental health literacy.

#### Theme 1, Sub-theme 1: The realities of intersectionality, mood disorders and denial.

Participants experience symptoms other than the ordinary and feel different than usual, yet, they deny having an illness and this contributes towards the unwillingness to seek medical attention or information about these symptoms. Denial presented as the most prominent contributor towards participants' disinterest in seeking information which hindered their mental health literacy: *"So yes, I have never looked at all those options the reason being that I did not believe that I have a problem. Until I came to the point where I said: yes, I have a problem".*

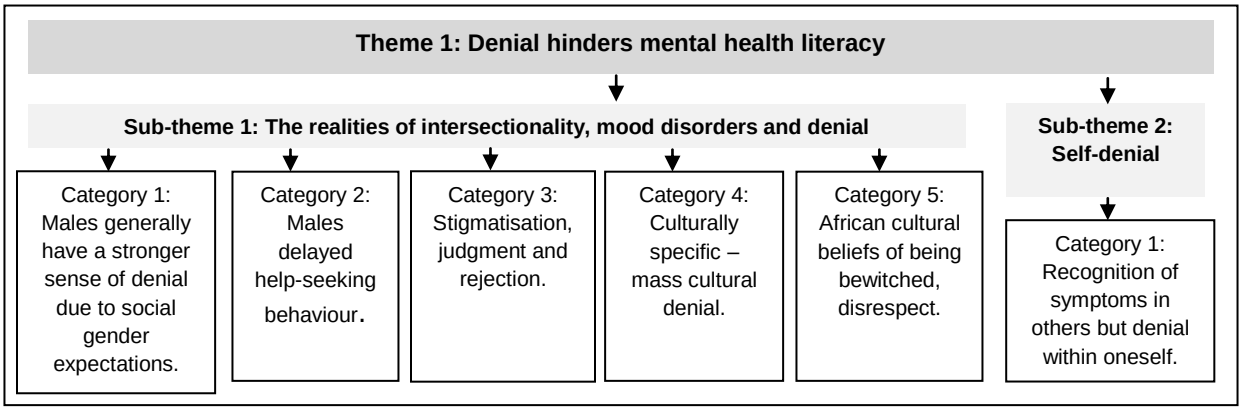


**Figure 3-2: Theme 1: Denial hinders mental health literacy**

The hospitalised mental healthcare users perceived that intersectionality contributed towards their denial. Research indicates that stereotypes of gender and mental disorders can intersect, leading towards perceptions of gendered mental disorders that are directly correlated with stigma (Boysen *et al.,* 2014:546). According to Seng *et al.* (2012:2437) the term intersectionality refers to the marginalizing characteristics that contribute towards social identity and affect health, examples include race, class and gender.

It is evident from the data that the social expectation of the gender role of males created a stronger sense of denial in males in comparison to their female counterparts (1st category). Men are raised within a socially expected set of cultural norms, values and expectations (Lindinger-Sternart, 2014:2-3). It appears that having a mood disorder is perceived as a sign of weakness as one male participant describes the following: "*Because when you are a male, you do not want to be seen as weak... You must work hard, you must always be strong, you must not cry, you must not show when you are sick and all that..."* It is not only being a male that strengthens denial, but also when the male fulfilled the father role within the family. One male participant voiced: "*And sometimes a person is then not willing to admit it* [that you have a mood disorder]*. As results of pride, as result of I am a father; I must show the men* [the sons of the participant] *that I am all right".* Gender is an important determinant of attitudes toward seeking help for mental health issues (Tieu & Konnert, 2014:140). A study assessing mental health help-seeking intentions and preferences in China reported that men have the most negative attitudes toward mental health help seeking (Yu *et al*., 2016:1). Generally, men show reduced help-seeking attitudes' with the intention of avoiding discussing disturbing events, avoiding hurting emotions and preventing social stigma (Lindinger-Sternart, 2014:1). It became apparent in the research findings that fulfilling the socially accepted gender role of a male contributed to delayed help-seeking behaviour (2nd category). One mental

healthcare user admitted that for two years he delayed seeking mental healthcare help for *"By not seeking help and admitting you have a problem you are killing yourself".*

Hospitalised mental healthcare users perceived that 1) stigmatisation, 2) judgement and 3) rejection for having a mood disorder was detrimental and impacted negatively on the mental health literacy mainly due to its contribution towards denial (3rd category). Ignorance about mood disorders had to be overcome because stigma, judgment and rejection were barriers in patients' growth in their mental health literacy. For example, patients diagnosed with mood disorders are stigmatised against under misconceptions such as being dangerous or poisonous. "*...there is such a big stigma if you are bipolar, because "we are going to bite", "we are poisonous"*. Although participants admitted that stigma has reduced, it remained a significant challenge because "...*it is going better already but we are not yet at the point where we want people to...have fewer stigmas and so, it is going a lot better*". Świtaj *et al.* (2016:370) state that stigma is a complex model that involves various integrative components such as stereotypes, prejudice, discrimination and ignorance related to misinformation. According to Świtaj *et al.* (2016:370) there are three main aspects of stigma that affect mental healthcare user's subjective experiences of stigma namely: 1) perceived stigma such as beliefs about the degree of social stigma, 2) experienced stigma, i.e. actual experience of rejection and discrimination and 3) self-stigma or internalised stigma. Self-stigma, also referred to as internalized stigma refers to the internalisation process of social attitudes that result in fear, discrimination, social withdrawal, feelings of shame, guilt, hopelessness and overall decrease in self-esteem and self-efficacy (Świtaj *et al.,* 2016:370-371). A recent study conducted in Australia suggests that although mental health promotion creates a sense of awareness in public and mostly reduce public stigma, there are some circumstances in which mental health promotion and awareness contribute toward self-stigma of mental healthcare users (Larkings *et al.*, 2017:207). Larkings *et al.* (2017:207) suggest that casual beliefs impact mental healthcare users' self-perception and their journey to recovery and these perceptions are suggested to be the most contributing influence on the internalisation of self-stigma.

In addition to self-stigma, participants stated that having a mood disorder is judged by others as "*… a sign of weakness of people saying you are crazy or something*". Patients' families' lack of understanding, judgment and disinterest in the diagnosis creates recurrent rejection as one participant said *"…that whole story of rejection, rejection, rejection".* Within the perception that denial is a barrier to health literacy, the 4th category emerged: denial within the African context. Denial was perceived to be more intense within African cultures. According to participants, more illiterate groups and masses of society within Africa remain ignorant about mood disorders and

African cultures tend to avoid mental disorders. It was also referred to a mass denial and ignorance. African-American men are generally more self-reliant, emotionally avoidant and have cultural distrust experiences that contribute towards poor help-seeking (Lindinger-Sternart: 2014:2-3). This corresponds with black male participants views: "*I am a black person. You know black people, they really don't believe that the mood…depression. It is a sign of weakness to them. So, they don't have information of that. And I realised when I came here that a lot of my people….Africans, they… they are really sick, they don't even know that."; "My culture (silence) … they don't believe in such things namely because…..they don't think there is that…"* Closely aligned with the perceived mass denial and ignorance about mood disorders within the African context, participants also explained that mental disorders in general, are perceived as a consequence of being disrespectful, bewitched, and punishment within some African cultures (5th category).

One participant stated *"But this person is busy with witchcraft, sometimes someone can maybe be dimentious then we think this person is just old and you know, like in black cultures they would say they bewitch a guy like...but it's not that at all. They are sick, they need help".* Another participant explained that "*You must really, really pick your words very carefully because you will get a hiding. Not just a hiding with a "sambok" or something or a cane, like physical, you will say it is abuse, but we are already used to that….beating."* Furthermore, participants perceived religion and religious organisations such as churches as having a negatively influence on mental healthcare users, increasing perceived stigma and decrease mental health literacy.

Based on the Substance Abuse and Mental Health Services Administration (SAMHSA) within the USA Department of Health and Human Services (HHS), recently published Treatment Improvement Protocols (TIPs) focussed on addressing behavioural needs of men specifically. The SAHMHSA confirmed the statement that males generally have a stronger sense of denial than females and that socially defined concepts of masculinity steer males towards competitive, aggressive and self-reliant practices. Social expectations generally lead towards male patients' denial and reluctance to manage their emotional responsiveness efficiently (SAMHSA, 2013:2). Masculine roles generally influence males in a sense that they delay or avoid seeking treatment for various health concerns including behavioural and mental health issues. The socially expected role and values of masculinity differ according to the role the male plays. Although masculinity values differ between cultures, men are often ambivalent about seeking help (SAMHSA, 2013:3).

According to Corrigan *et al.* (2014:37) many people with serious mental disorders avoid seeking treatment or drop out of services early; possibly because of discrimination and prejudice that comprises stigma of mental illness. In addition, Kermode *et al.* (2009:477) stated that mental

healthcare users and their families delay or avoid seeking help due to the substantial discrimination and stigmatisation they experience within their communities. When comparing non-Western and Western populations, it seems that Western populations are generally more informed and show less stigma towards mood disorders than their non-Western counterparts (Altweck *et al.,* 2015:2). The degree of stigma towards mental healthcare users differ from country to country (Wu *et al.,* 2014:34). Asian countries, due to their strong traditional and cultural beliefs, have increased stigma towards mental illness that corresponds with South Africa; where culture and traditional beliefs widely influence community attitudes towards individuals living with mental illness. One of the main reasons why mental health disorders are often misinterpreted or not recognised is due to poor literacy accompanied by cultural beliefs. Ganasen *et al.* (2008:28) stated that recognition of mental illness is just one aspect of mental health literacy that influences attitudes and behaviour towards the mentally ill. Ganasen *et al.* (2008:25) reported that in Malaysia and Ethiopia mental illness is mainly viewed as result of supernatural causes and thus often cultural or spiritual healing is their first step towards seeking. In addition, Nigerians and South Africans generally believe that mental illness is mainly attributed to drug abuse as well as supernatural causes such as the will of God, spiritual possession and spiritual healing (Ganasen *et al.,* 2008:26). African cultures traditionally believe that physical and mental illness originates from external agents such as magnetic fields, demons, spirits or other driving supernatural forces (Kruger, 2012:20). This perception seems to be a common cultural, religious and racial barrier to mental health, yet it is said that traditional healers or religious advisors are often more accessible than Western forms of mental healthcare (Sorsdahl *et al.*, 2009:434-435). In contrast to the participants' perceived religion-related stigma, religion or spirituality has generally been regarded as one of the main coping mechanisms that has been used for mental healthcare users in the past. Religious beliefs provide meaning and purpose to circumstances and promote positive views and optimism (Koenig, 2009:285). Religion is available anytime, anywhere and to anyone and can provide a sense of indirect control, reduce isolation and offer community support for individuals with mental health disorders (Koenig, 2009:285).

**Theme 1, Sub-theme 2: Self-denial**

In addition to the intersectionality of mood disorders, participants also described how they denied experiencing symptoms of mood disorders. Participants described that they thought they coped, were able to manage any situation and that symptoms will soon pass by. Despite having previous mood disorder incidents and associated treatment and despite having some knowledge regarding the signs and symptoms of mood disorders, participants admit to having a sense of denial within themselves prior to their admission and this self-denial hindered them to truly increase their mental health literacy. Because *"it just happens to other people"* or *"saying to yourself it will get better if you*

*keep it to yourself"* seemed to be standard behaviour of participants prior to admission. Three of the participants were healthcare professionals, yet they were unable to recognise typical symptoms and stated that they cannot accept a mood disorder within themselves. One professional stated: *"It's easy to give that caring, to help and to share that knowledge, but when it comes to myself I really struggle to do it and to really do it every day".* Participants also acknowledged that self-denial prevented them from following the correct channels in order to obtain help. One participant admitted that hospitalisation was the only mechanism that made him look past the denial of his mood disorder: *"I didn't think I have a mood disorder. I thought like normal. Like I am a normal person. And nothing is wrong with me. Until my doctor sent me here. That is when I realised that I have a serious problem."*

Recently a qualitative research article was published regarding the factors that influence psychological help seeking in adults, it is suggested by Topkaya (2015:25) that five main themes prevent mental health literacy development and help seeking behaviour. These themes include social stigma, unwillingness to talk to strangers about personal matters, beliefs that an individual can solve their own problems, the belief that private matters may only be known by themselves or a close family member and lastly, lack of knowledge on help seeking pathways. The researcher notes similarities of these themes of denial and is of the opinion that individual's beliefs that they can resolve their own problems without help could be strongly associated with denial.

In 2017 a study done in Denmark at the Copenhagen psychiatric centre assessed the coping styles of 344 individuals diagnosed with bipolar mood disorder, coping styles were assessed using a self-report Coping Inventory for Stressful Situations (CISS) tool that measures 1) task-orientated, 2) emotion-orientated and 3) avoidance-orientated coping. Based on the results of this study, denial and blame shifting seems to be maladaptive emotion-orientated avoidance coping styles that are most often seen in bipolar mood disorder (Vinberg *et al.,* 2017:526). Avoiding stressful situations, wishful thinking and withdrawal are directly linked to an avoidance- orientated coping strategy (Vinberg *et al.,* 2017:522), this brings the researcher towards the conclusion that the denial experienced in this research could also be a means of coping for mental healthcare users diagnosed with mood disorders.

**THEME 2: ACCEPTANCE FACILITATES MENTAL HEALTH LITERACY**

The second theme describes how the participating adult mental healthcare users' perceived that through the process of accepting their mental mood disorder, facilitated their health literacy. The

second theme and the five categories are graphically depicted in figure 3-3 and discussed thereafter.

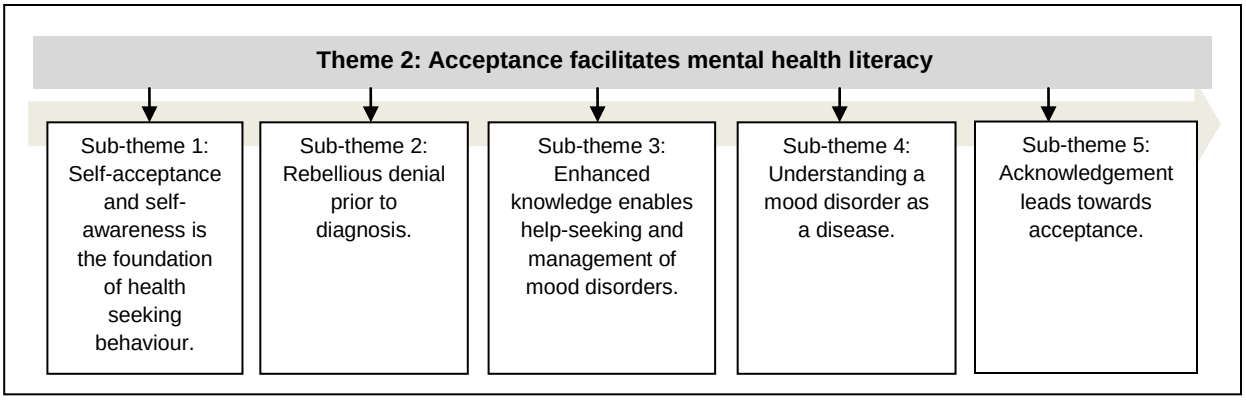


**Figure 3-3: Graphic depiction of theme two: Acceptance facilitates mental health literacy**

### Theme 2, Sub-theme 1: Self-acceptance and self-awareness is the foundation of health seeking behaviour

Adult mental healthcare users realised that being admitted into hospital became the change agent that brought them towards accepting their mood disorder as a disease and encouraged them to embrace knowledge in order to take control of their mood disorder. Self-acceptance and self-awareness therefore become the foundation for help seeking behaviour. The majority of participants were ignorant about the impact of their mood disorder prior to diagnosis. Not being diagnosed implied not seeking mental health-related information deliberately and systematically. Acceptance of their mood disorder enabled the participants to seek help and to manage their mood disorder(s); as one participant stated that *…but I also realise, it is, it is part of my management, it is part of my wellbeing to accept it".*

In contrast to the findings of this research, current trends in literacy do not refer to the link of self-acceptance and self-awareness specifically, but rather focuses on self-determination and how it is linked to self-confidence. According to Piltch (2016:77) determination and confidence are linked because having control over ones' life decisions creates confidence in achieving goals, thus active patient participation has positive influence on help seeking.

Wei *et al.* (2015:1) conducted a literature review of 35 articles related to mental healthcare users' perceived facilitative and detrimental factors associated with help-seeking for mental health. It was found that measures toward mental health help-seeking mostly included the recognition and

acceptance that one needs help, interpersonal openness, confidence and willingness to seek help (Wei *et al.,* 2015:14). These factors are linked towards acceptance, accepting that one has a problem, accepting that one needs help, and then accepting that one needs to take the responsibility of seeking professional help. Wu *et al.* (2014:34) agrees that mental health literacy is a correlate to help-seeking behaviour due to its positive influence self-awareness; it is suggested that enhanced mental health literacy has the potential to positively initiate the onset of medical or informal help-seeking for symptoms associated with mental illness. According to Federman (2010), initial diagnosis of bipolar mood disorder can be traumatising and mental healthcare users may have difficulty to accept and manage the disorder; the process of acceptance takes place gradually. Federman (2010) adds that between two and five years post-diagnosis individuals living with bipolar mood disorder are generally more accepting of their condition and have adapted their lifestyle in order to manage the condition with a more positive approach.

**Theme 2, Sub-theme 2: Rebellious denial prior to diagnosis**

The participating adult mental healthcare users perceived that being confronted with the symptoms of a mood disorder lead to being rebellious, rude; feeling criticised and misunderstood. But After they were formally diagnosed and introduced to the signs and symptoms of mood disorders; these participants started to accept their condition and became progressively more involved in the management and coping of their own health, as a female participant stated that "….*I knew nothing, I didn't understand anything, I was rebellious, I was...I was difficult, I was a difficult patient, I was rebellious, a rebel!";* and another participant voiced that "*...other people don't know they have it, so they won't go through the effort of looking at a disease that they do not have"*.

Proudfoot *et al.* (2009:120-124) state that little research is available regarding the subjective experiences of newly diagnosed individuals with bipolar mood disorder prior to diagnosis. Yet, poor adherence and self-management were generally common in bipolar mood disorder. Relapse and poor adherence risks were high due to reluctance to speak about the disorder, fearing judgment and undermining treatment. Patients that were newly diagnosed with bipolar mood disorder enjoyed manic symptoms and admitted that they initially refused to take prescribed treatment and only later started accepting it. According to Nitzburg *et al.* (2015:186) individuals with mood disorders, specifically bipolar mood disorder often respond to adversities with increased risk-taking, more remuneration, substance use, maladaptive coping and less emotional or instrumental support seeking that can be directly correlated with rebellious denial. The contrast being: having control over reactions to situations, active coping, planning, positive reframing, acceptance and support seeking (Nitzburg *et al.,* 2015:185).

**Theme 2, Sub-theme 3: Enhanced knowledge enables help-seeking and management of mood disorders**

Participants perceived that being aware of the causes, risks, management and treatment associated with mood disorders created a sense of interest within oneself that motivated mental healthcare users to become active participants in the management of their own mood disorder, *"Now I am more informed and more motivated"*. Participants perceived that continuous exposure to information enabled them to Participate in managing the mood disorder because they became familiar with the *"do's and don'ts' as one gets to know yourself in ways that no one else can".* These results correspond with literature that states higher levels of education, social support and sufficient psycho education related to the disease results in increased adherence (Subramanian, 2017:21). Furthermore, participants voiced that they reached a point of saturation in obtaining mental health information. "*I have to be serious and honest, I feel I'm at the point where I cannot learn anything anymore, and I'm not saying that I know everything*".

Piltch (2016:77) recently investigated the role of self-determination in mental health recovery and concluded that one essential factor associated to develop acceptance of one's disorder and the determination to manage it, is access to appropriate information. As discussed in the literature review 2.5.3 (*see* p.66.), this theme corresponds with current literature stating that mental health literacy could enhance prevention, recognition, management, help-seeking behaviour and self-empowerment.

Camerini *et al.* (2012:337) recently investigated the combined effects of health literacy, empowerment and self-management on health outcomes of individuals living with chronic diseases in Italy. Camerini *et al.* (2012:339) developed a model depicting the positive attributes of knowledge and empowerment collectively, to contribute positively towards health outcomes, enhanced self-management. The model of empowerment and health knowledge effects over self-management and health outcomes suggests that the main two elements of self-management are knowledge (meaning, competence, self-determination and impact) and secondly drug intake. Together these combined aspects enhance self-management and lead towards positive outcomes and eventually empowerment. The researcher is of the view that the main elements of this model could be applied to mental health because it follows the same principles, that enhanced knowledge positively affects outcomes and self-empowerment.

**Theme 2, Sub-theme 4: Understanding a mood disorder as a disease**

Mental healthcare users' present with a variety of views related to the causes associated with mood disorders. These views extend also to society where mood disorders aren't viewed as a disease. Yet, participants in this research perceived that by understanding a mood disorder as a disease, it improved their acceptance thereof. "*I am not crazy, I have an illness… a mental illness*". Yet, participants acknowledged that they only understood mood disorders as a disease that occurred during in-hospital care, prior to admission they had limited insight into the true cause and manifestation of mental health disorders. In fact, one participant stated that she believed that being depressed or bipolar was a general excuse to avoid responsibilities: *"…it's* [the mood disorder] *an excuse to stay away from work. There is nothing wrong with them! "*

From as early as 1997, Jorm (2000a:396) documented that the general members of society (in Australia) were unable to recognise symptoms of mental health disorders and lacked knowledge related to psychiatric symptoms and terminology which impacted negatively on the diagnosis of mental healthcare users. Since this first documentation up to now, it seems that not much changed in this regard. Mood disorders or any mental health disorder for that matter are still not recognised as a disease in most communities. According to Rogers and Pilgrim (2014:1) psychiatric disorders have no direct physical or biological etiology, this plays a contributive role towards negative attitudes of mental healthcare users and their families towards mood disorders. Due to the lack of bodily signs and symptoms, mental disorders are often undermined and not seen as a disease (Rogers & Pilgrim, 2014:2). The lack of knowledge related to mental health is a driver of stigma that in turn initiates a cycle of prejudice towards mental health, resulting in discrimination (Kutcher *et al.,* 2016:155).

**Theme 2, Sub-theme 5: Acknowledgement leads towards acceptance**

In the similar manner that denial about a mood disorder hindered health literacy, participants perceived that acknowledging that one has a problem and requires help became foundational for acceptance, which in turn played a facilitating role in the growth and development of mental health literacy. Participants voiced that they never accepted having a mood disorder prior to admission as this was an opportunity to learn about the impact of mood disorders on their lives and the lives of significant others. Acknowledgement occurred prior to acceptance of having a mood disorder, and this emphasised the transformational role of in-hospital care to facilitate mental health literacy. *"I only found out when I got here that I needed to be here"*. Once the participants acknowledged their mood disorder, understood their mood disorder and accepted the mood disorder, they developed a positive perspective about mood disorders, "…*it's part of growth, it's part of the insight you get with*

*time ... the knowledge you get with time. Then comes acceptance, and yes I can admit it's not like many years back when you did not want to say to anyone…"*

Insufficient literature was obtained confirming that acknowledgement of a mood disorder in general, leads towards acceptance. However, one article referred to finding meaning as a basis of self-motivation which can lead to the management of mental health disorders (Kidd *et al.,* 2014:187). Finding meaning is the center of creating one's journey towards mental health management, recovery and re-establishing hope (Kidd *et al.,* 2014:187). Contradictory literature states that acknowledgement of a mental health disorder does not necessarily have positive outcomes and could contribute towards increased depression, denial, suicidal ideation and life dissatisfaction (Fergusson *et al.,* 2015:2427; Haw *et al.,* 2001:48).

**THEME 3: MENTAL HEALTH LITERACY CREATES AN IMPETUS TOWARDS HEALTH ACTION**

The third theme presents mental health literacy as a powerful drive that enabled the participants towards various health actions. Being informed, understanding one's mood disorder and healthcare processes enabled the participants to take action and participate in their own mental health journey to recovery. The themes and sub-themes are presented in Figure 3-4.

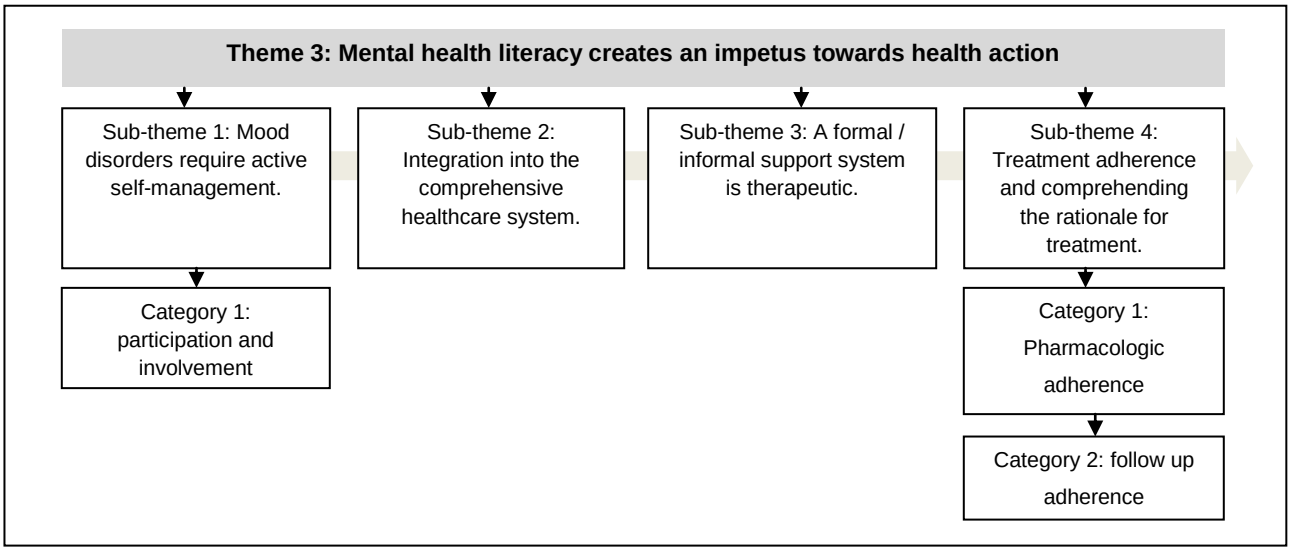


**Figure 3-4: Graphic depiction of theme three: Mental health literacy creates an impetus to health action**

Kidd *et al.* (2014:182) explored the meaning of recovery for mental healthcare users in Australia and found that various factors are regarded as part of recovery and management of mental disorders. Collaborative recovery and management of mental disorders are perceived as the ability to actively

engage in life activities, having personal autonomy, social identity, meaning and purpose in life, obtaining a positive self-image and understanding their disorder (Kidd *et al*., 2014:182). Based on the abovementioned literature and results, there is a clear consensus that managing mental health disorders require involvement of mental healthcare users in order to equip them to comprehend and manage their mood disorder efficiently. Participants further explained that mental health should be integrated into the comprehensive healthcare system and that mental healthcare users need to have a support system in place, especially after being discharged from the hospital.

**Theme 3, Sub-theme 2: Integration into the comprehensive healthcare system**

Mental healthcare users perceived that there is a gap between the management of mood disorders and other chronic disorders within the healthcare system. Chronic disorders such as diabetes, cancer and hypertension are generally more integrated into healthcare, leaving less space for mental health due to misperceptions and pre-conceived ideas of mental health disorders. A study performed across 11 districts in Cape Town, South Africa revealed that health promotion services at primary health care (PHC) facilities are mainly focused on diagnostic tests such as blood pressure monitoring (97%), weight monitoring (88.3%) and blood glucose monitoring (80.9%). Yet, basic services such as health education and clinical counselling are available, but mental health screening and education does not take priority alongside other physical health conditions (Parker *et al.,* 2012:503).

Participants furthermore described that the gap between mental healthcare and chronic healthcare should be integrated into both private and public healthcare systems because mood disorders are neglected in both sectors in comparison to other chronic conditions: *"… South Africa might be a changed world where everybody can access that information…. People will speak to people about mood disease but now people are just talking about cancer*". Participants voiced that having a chronic disease is easier accepted and understood by significant others than a mental health disorder, as if mental health disorders aren't seen as a disease. *"The thing with bipolar is, if it were diabetes or something like that, "same thing", in the sense of the biological factor. But no, it is just so much more acceptable for everyone around you".*

Participants perceived that mental health literacy decreases stress and improves overall well-being especially when mental health disorders co-exist with other chronic disorders. Poor management of a mental health disorder could contribute towards the development of disorders such as diabetes and hypertension. Balhara (2011:274) determined the link between diabetes and mood disorders in India. This comorbidity exists in different patterns and increases the risk of diabetes and

hypertension (Ku *et al*., 2016:2218). One participant voiced that people taking chronic medication are weaker than individuals who are able to manage a mood disorder and prevent other chronic diseases from developing: *"Because then you are weaker because then you have to take your pills for the rest of your life. So you didn't actually solve your problem, you made it worse".*

Due to mental health being a neglected issue in most countries, the notion of integrating mental health into PHC can be a strategy to enhance community mental health awareness (Kermode *et al.,* 2009:476). Furthermore, it becomes apparent that mental healthcare users often present to PHC facilities with a variety of somatic symptoms and complaints but lack of knowledgeable health professionals leads to misdiagnosis or inadequate provision of treatment (Kermode *et al.,* 2009:477).

**Theme 3, sub-theme 3: A formal / informal support system is therapeutic**

Participants perceived the lack of support to mental healthcare users contributing towards negative, destructive behaviour that can lead to poor adherence and relapse. Support is viewed as essential as it enhances self-management and willingness to take action in one's own healthcare. Two main support systems were identified, namely formal and informal. Formal support referred to trained professionals, whilst informal support is family, friends and colleagues. Having a professional support system in place assists one during the recovery process, because besides pharmacological treatment, psychological support enhances ones' skills to manage a mood disorder. Follow-up visits to a healthcare professional can enhance adherence to treatment and prevent relapse through early identification of symptoms. As Subramanian *et al.* (2017:18) confirmed, early detection improves response to treatment. *"The only thing I've learned now is about a system, a "support" system in the sense of psychologists all the way, and to check every month whether your system is still in place. This time I really focused on systems because my medication is perfect…"*

Contradictory results surfaced from participants' perceptions about support from non-professionals. Firstly, participants acknowledged that although support by family and friends was necessary, poorly informed family and friends could impact the management of mood disorders by mental healthcare users negatively. Negative family support elements could overrule possible support to participants, leading participants to avoid family members because *"…on the one hand, that's your 'support system' but they do not want to and they hurt you and reject you ... so you rather avoid them".* Lack of support by non-professionals could lead to feelings of worthlessness although a mood disorder in itself contributes towards negativity and broken relationships: *"The support system is very important, and that's what's always got me, my support system is not strong. The thing is*

*from depression, you make the wrong choices, or one big thing about what is detrimental is your relationships with your family or your family get a lot of damage…. And because you cannot reverse, it's half a "vicious" circle, it makes you feel even more real you're not worthless..."* Świtaj *et al.* (2014:370) state that regardless of enhanced public mental health literacy, social rejection of mental healthcare users has not improved during the past decade and it continues to exert negative effects on mental healthcare users as well as their families, health providers and communities. Some mental healthcare users are supported by informal systems such as family, friends and colleagues, a literature review conducted by Subramanian *et al.* (2017:23) stated that family support along with adherence improved outcome and functioning of bipolar patients in Asia as well as in Western countries.

Gumus *et al.* (2015:174) explored the efficiency of a four-session psychoeducation program in Turkey that evaluated the symptom recurrence in individuals diagnosed with bipolar mood disorder over a period of one year. The findings suggested that a four-session follow up program wasn't statistically efficient in decreasing relapse and more research is needed to determine how many follow up psychological support sessions will lead to effective outcomes in preventing relapse and readmission (Gumus *et al.,* 2015:176). Yatham *et al.* (2014:13) confirmed that psychoeducation, individual and family therapy, and other professional psychotherapeutic interventions could decrease recurrence and improve symptoms of individuals with bipolar mood disorder. Nitzburg *et al.* (2016:188) suggests that psychological cognitive-behavioural intervention may prevent downward spiralling of negative attitudes and behaviours towards bipolar mood disorder that could positively contribute towards adherence and positive coping.

In addition, various informal support systems emerged such as peers and social networks that can serve as informal support systems for the mental healthcare user. Proudfoot *et al.* (2012:196) evaluated the effects of knowledgeable, trained peer online support among Australian mental healthcare users and found that it enhances compliance to supportive measures, therapies and social networking, encourages adherence to treatment and provides a sense of acceptance and satisfaction leading towards overall improved functioning. Rickwood *et al.* (2015:2) conducted research in Australia and determined the main sources of help seeking via self-report in young adults, concluding that the role of family support in mood disorders is under researched. However, young people who reach out for mental health support generally prefer informal support from family and encouragement rather than professional assistance (Rickwood *et al.,* 2015:2). In addition to having formal and informal support systems, comprehending the rationale for pharmacological

treatment as well as the importance of follow up treatment sessions such as psychotherapy also forms part of theme 3.

**Theme 3, sub-theme 4: Treatment adherence and comprehending the rationale for treatment**

Although individuals with bipolar mood disorder are generally poor adherers (Moczygemba *et al.,* 2014:474), mental health literacy encourages adherence by making mental healthcare users more aware and understanding towards the rationale for pharmacological (category 1) and professional follow-up adherence (category 2). From the interviews conducted there was generally a lack of interest of newly diagnosed individuals with mood disorders regarding their medication. One participant admits not having any need to learn more about her medication because: *"It was never interesting for me, for me it was a thing of... I get my tablets, I take my tablets and it's alright".* Recently Subramanian *et al.* (2016:11) assessed adherence attitudes of 109 individuals with bipolar mood disorder in India using the Structured Clinical Interview for DSM-IV-TR Patient version (SCID-I/P) and the Medical Adherence Rating Scale (MARS). Among the sample there were 85 adherent and 24 non-adherent participants. In the non-adherent patients group 91,7% were generally "careless or forgetful" about taking their medication and were symptomatic for longer times. In contrast the adherent group where 85,9% confident regarding their treatment with shorter symptomatic episodes. The non-adherent group tended to become more adherent over the course of their illness due to the knowledge obtained (Subramanian *et al.,* 2016:11). These findings correspond with the results of this research regarding comprehending, understanding and being more literate in terms of mental health treatment to impact positively on adherence: *"you need to know more about yourself and what you are using... so that you don't relapse to your sickness... from here I want to get better and not worse".*

Participants seemed to understand the importance of and need for treatment and follow up, explaining that it automatically creates a sense of awareness and enhanced self-management. Participants comprehended the need for adherence in order to prevent relapse, readmission and the development of other chronic diseases: "*…if you can solve the problem and you are fine again with these pills, it means you have recovered from your weakness…That makes you strong, because then you know how to deal with the problem…".* Comprehending the rationale for treatment and adherence created a sense of interest into the disorder and empowered participants to take action in managing it (Subramanian *et al.,* 2016:11). Participants realised that adherence is not only to treatment, but also to follow up with support systems: "*By using my medication as it is prescribed and by talking to someone and not cropping everything up inside".*

**THEME 4: MENTAL HEALTH LITERACY IS A POSITIVE ENABLER**

Theme four describes how mental health literacy enabled participants towards improved management of their mood disorders. As one participant voiced: "*I really think if you know you would really do it and you are more receiving towards people who give you knowledge and information, to really empower you.*

**Theme 4, sub-theme 1: Mental health literacy strengthens active coping although coping remains difficult**

Although mental healthcare users were ill informed of their condition on admission, once they became more informed and understood their mood disorder, self-empowerment and awareness encouraged positive coping strategies in contrast to maladaptive, destructive coping. Contradictory Nitzburg *et al.* (2015:185) state that individuals diagnosed with bipolar mood disorder generally encounter significant life adversity that contributes towards the disability. The 1st category describes how individuals are aware that they cannot change the reality of their diagnosis and their live circumstances and need to develop coping mechanisms to deal with it. *"…I can also not resent my wife for things that happened say 30 years ago. She cannot resent me for what happened 24 years ago.… I am in control of my life again". "…the more knowledge I have about my disorder, the better I will be able to control the disorder…".* Participants' awareness about the importance of learning and applying more positive coping mechanisms such as planning, positive approaches and support seeking despite difficult circumstances increased. Hospitalised mental healthcare users valued basic life skills training, coping mechanisms and conflict management tools during their in-hospital program. "*…number one I made a checklist and said to myself 'what went wrong, what happened".*

It emanated from the interviews that denial and rebellious behaviour prior to diagnosis go hand in hand with illiteracy and overall poor understanding of mood disorders. Various participants admitted that once they were aware of their diagnosis and learnt more about mood disorders, they understood themselves better, improved their coping skills and decreased destructive and defensive behaviour (2nd category). *"...If I could change that thought, that piece where I can take that emotion and change it positively... stand back, look at the situation and evaluate it…", "…the result that would take place will be a positive reaction that will break the negative chain".* The 3rd category describes increased self-motivation and self-reliance, making enhanced mental health literacy foundational for empowerment. Participants voiced that by learning more about their diagnosis and its management during hospitalisation created a pathway for self-care. Participants voiced that as they became more mental health literate it actually increased their susceptible towards information.

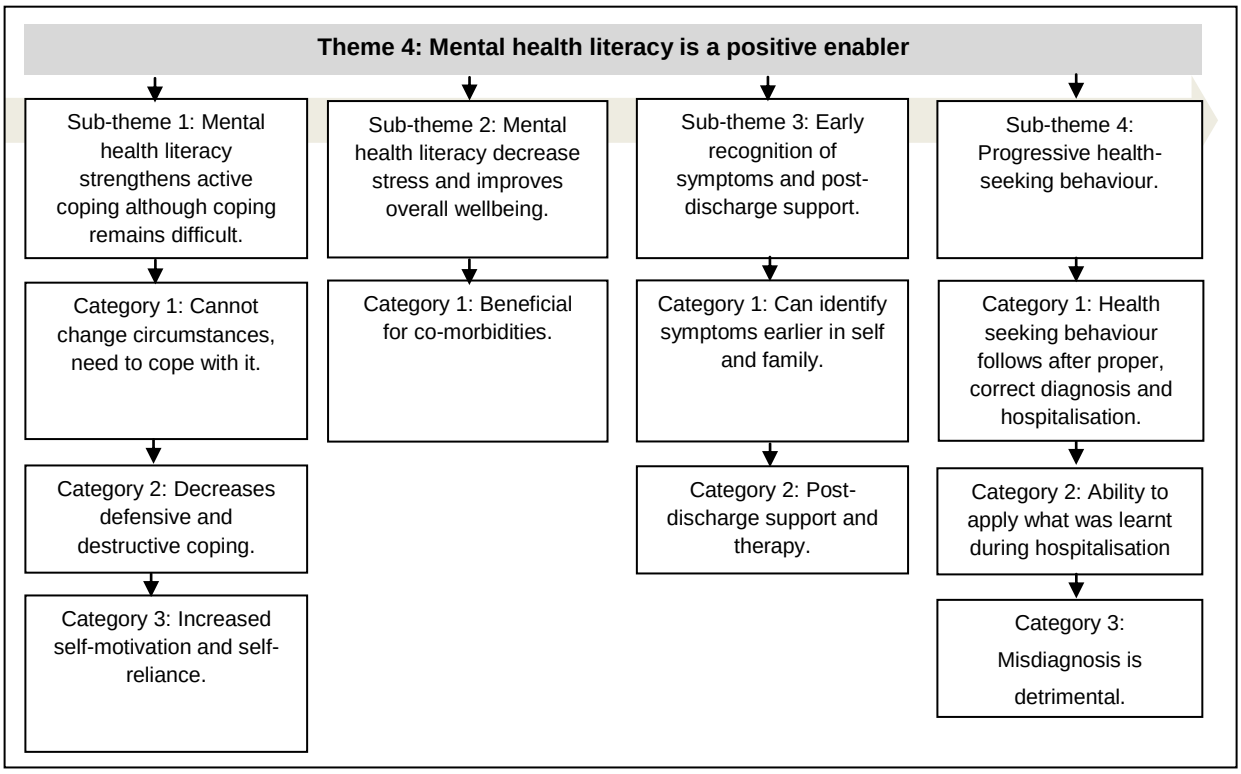


**Figure 3-5: Graphic depiction of theme four: Mental health literacy is a positive enabler**

### Theme 4, sub-theme 2: Decreases stressors and improves overall wellbeing

Participants perceived that understanding and managing one's mental health disorder in a positive, constructive manner contributes towards their overall health and wellbeing. During hospitalisation patients are encouraged to eat a balanced diet, to exercise at least three times a week, avoid alcohol and other substances, adhere to medication and follow up dates. These positive lifestyle changes improved their wellbeing and were perceived as a positive mechanism to managing and preventing co-morbidities (1st category). "*Oppressing your feelings. That is a very dangerous move. You are killing yourself…and that causes a lot of stress… a lot of sicknesses: high blood and diabetes*". Clausen *et al.* (2015) confirmed the association between mental illness and co-morbid chronic diseases as mentally ill individuals are at higher risk to develop preventable chronic disorders whereby enhanced health literacy could prevent the development of chronic diseases (Clausen *et al*., 2015).

### Theme 4, sub-theme 3: Early recognition, acknowledgment and support

Recognising symptoms and acknowledging the need to obtain assistance are the first action steps towards mental health problems. Participants voice that they initially did not recognise the need to

seek support or treatment but if they were aware of their symptoms earlier, it might have created earlier help-seeking behaviour yet they had to be hospitalised first (category 1). "*Then you would have said long ago "listen, this I think I have depression or bipolar or something, but…you don't see it that way. It just happens to other people*". Knowing mood disorders' signs and symptoms enabled participants to recognise it within others.

Furthermore, participants feared discharge from the hospital because it is more difficult to cope in an unsafe, non-supportive environment. Participants declared the need to have follow-up care and support after discharge to prevent relapse. Having a post-discharge support system (2nd category), formal or informal encourages self-growth and awareness and enhance the application of techniques and coping mechanisms learnt during hospitalisation. "*The difference with discharge now, in comparison to other times is long term therapy... my psychologist and I have put systems in place on the path I am going to walk now... I am aware of it and understand it now and if there are things that I can't deal with we will do something else*".

**Theme 4, sub-theme 4: Progressive health-seeking**

Poor knowledge related to how to access professionals and not knowing the role of professionals is a contributing factor towards poor health-seeking behaviour (Topkaya, 2015:28). Being formally diagnosed and hospitalised for a mental healthcare disorder (1st category) encouraged participants to learn more about their condition and facilitated their willingness and ability to seek help and information. According to Camerini *et al.* (2012:338) knowledge of self-management creates positive health outcomes because it enhances constant uptake of health promoting actions, adherence to treatment and help seeking. Participants admit that they were never interested in learning about mood disorders until hospitalisation. Hospitalisation encouraged participants to learn more and apply their new knowledge (2nd category) and participants voiced that they wanted to become an active participant in their own mental health management: "*I really think if you know you will really do it and you will be more susceptible towards people who give you knowledge and information, to really empower you*". In the interviews the researcher identified that various participants were previously misdiagnosed and participants felt a sense of relief for finally receiving correct treatment (category 3). One participant referred to be seen by various general practitioners but due to misdiagnosis gave up on seeking further medical help: "*I just saw that those guys* [doctors] *don't really care…and then I just said no. Enough!"*. Misdiagnosis often occurs when clinicians diagnose bipolar mood disorder based on symptoms and not in conjunction with the course of illness, genetic factors and biomarkers (Ghaemi, 2016:171).

## THEME 5: EXISTING KNOWLEDGE INFLUENCES PERCEPTIONS OF MOOD DISORDERS

### Theme 5, sub-theme 1: Knowing symptoms as fluctuating on a continuum between manic and depressive

During interviews participants voiced that through hospitalisation they learnt about specific symptoms related to contrasting episodes and the link between unstable mood and unstable behaviour and the associated social inappropriateness. Participants were able to cluster emotions and behaviours as depressed or manic and realised that longer duration of the diagnosis enhanced mental health literacy.

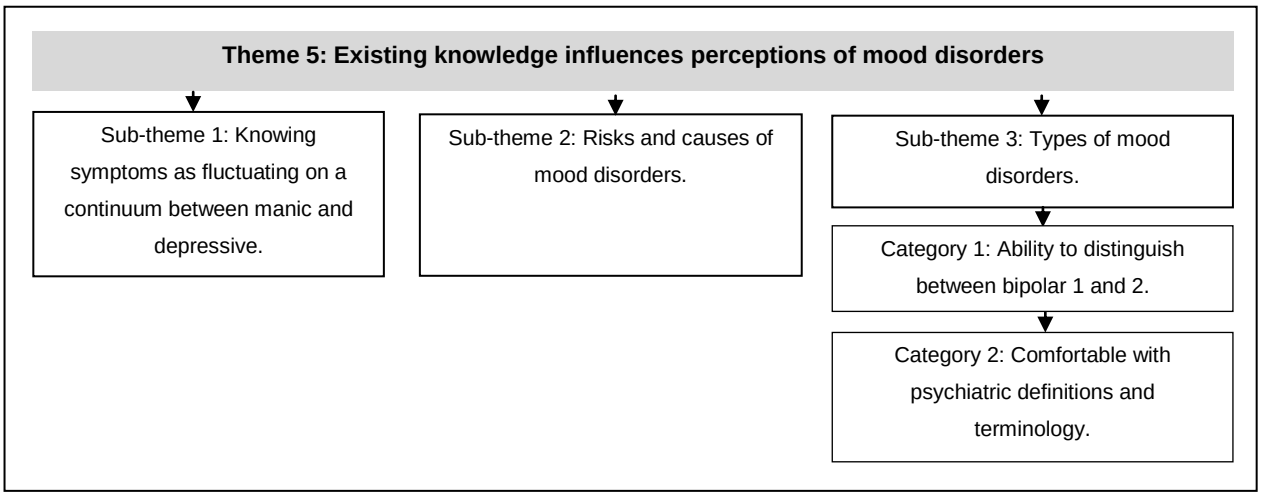


**Figure 3-6: Graphic depiction of theme five: Existing knowledge influences perceptions of mood disorders**

Prior to diagnoses and treatment, participants explained their awareness that 'something was wrong', not feeling themselves, being unable to cope they used to and not knowing why they felt this way. They further voiced that admission and an in-hospital program was essential to enhance mental health literacy as essential. Participants learnt to associate terms and definitions (category 1) with feelings and symptoms previously experienced. Although not all participants were able to recall formal terminology associated with fluctuating moods, all the participants were aware of "mood swings" (category2) and the ever-changing change of moods ranging on a continuum from manic to depressive. *"I know they say your high is your high and your low is your low…and then you are happy and the next moment you are like super grumpy and then…so, you change from one thing to another in seconds".*

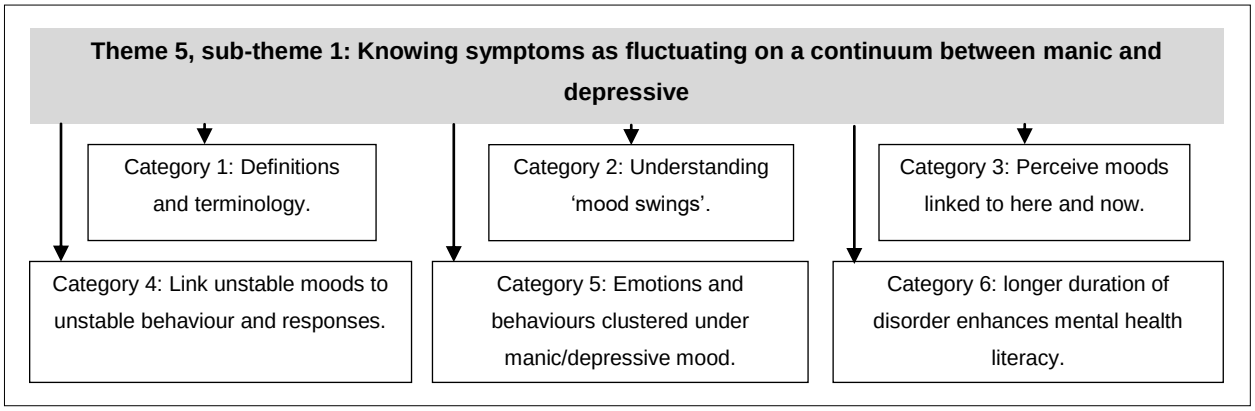


**Figure 3-7: Theme 5, sub-theme 1: Knowing symptoms as fluctuating on a continuum between manic and depressive**

Participants perceived that moods were linked to the "here and now" (3rd category) in the hospital which differed from being discharged and in non-supportive environments. Unstable moods were linked to unstable responses (category 4) and highly destructive responses *"Since the beginning it was an unstable destructive road. I did not understand it very well then".* Furthermore, participants perceived mood disorders generally associated with destructive thoughts and behaviours towards themselves and others and having a mood disorder could place one at risk for inadequate self-care, poor adherence and increased risk for relapse. Individuals with bipolar mood disorder generally adapt destructive, maladaptive responses a way of coping, they are often unable to control such responses (Nitzburg *et al.,* 2016:185). Participants associated physical symptoms with mood disorders, such as palpitations, sweating, dizziness, headaches and disturbances in eating and sleeping patterns, and distinguished between emotions and behaviours associated with depressed mood versus manic mood (category 5). One participant stated that *"Hypomania can be classified as a tremendous irritability, agitation and then also, depressive as fact of the matter". "…It's very bad because if you are very euphoric and you fall flat into a whole there, it will be terribly bad. The moment you are also manic, you become half psychotic…".* The duration of a mood disorder (category 6) and repetitive hospitalisation made participants more knowledgeable and comfortable to use psychiatric terminology.

These clusters of emotions and behaviours paired by the participants are summarised in Table 3-2.

**Table 3-2: Hospitalised mental healthcare users' perceived emotions and behaviours clustered under manic and depressed episodes**

| | Manic episode | Major depressive episode |
|---|---|---|
| Behaviour | Restlessness, irritability, aggression and difficulty sleeping; heightened energy levels and restlessness. | Excessive sleeping and fatigue; decreased energy, fatigue, lack of motivation and disinterest in pleasurable activities; feelings of hopelessness. |
| Emotion | Overinflated self-value and dominating, controlling opinions; destructive behavioural patterns feel comforting. | Insecurity and feelings of worthlessness towards oneself, guilt and disappointment towards others; being unstable affects personal relationships experienced as negative. |
| Cognition | Both manic and depressive episodes can lead towards forgetfulness, lack of concentration and irritability. | |
| Thoughts | Distractibility, difficulty rationalising and analysing reactions, uncontrolled, abrupt responses. | Suicidal ideation and irrational thoughts. |

**Theme 5, sub-theme 2: Risks and causes of mood disorders**

Participants perceived that various factors increased the risk to develop a mood disorder and differ from individual to individual.

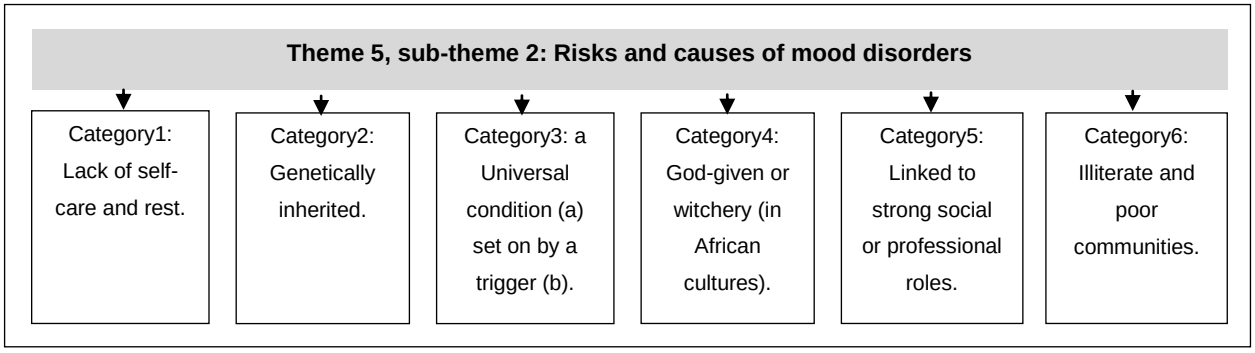


**Figure 3-8: Theme 5, Sub-theme 2: Risks and causes of mood disorders**

Participants attributed mood disorders to the lack of rest, not caring for one-self and exhaustion (category 1). These perceived causes are symptoms of mood disorders and not necessarily the causes thereof. Uys and Middleton (2014:398) described the early signs of mood disorders as hypomania – highly energetic with mood swings, irritability and impulsivity or it may present as drug abuse, alcohol abuse or poor performance. The depressed continuum of bipolar mood disorder is generally characterised by sadness, lack of self-care, withdrawal and guilt (Uys & Middleton, 2014:359). In addition participants linked the development of mood disorders to genetic factors (Category 2). *"…but I realised or I heard that it is actually genetic and it runs in the family. So it is inherited…"* The offspring of individuals with bipolar mood disorder are more prone to developing the illness (Grande *et al., 2016:1567).* Mood disorders are universal and can affect any person regardless of race, ethnicity, culture and age and is thus regarded as a universal condition (category 3a)*"….* More than 1% of the global population is affected by bipolar mood disorder, regardless of age, nationality, ethnic origin and socioeconomic status (Grande *et al.,* 2016:1561). Participants agree by stating: "*because when I got here, the first thing I realised, everyone who is here – we all have the same emotions. We all have the same feelings; we all have the same problems".* Yet, traumatic and dramatic life events could possibly trigger the onset of a mood disorder (category 3b). "*Mood disorders is sometimes… you know, family pressure that is sometimes a little too much. Sometimes its trauma or something that you have not really processed that still comes back later because you didn't process it".* Bipolar mood disorder generally has an abrupt onset and is triggered by stressors (Grande *et al.,* 2016:1563). In various religious and cultural groups, participants perceived that mood disorders are a God-given disorder to make one more humble and to draw strength from one's brokenness or due to witchery (category 4) whereby a curse or spell was cast unto the patient. African participants state that cultural beliefs increase mass denial and discourage prospective patients to seek help. Cultural beliefs in some instances increased stigma and the risk of being left untreated: "*because of culture I said to myself you are still a man and you have to come right*". African-American men are generally emotionally restricted and self-reliant thus increasing internalised stigma (Lindinger-Sternart, 2014:2-3).

Other perceived risk factors associated with the development of a mood disorder were strongly related to societal roles and demands such as leaders in the workplace or breadwinners in the family (category 5). High social expectations and demands create an additional sense of pressure that contributes towards the risk of developing mood disorders. Participants voiced that the social role of men that are expected to be strong leaders, breadwinners and being in control; when in fact, men do have mood disorders as well. Traditional norms of the masculine gender are generally associated with reduced help-seeking behaviour (Lindinger-Sternart, 2014:2), a participant explains:

"*I am a man, I have been taught to have force…I am the man…during my life, the army and school that has been strengthened in me".* Although the general expectation is that males are breadwinners, one female participant states: "*I am the only breadwinner…I have too much pressure on me and sometimes it just becomes too much…so that you can't anymore. It makes you hopeless because you don't see the light and you see things won't get better for you"*. Category 6 describes participants' identified financial difficulty, strain of daily living and poor literacy as contributive factors towards developing a mood disorders. Lack of knowledge contributes towards ill health and inappropriate management of stress and anxiety that increases risk of developing mental health disorders and other chronic diseases. Pleasant (2014:1481) confirmed poor literacy, poverty, poor health literacy and poor health outcomes. Sturgeon (2007:38) confirmed that socio-economic factors such as poverty and lack of education contribute towards "poverty traps" that deprive developing countries of health and creating a risk of poor health for underserved communities.

**Theme 5, sub-theme 3: Types of mood disorders**

After diagnosis, hospitalisation and exposure to an in-hospital educational program, participants gained knowledge into different types of mood disorders, its symptoms and management thereof. The therapeutic effect of self-help and support practices encourages mental healthcare users to become 'experts by experience' when it comes to their mental health (Noorani, 2013:50). Participants were able to distinguish between various types of mood disorders. *"Bipolar, you get bipolar one and bipolar two. It is a mood disorder that you, where there are two poles. One is from depressive to manic and then…in bipolar one there are always more worries in the sense of the up's and the euphoria and everything that you can do that can make you manic. Then many things are in danger, you are a danger to others. Whereas the depressive is more…bipolar two is diagnosed if you have been hypomanic more than once in your life".* Mood disorders are characterized by mood fluctuations ranging from manic to depressed and individuals diagnosed with mood disorders has had at least one manic episode in their life (Mukherjee, 2017:87). In contrast to pre-admission knowledge, hospitalisation and obtaining mental health literacy informed participants of mood disorders and made them more comfortable to use appropriate psychiatric terminology.

**THEME 6: THE INFLUENCE OF FAMILY, SIGNIFICANT OTHERS AND PROFESSIONALS ON THE ATTITUDES AND COPING OF MENTAL HEALTHCARE USERS WITH MOOD DISORDERS**

Participants voiced that family and significant others influenced (positively or negatively) how they perceived their condition, willingness to receive and adhere to treatment, motivation to continue receiving treatment and managing mood disorders.

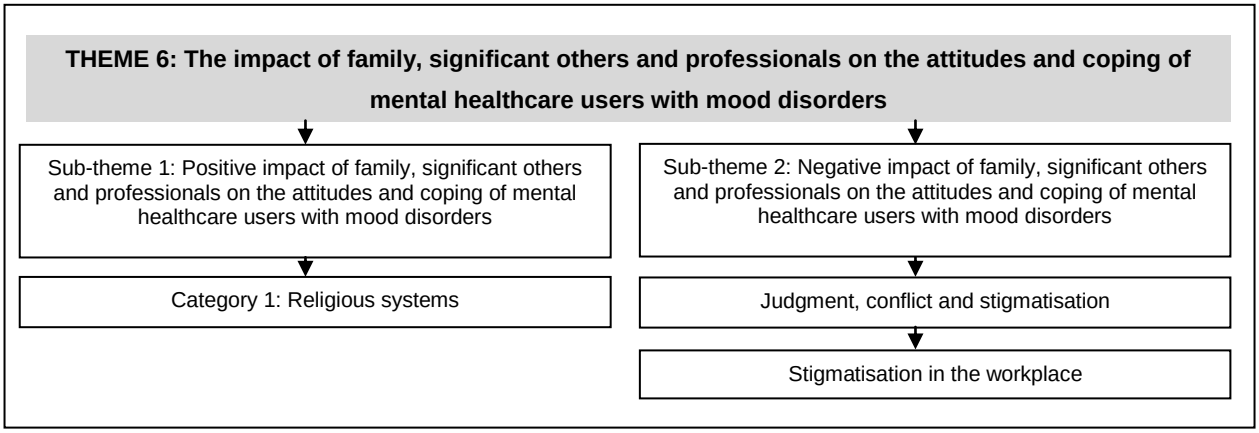


**Figure 3-9: Graphic depiction of theme six: the influence of family, significant others and professionals on the attitudes and coping of mental healthcare users with mood disorders**

### Theme 6, sub-theme 1: Positive influence of family, significant others and professionals on the attitudes of mental healthcare users

Participants with family support tend to accept their diagnosis more easily and show more interest and motivation in recovering and managing their mood disorder. Families with positive attitudes towards mental healthcare users encouraged help-seeking, treatment and hospitalisation. Chatzidamnios (2015:2) confirmed that positive influence of family-focused support in bipolar mood disorder enhanced treatment adherence, prevented relapse, assisted in overall recovery through early recognition of warning signs and development of self-management strategies. In addition, family-focused treatment plans enhance self-management and reduces depressed episodes and risk behaviour of patients (Yatham *et al.,* 2013:4; Grande *et al.,* 2016:1567). According to participants, knowledgeable friends encouraged them towards help-seeking behaviour and motivated them towards recovery. Professional networking and appropriate referrals were perceived as positive to enable correct diagnosis and treatment. For participants who lacked family and friends, religious systems were accessed for support (category 1). Spirituality could contribute towards mental health promotion and forms part of mental health wellbeing (WHO, 2004b:31).

### Theme 6, sub-theme 2: Negative impact of family, significant others and professionals on mental health literacy and coping of mental healthcare users

Khalil (2017:69) recently investigated the level of mental health literacy and the attitudes towards individuals with mental disorders and found that 240 out of 255 (94.1%) of participants stated that family can play an important role in the treatment of individuals with mental disorders. Although family is reported as the strongest help-seeking influence, there is no conclusive evidence that relative involvement in mental health management improves the outcomes of mental healthcare

users (Chatzidamnios *et al.,* 2015:12). Little research is focused on family functioning even though it has a role in the illness outcome of mental healthcare users (Reinares *et al.,* 2016:66). It is argued that the relatives of individuals with bipolar mood disorder are generally supportive at a young age but with age their involvement declines (Chatzidamnios *et al.,* 2015:12). Participants voiced also the negative realities of support such as judgment, conflict and stigma which decrease participants' willingness, ability and interest to manage the mood disorder actively. Negative comments and attitudes from significant others increased participants' low self-esteem, denial, maladaptive coping and insufficient management of mood disorders. In a study conducted in Spain it was found that bipolar patients and their caregivers generally perceive that a negative family environment is influenced by the number of suicide attempts, the duration of the disorder, family burden and coping skills (Reinares *et al.,* 2016:71). Negative family attitudes and poor social support are viewed as predictors of recurrence, relapse and the onset of depressive symptoms (Reinares *et al.,* 2016:66-67).

Negative support leads towards inner conflict within the participants regarding their mood disorder and increased risk of conflict with family members, colleagues and friends. In 2015 SADAG confirmed the impact that stigma within the workplace of employees with mood disorders (SADAG, 2017). According to SADAG (2017) 61% of diagnosed mental healthcare users have disclosed their condition to their managers, 69% of these respondents reported that disclosing their condition is uncomfortable and lead to negative responses or no responses from management.

### THEME 7: PERCEPTIONS RELATED TO INFORMATION SOURCES

Information is conveyed to participants through various sources, is dependent on attitudes and interpretation as described hereafter.

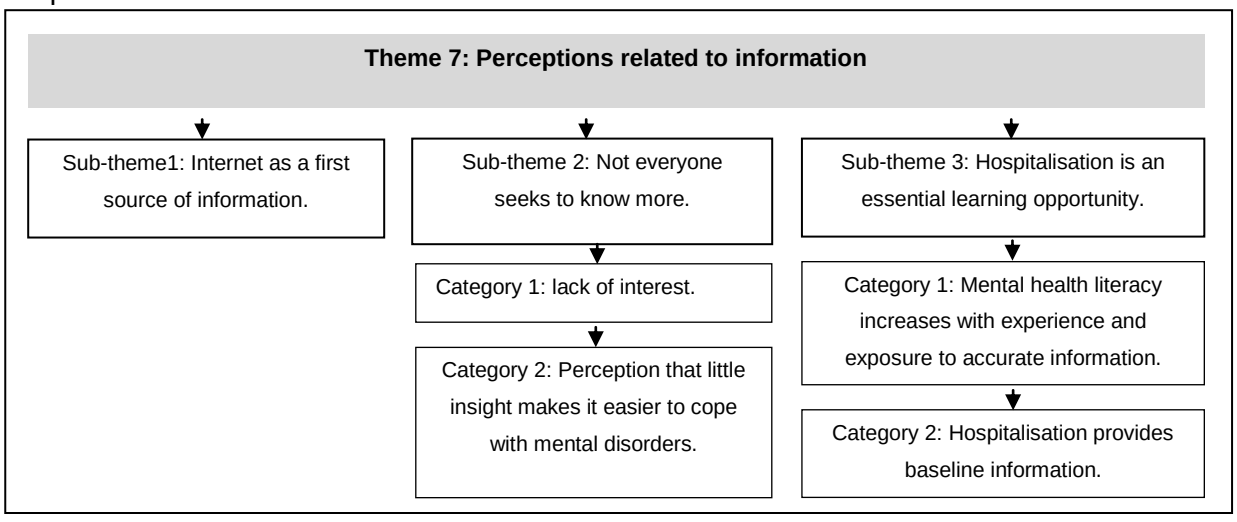


**Figure 3-10: Graphic depiction of theme seven: perceptions related to information**

**Theme 7, sub-theme 1: Internet as a first source of information**

The majority of participants utilised the Internet as their first source of information, thereafter follows psychiatrists, psychologists and healthcare personnel. In recent years Internet access has escalated and it has become a popular source of health-related information (Reavley *et al.,* 2011:1276). Self-initiated online searches are the preferred source of obtaining health and mental health information, especially for the youth (Rickwood *et al.,* 2015:6). The internet is private, user friendly and it provides the user with the ability to access relevant information and the opportunity to network and consult online (Srivastava, 2015:2). In contrast to the findings of this research, a survey assessing mental health information sources amongst Australians suggested that television is the preferred information source (Reavley *et al.,* 2011:1269).

**Theme 7, sub-theme 2: Not everybody seeks to know more**

According to the participants, not everyone is interested to know more about their mood disorder. In addition to denial, participants explained that there is a general lack of interest (category 1) contributing towards poor mental health literacy. While some participants admit that they were just not interested in reading about mood disorders, others suggested that when they first became aware of mood disorders and noticed the symptoms in themselves, it created a sense of interest to learn more. Contradictory, some participants perceived that having had mental health literacy could have hindered them to obtain more information and obtain a proper diagnosis (category 2). *''Sometimes I wish I hadn't known what it is, that I didn't have the insight…I wish I had complete illiteracy".* Mental health literacy could initiate an intrapersonal struggle between acceptance and denial and could make it difficult for the individual to cope with initially: *"I think if you hadn't known and you were half stupid about everything it might have been somewhat easier. But now you know things and it is as if you then struggle more with yourself", 'It makes it difficult, it makes it very difficult for me to know exactly".* Fergusson *et al.* (2015:2427) stated that various mental healthcare users feel more depressed and dissatisfied with their lives as they obtain more insight into their condition. Besides positive factors associated with mental health literacy, negative aspects such as increased hopelessness, poor self-esteem, higher suicide risk, lower physical health and lower subjective quality of life must not be overlooked (Fergusson *et al.*, 2015:2427).

**Theme 7, sub-theme 3: Hospitalisation is an essential learning opportunity**

Participants suggested that hospitalisation is an essential learning opportunity because it forced participants to increase their mental health literacy (category 1). One participant suggested that lack of knowledge contributes towards suicide and he highly recommended that individuals be more informed to prevent trauma. Hospitalisation provides the appropriate mental health toolkit of

baseline information that participants voiced they needed (category 2) to continue to manage their mental health. According to Roessler (2006:151) psychiatric institutions can assist admitted mental healthcare users to develop emotional, social and cognitive skills required to live, learn and work in their respective communities with little or no support from health professionals. Being part of a patient self-management educational program enables individuals to learn about their illness process and its management, it also includes benefits such as decreased distress, enhanced self-awareness, self-management, peer support and growing hope (Stenberg *et al.,* 2017:1768).

### THEME 8: SPECIFIC PERCEPTIONS OF TYPES OF INFORMATION SOURCES

The evolution of types of information sources from printed media towards the development of mass media and the leap towards digitalized ICTs created a wide variety of sources accessible for mental healthcare users. In the paragraphs below the perceptions of these sources are described.

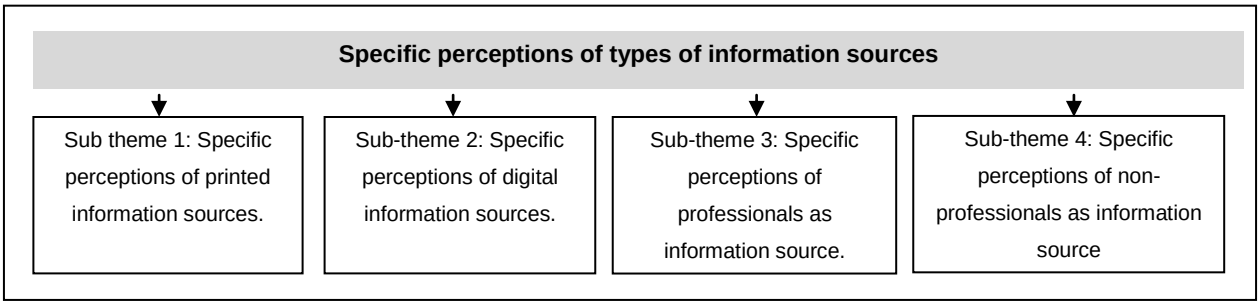


**Figure 3-11 Graphic depiction of theme eight: specific perceptions of types of information sources**

#### Theme 8, sub-theme 1: Specific perceptions of printed information sources

Participants voiced that printed media, specifically brochures, pamphlets and leaflets are generally one of the most accessible sources of information (1st category), especially at healthcare facilities such as hospitals, clinics or consultation rooms. Printed media are informative and affordable. Yet, some of the participants reported that printed media are useless if it is not disseminated to the larger community that doesn't enter specific health facilities and highly unlikely to be usable by illiterate individuals. Participants questioned the credibility of information disseminated in secular magazines and newspapers and suggest that even if they read about information in these sources, they would preferably still confirm the information through using another source of information. Furthermore, some participants liked reading and preferred self-help books. It is said that self-help and informative books are available at any library and is thus an obtainable source for them.

However, not all participants are avid readers and preferred digital information sources. Although medication inserts are available in all treatment packages and the information provided in these leaflets are seen as accurate and trustworthy, participants voiced that they didn't obtain information from these inserts. The difficult terminology on leaflets guides participants towards professional sources of information such as pharmacists, nurses and psychologists. These findings are consistent with what was reported in a study by Rains (2007:667). The author explored the perceptions of traditional information sources and found that some individuals prefer consulting health professionals instead of seeking information from the internet. Although electronic information distribution is rapidly growing, Reavley *et al.* (2010:1272) suggest that individuals over the age of 45, especially males, may be better targeted through printed media.

**Theme 8, sub-theme 2: Specific perceptions of digital information sources**

Participants perceived mass media as accessible and accurate, yet the topics were too general and not specific enough for mood disorders. Participants admitted that they were aware of health programs but not necessarily placed effort into watching these programs or listening to it on the radio. In general participants questioned the credibility of digital mass media. A participant acknowledged that media depicts negative habits in advertisements that could influence health and wellbeing negatively. Parker *et al.* (2012:503) explored the feedback from patients and healthcare providers in South African PHC clinics and concluded that patients want to receive education but don't want to read printed media. Preferred methods were videos, interactive support groups or clubs. Participants experienced that social media can be supportive, user-friendly and private. Information provided on social media is generally widespread and could trigger help-seeking behaviour. Literature confirms that online access to mental health information crosses the access barrier, it is affordable and generally anonymous and confidential (Rickwood *et al.,* 2015:2). According to Naslund *et al.* (2014:1) digital platforms are becoming increasingly popular amongst individuals with mental illness and pose various benefits to the mental healthcare user including social support acceptance, confidentiality, anonymity and the sharing of common life experiences. Contradictory, social media opens a doorway for critique and provide less reliable information. According to participants, there are many groups in society who are resistant, or lack the technological literacy and skills to use this as a valuable information source. There remains uncertainty as to what information on social media is valuable and trustworthy (Naslund *et al.,* 2014:7). Content on digital sources are largely unregulated and could create anxiety in the mental healthcare user related to symptoms, inferiority when comparing themselves to others who are coping better, unrealistic treatment expectations and exposure to information that is misguiding or inaccurate (Naslund *et al.,* 2014:7).

**Theme 8, sub-theme 3: Specific perceptions of health professionals as information source**

Participants perceived the ultimate source of information the learning and training that occurred during their contact with health professionals, with specific reference to psychologists and psychiatrists. They explained that health professionals are not only able to recognise and identify symptoms but also the gateway to a correct diagnosis and correct management, described as the pathway to all levels of care and trustworthy sources of information. Health professionals were described as being experienced, knowledgeable, trendy and professional; especially relating to their exposure to health professionals during this hospitalisation. Yatham *et al.* (2013:4) agree by stating that professional therapy and education used in adjuncts to pharmacological therapy demonstrates benefits in acute- as well as long-term episodes of bipolar mood disorder. Professionals assist in decreasing relapse rates, mood fluctuation, re-hospitalisation, increased functioning and improved adherence; providing psychoeducation is an essential aspect of managing individuals with bipolar mood disorder (Yatham *et al.,* 2013:4).

It is noteworthy to report that one participant continued to express the opposite view, experiencing that his journey to being diagnosed and treated was unnecessary delayed by inefficient health professionals; "…..*these guys don't really care… they just ask you what is wrong, give you a prescription and there you go…".* According to Oyffe *et al.* (2015:96) misdiagnosis could delay treatment and is generally associated with poor outcomes in social functioning, recurrent hospitalisation, increased mortality rates and suicide attempts. Obtaining a differential diagnosis enhances the prognosis of mental healthcare users (Ghaemi, 2016:171), thus clinicians need to be trained regarding the recognition of bipolar mood disorder because the longer it takes to diagnose, the longer it takes to treat (Oyffe *et al.,* 2015:104).

**Theme 8, sub-theme 4: Specific perceptions of non-professionals as information source**

In addition to traditional professional support-seeking structures, mental healthcare users often seek support from informal sources such as friends, family, self-help groups, the internet and colleagues (Findlay & Sunderland, 2014:3). The participants perceived fellow patients as health information sources during hospitalisation as the first type of non-professional information source. Fellow patients face similar experiences and were supportive. A second non-professional information source was traditional healers; although participants voiced being aware of their role within health systems but not accessible for accurate mental health information. Participants voiced that Traditional healers contributed to stigmatisation through cultural attitudes and beliefs about mental health disorders. The third type of non-professional information sources included family, friends and colleagues that held a positive attitude towards mental health. Participants explained that family,

friends and colleagues with a negative attitude towards mental health were in contrast debilitating and no source of information.

## 3.5 SUMMARY

The research results indicate that participants' perceptions of information sources regarding mental health literacy revolved predominantly around the process of hospitalisation. Multiple processes of accurate diagnoses, activation of appropriate treatment and in-hospital support programs occurred simultaneously with acceptance of the mood disorder and became an integral part of the participants' journey towards improved health literacy. Participants perceived that health professionals exposed to during their hospitalisation, especially psychologists and psychiatrists, were their preferred source of professional health information. Non-professional sources of information from family, friends and colleagues were dependent on these role-players' attitudes towards mental health. In general, the participants preferred the Internet as mental health information source as well as printed media and voiced that mental health information sources such as brochures aren't accessible to the larger public and is only limited by people that can read. Participants explained that mental health literacy is a powerful enabler towards help-seeking behaviour. In chapter four follows an evaluation of the research and the formulation of recommendations.

# CHAPTER 4: CONCLUSIONS, LIMITATIONS AND RECOMMENDATIONS OF THE RESEARCHER WITH SPECIFIC REFERENCE TO THE FORMULATION OF APPROACHES TO ENHANCE MENTAL HEALTH LITERACY

## 4.1 INTRODUCTION

Chapter 3 presented the research findings with a literature control. In Chapter 4 follows the conclusions, evaluation and limitations of this research followed by recommendations. The recommendations aim toward informing psychiatric nursing education, - research and psychiatric nursing practice. The chapter concludes with recommendations for mental health practice to inform the mental healthcare provider to enhance mental health literacy. Recommendations are also applied to the individual, family, community and national mental health literacy through the distribution of appropriate information through a variety of information sources.

## 4.2 CONCLUDING STATEMENTS

Based on the literature review and research results, the following concluding statements regarding the mental health literacy and information sources of adult mental healthcare users with mood disorders are formulated:

- Hospitalisation, correct diagnoses and accurate treatment are essential to obtain and increase mental health literacy regarding a diagnosis of a mood disorder.
- Poor mental health literacy relates to denial, avoidance of help and not being able to identify signs and symptoms of mood disorders.
- Mental health literacy is self-empowering and a stimulus to become actively involved in one's self-care.
- Intersectionality of gender impacts on mental health literacy whereby masculine roles are easier linked to denial, impacting on help-seeking behaviour.
- Although participants could recognise symptoms of mood disorders, these participants weren't necessarily immediately ready to accept it within themselves.

- Mental health literacy is progressive in nature.
- Mental health literacy is one aspect in the comprehensive management of mood disorders.
- Health professionals and the Internet are the two main information sources for mental healthcare users with mental health disorders.
- Mental health literacy sources are under-resourced considering the potential thereof to empower mental healthcare users.

## 4.3 EVALUATION AND LIMITATIONS OF RESEARCH

### 4.3.1 Evaluation of research objectives and methodology

The objectives of this research were to explore and describe adult mental healthcare users', diagnosed with mood disorders, perceived mental health literacy of mood disorders and the sources of information they utilise in order to learn more about their mood disorder. The objectives have been met as the semi-structured interviews brought about various perceptions of hospitalised mental healthcare users about their mood disorder and information sources participants generally used. A qualitative, interpretive descriptive and contextual research design was used and was appropriate because it produced in-depth insight and dense descriptions of the participants' perceptions, feelings, thoughts and understanding of mental health literacy and information sources. The ethical considerations were adhered to. The competency to consent assessment (MacCAT-CR) was performed by the mediator (psychologist) and re-evaluated by the researcher before commencement of data collection. Passing the MacCAT-CR assessment accompanied by written informed consent as required prior to commencement of data collection was efficient as it ensured that participants had the mental capacity to make informed decisions and truly comprehended the aim of this research, it also ensured involvement of mediators to enhance ethicality of this research.

### 4.3.2 Limitations of this research

The following limitations were identified in this research:

- Although the participants of this research were hospitalised with a mood disorder, the private hospital sample represents a very small portion of mental healthcare users within the overall community. Undiagnosed mental healthcare users within the community, mental healthcare users with mental illnesses other than mood disorders, and hospitalised mental healthcare users

within the government sector were not reached by this research. The research results are therefore context bound.

- The researcher conducted the interviews herself and was guided by her supervisors to conduct research interviews and not therapeutic interviews. This was a new skill to the researcher and required that the researcher had to return to the private healthcare facility to conduct more interviews as interviews with a therapeutic undertone couldn't be utilised further.

- The researcher experienced difficulty in obtaining time in the participant's hospital schedule, and there wasn't a focused time for data collection. Data collection became fragmented opportunities for interviews and it was difficult to be available in similar time slots with participants to ensure uninterrupted interviews.

## 4.4 RECOMMENDATIONS FOR MENTAL HEALTH EDUCATION, RESEARCH AND PRACTICE

Recommendations are formulated to enhance mental health literacy of patients with mood disorders on individual, community and public levels. Recommendations are categorised under mental health education, research and practice.

### 4.4.1 Recommendations for mental health education

These recommendations are intended to assist mental health practitioners to develop appropriate mental health education strategies, and provide appropriate information through various sources in order to enhance mental health literacy on individual, community and public levels.

- Mental health education should focus on reinforcing admission and formal diagnosis of individuals presenting with mental health symptoms. In hospital information sessions provide broader opportunities for individual growth and learning possibilities for newly diagnosed individuals to learn about the specific symptoms and management of their mood disorder.

- Bearing in mind that poor mental health literacy relates to denial, avoidance of help seeking and the inability to identify signs and symptoms of mood disorders, individuals with poor mental health literacy can be targeted in the form of support groups where family, friends or colleagues form part of health education. Mental health literacy is self-empowering and a stimulus to become actively involved in one's self-care, health education should thus not just focus on the

individual affected, but also within their nuclear community in order to provide a sense of support that could possibly enhance self-awareness and contribute towards help-seeking behaviour.

- Mental health management and help-seeking should be reinforced as a strength during health education. Creating a sense of praise towards individuals who actively engage in the management of their mental health could possibly reinforce victims of intersectionality to continue help-seeking behaviour. It is recommended that a group approach in which individual mental healthcare users' strengths are identified and utilised, could positively reinforce engagement and active participation in the management of mood disorders, especially in individuals prone to denial such as males.

- Health education must provide information regarding the symptoms of mood disorders, the management thereof and information regarding where and how to seek further care for the mood disorder. Although participants could recognise symptoms of mood disorders, these participants weren't necessarily immediately ready to accept it within themselves. Support must be provided through immediate referral to appropriate internet support groups, applicable social network groups, professionals or community support groups.

- Education strategies must create awareness of the various information sources available to the community and must encourage mental healthcare user to explore information sources they have access to. Providing mental healthcare users with specific links, internet addresses, names of websites, books or contact details for professionals could positively contribute towards engagement and mental health literacy.

- It is recommended that mental healthcare facilities should utilize the latest trends in technology to communicate information to mental healthcare users. Patients who have been admitted and discharged must not be forgotten, mental health literacy is progressive in nature and thus sending frequent updates to discharged mental healthcare users could possibly encourage and motivate them to continue managing their mood disorder. Technology can also be used as a reminder method, discharged mental healthcare users can be reminded of support groups, follow up dates and medication collection or review dates via e-mail or sms. It is recommended that mental health education must use all available resources to reach their mental healthcare users instead of waiting for individuals to come to them.

- Mental health literacy and information sources to be included into the curricula of professional mental healthcare practitioners such as nurses, psychologists, community healthcare workers,

psychiatrists and counsellors. This might facilitate a holistic approach towards mental healthcare education that could enhance overall public mental health literacy and lead to reduced stigmatisation of mental healthcare users.

- Integrate mental health literacy and information sources into the in-service training programs of nurses employed in mental healthcare units in order to enhance in-hospital as well as post-discharge support system development.

### 4.4.2 Recommendations for mental health research

The potential for further research is listed as:

- Developing a program for community members and stakeholders in individual and community mental health literacy programs focused on mental health prevention, management and rehabilitation.

- Investigating follow up, adherence, relapse, and readmission rates of discharged mental healthcare users who are supported by family, friends and professionals.

- Determining mental health literacy levels of mental healthcare users and significant others measured quantitatively.

- Determining mental health literacy levels of mental healthcare users within different South African cultural groups.

### 4.4.3 Recommendations for mental health practice

The recommendations for mental health practice include individual, community and public approaches of mental health education strategies. Recommendations were guided by the perceived mental health literacy of hospitalised mental healthcare users with mood disorders and include the following:

- Recommendations regarding denial/acceptance/disinterest pertaining to mental health literacy: It is recommended that universities, colleges and clinics could utilise trained professionals and community members to provide information to all members of the community by combining mental health awareness information with various forms of information sources such as printed media, applications, radio and advertisements and information talks in the workplace. Specific recommendations regarding crossing the barrier of denial requires further research.

- Encourage students and professionals to volunteer within the communities. Professionals could possibly host training sessions for community leaders, mental healthcare users and their families in order to enhance their mental health literacy.

- Mental health professionals with a passion for mental health could be encouraged to assist community leaders in initiating and acting as consultant for mental health community support groups and training programs. With the assistance of professionals, community members willing to take the lead in such groups will have access to knowledge obtained directly from a professional. After training community leaders and supplying them with the appropriate information regarding mental health symptom identification, management, treatment and care options the professional can indirectly supervise the progress of the group and provide guidance as required.

- Appropriate information leaflets to mental healthcare users prior to, during and post-hospitalisation. It is recommended that mental healthcare users be equipped with self-help strategies based on their specific diagnosis and not the provision of generalised information.

- Develop a unique therapeutic program based on one's diagnosis and / or stressors and the provision of interactive group therapy sessions based on diagnosis and / or stressors.

- A mental health awareness campaign where discharged mental healthcare users who are actively coping and managing their mental illness is granted the opportunity to share their story and methods with fellow mental healthcare users. Mental healthcare users find being discharged from hospital challenging and returning to their homes after being discharged from hospitalisation increases fear and anxiety. Admitted mental healthcare users perceived that hospitalisation provides a safe, secure environment in which they can distance themselves from triggers that generally lead towards negative behaviour.

- Mental health literacy is progressive in nature, in order to enhance mental health literacy and limit the negative effects of sudden transition post-discharge, a 6-8 weekly follow up support program at the hospital is recommended. Follow-ups will provide additional support for the mental healthcare user, their family or friends. Enhanced support structures could contribute positively towards adherence and in contrast, decrease the possibility of relapse. Other benefits associated with a post-discharge support program include opportunities for the mental healthcare workers to assess the coping and progress of the discharged mental healthcare users and make appropriate recommendations and referrals if necessary. After follow-up

sessions have been completed, the mental healthcare user can be provided with an open invitation to continue attending monthly supportive, educational groups and further follow-up individually with their psychologists and psychiatrists on an appointment basis.

- Availability of reliable digitalised information from a known mental health professional employed at hospitals, clinics, universities or colleges could decrease seeking of information from unknown sources. Information should be provided in conjunction with a therapeutic relationship with a mental healthcare practitioner so that information can be clarified and the utilisation of the information can be discussed and evaluated. A known mental health professional to the mental healthcare user can develop a more trustworthy relationship with each mental healthcare user over time and will notice symptoms of relapse early. Mental healthcare users can contact designated healthcare workers from the hospital, clinic or university directly, at any time, should they deem it necessary.

- In order to enhance the use of professionals as a method of obtaining mental health information, information provided to individuals, families and communities should include the contact details of mental health facilities, professionals and support groups within the area of the specific target group. Information provided to the public should also include the appropriate referral channels of help seeking in terms of both private and professional practice.

- In addition to health professionals as information source, digital technologies were the most popular information sources utilised. Managers of psychiatric mental health facilities should develop and activate an eHealth platform using Twitter™, Facebook™ and YouTube™ can be utilised to engage with mental healthcare users, decrease stigma and provide correct mental health information within a safe environment.

- Psychiatric facilities providing mental health treatment and care to formulate proper discharge information available in a printed and digital format. Upon discharge mental healthcare users are generally provided with verbal information related to the basic follow-up care such as adhering to appointments, avoiding alcohol and substances, continuation of treatment etc. This information can easily be forgotten by the mental healthcare user who is anxious to go home and the family and friends who support the individual may also have poor knowledge related to appropriate management and follow-up care, thus enhancing risks of poor adherence and relapse.

- In addition to a post-discharge program, providing hospitalised mental healthcare users with accessible information even post-discharge could enhance not only their own mental health literacy, but sharing this information with family and friends could enhance the mental health literacy of more individuals that could create a more positive environment for the mental healthcare user. It is suggested that in addition to available digital sources, that a DVD could be developed in which health professionals share information related to mental health management, adherence, warning signs and early recognition of relapse as well as the importance of follow-up appointments and available supportive resources. As supplemental source, this information could also be distributed to mental healthcare users in pamphlet or leaflet form.

- Mental health literacy can be reinforced post discharge through the activation of a supportive information and reminder system. Mental healthcare users that fail to adhere to follow-up appointments due to forgetting the dates, not arranging appointments in time, unavailable leave to attend, or due to relapse should be prevented. In order to enhance adherence and follow-up a follow-up reminders and information system can be activated, and information could be provided regarding the negative effects of defaulting. Due to the large amount of accessibility to electronic communication devices such as cellphones and computers, the preferred method of communication in this regard is the distribution of e-mails and SMS.

#### 4.4.3.1 Recommendations aimed at family interventions

- Mental health literacy is progressive in nature and can evolve more with encouragement, motivation and support. Involving family, friends or colleagues is recommended as part of the recovery process to ensure a sustained supportive recovery environment.

- From admission family members, friends or supportive individuals must be provided with learning opportunities on how to assist, deal, cope with and support their loved one's affected by a mood disorder. It is recommended that psychiatric nurses who form part of the multidisciplinary team should be granted the opportunity to consult with the psychiatrist and psychologist to identify the needs of the mental healthcare user. Once needs have been identified, the psychiatric nurse together with the mental healthcare user and their main supportive members eg. Family, friends, partners or colleagues can initiate family therapy sessions. Family therapy will not only confront problem areas, it will also enhance relationships between family members, create a sense of awareness, and create and additional opportunity

for providing mental health education and information that could enhance the mental health literacy of supportive individuals such as family, friends or colleagues.

- Family therapy sessions can be provided where the family and mental healthcare user can work through mental health related signs, symptoms, management and treatment together. Implementing a family approach could provide support to the mental healthcare user as well as the family. Enhanced mental health literacy as a family could enable family members to identify signs and symptoms early and assist the mental healthcare user to obtain relevant treatment and care.

- Post discharge family therapy sessions to be available on request of the family and / or mental healthcare user. These sessions could allow the family to understand the mental healthcare user's mood disorder, but also to learn how they can effectively support their loved one and at the same time also gain more knowledge and mental health literacy.

#### 4.4.3.2 Recommendations aimed at community and society interventions

Based on the findings of this research and the evaluation of available literature, a social ecological model is recommended as a method that could possibly enhance information delivery, further research is needed in this field. McCormack *et al.* (2017:9) support this view by stating that the social ecological model approach could positively contribute towards mental health literacy and patient engagement by means of creating a supportive environment for mental healthcare users. The implementation of the ecological model to enhance community and society interventions aimed at enhancing mental health literacy however requires further research.

##### 4.4.3.2.1 Enhance public mental health literacy using a social ecological approach

McCormack *et al.* (2017:12) suggest that a social ecological approach moves away from individual mental health education interventions and steers into how individual interventions can be augmented through a supportive, facilitative environment. Thus health outcomes are aimed at enhancing mental health literacy of individuals by means of enhancing mental health literacy of the community as a whole. Include major role-players in the community in mental health literacy interventions, provide training and appropriate information and educate individuals and groups on the pathways of managing mental health.

#### 4.4.3.2.2 Identify and educate community leaders

- Mental health professionals and students working in the community setting could assist in the development and inclusion mental health ambassadors in community mental health awareness programs. Main stakeholders identified including occupational facilities; employers and employees; community health facilities such as clinics and old aged homes; religious groups including churches, pastors and youth groups; educational facilities such as schools, colleges and universities; trained health professionals and discharged patients. It is recommended that nursing students could assist in providing mental health education to individuals, families, communities, community professionals and community leaders during their completion of community health nursing requirements. Thus it is suggested that mental healthcare should form part of and be integrated with community health nursing.

- **Occupational facilities**

Mental healthcare users might experience intolerable judgement, stigmatisation and discouragement from their workplace. The lack of mental health literacy amongst employers and colleagues can impact negatively on mental healthcare users, causing fear and decreasing help-seeking behaviour; fear of missing work due to a reason regarded as ‘‘invalid’’ by employers and finally fear of returning back to work post-discharge. Workplace plays a big part in managing mental health disorders. The general lack of mental health literacy places additional stress on mental healthcare users and the following recommendations aimed at enhancing mental health literacy in the workplace are essential:

- **Community health facilities**

Integrate primary healthcare and mental health more comprehensively because many mental healthcare users seek help first at their PHC facilities. Mental healthcare professionals to take the initiative to reach out to PHC facilities to educate their staff, management and patients about mental health related topics. Healthcare staff, general practitioners’ at consultation rooms/centres as well as stakeholders to be educated regarding mental health and specifically mood disorders. Professionals and students who are willing to volunteer can be utilised to enhance mental health literacy in community facilities and encourage mental health program development.

- It is recommended that community clinics must take the lead in initiating support groups and training community leaders and members of the community to sustain such support group. Professionals employed at the clinics must still be available for consultation if required and can

indirectly supervise the progress of the support groups or allocate students to assist in this regard.

- Community clinics are centrally located to most communities and actively engaging in a mental health program, frequently inviting guest speakers such as lecturers or professionals from private practice could positively enhance support group attendance and community engagement in community mental health programs.

- **Church and youth groups**

Community clinics and professionals working within the community could include churches and youth groups in mental health education programs. By visiting leaders of such groups or inviting them to a periodic meeting at the clinic and providing indirect support from the clinics, mental health literacy of church members and their families could be enhanced. Members of various generations can be reached by means of this approach if you take into account that youth groups are often for children and adolescents. Thus the overall recommendation is that professionals should support and educate community leaders in order for them to support and educate their community.

- **Old age homes**

Mental health education sessions at old age homes and facilities could enhance early detection of mental illness not only in older persons themselves, but also amongst the staff and visitors. All the staff, patients and visitors. In order to obtain this, the universities or colleges could take the lead in utilising mental health students to offer staff with opportunities to learn more about mental health via community visits or lectures.

- **Schools (children and adolescents)**
    - Strengthening the current school health initiatives from the present re-engineered PHC as a possible vehicle to provide essential mental health literacy.

    - It is recommended that primary healthcare facilities such as clinics in the community could utilise their staff to confront schools with mental health and make themselves available to provide mental health consultation on a voluntary basis.

    - The nursing universities and colleges could develop a mental health community program that utilises the students in an extended approach to reach the community. During the community healthcare study year, students could be allocated to go to schools, provide a

short basic educational session for teachers and students and make themselves available for consultation and appropriate referral afterwards.

- Students, professionals and community members trained in mental health can provide mental health information related to the symptoms of mental health disturbances, the management and treatment thereof and how to identify and assist mental healthcare users who have relapsed or who have not been formally diagnosed.

#### 4.4.3.2.3 Enhance mental health awareness, program development, screening and appropriate referrals

Mental health screening and appropriate referrals are aimed at all the above mentioned stakeholders. The following interventions are recommended to enhance mental health literacy:

- Universities and colleges teaching nursing together with primary healthcare community clinics could develop a program that provides informative sessions for the abovementioned target groups and provide appropriate screening tools and referrals. Thus it is recommended that students, community members, lecturers and clinic staff with mental health experience can all actively contribute and form part of a program that provides the community with mental health education, screening and appropriate referral. The specific information required in specific areas or community groups requires further research.

- Encourage mental healthcare professionals within the private sector to volunteer in the development and roll-out of the screening and referral program.

- Establish networking, referral and communication relationships between health professionals in both the public and private health sectors.

- After screening, refer individuals at high risk of mental healthcare disorders for consultation. This consultation will only serve as an informative session regarding available treatment and resources and will include a referral to the appropriate facility or professional (private or public), based on the needs of the identified individual.

- A referral system with added contacts details could possibly enhance help-seeking behaviour and eventually not only enhance individual mental health literacy, but also lead towards associated positive outcomes.

#### 4.4.3.2.4 Enhance involvement and distribution of reliable information through a variety of sources including informal consultation and follow up

- It is recommended that individuals, groups and companies working with, and training mental health professionals could actively engage in raising mental health awareness and educating the community regarding mental health. A variety of information sources (Internet, television, brochures and pamphlets, etc.) could be made available to the public including printed and electronic leaflets and newsletters; video clips; support groups and awareness campaigns. The variety of information sources should be appropriate to specific target groups' diversities and personal preference (further research is required related to these specifics).

- Various programs are available on radio and television, but are focused on general health and not specifically mental health, it is recommended that mental healthcare practitioners should be more actively engaged in community mental health. Mental healthcare providers who are not actively involved with the community themselves could enhance mental health literacy by making themselves available for interviews on radio, television or for newspapers. The media that is currently available could be consulted by mental health lecturers from the university or colleges to assist in developing a mental health programme. Mental health literacy could decrease first admission emergencies due to attempted suicide, attempted overdose and crimes. Mental health literacy enhancement, screening and referral could enhance early identification, recognition and management of mental health disorders and thus also decrease stigmatisation and discrimination against mental healthcare users. Because mental health information distribution is generally limited, mental health information should be widely distributed among a variety of sources in order for it to be accessed and accepted by the broader community.

## 4.5 SUMMARY

Preceding this research, the researcher conducted a literature review that indicated that mental health literacy is neglected globally and in South Africa and that mood disorders are often misdiagnosed and stigmatised, thus creating fear of rejection and avoidance of seeking professional help. The objective of mental health literacy is to develop a society where mental healthcare users, their families, friends, colleagues and employers are able to recognise symptoms and take rapid action in its management and providing public and social support. Mental health literacy as a positive outcome of information can be applied on various societal levels in order to contribute towards awareness and positive change. This research investigated information sources and

perceived mental health literacy of mental healthcare users and results were obtained by means of semi-structured individual interviews with hospitalised mental healthcare users with mood disorders. This research determined the preferred information sources of hospitalised mental healthcare users with mood disorders and the results gave rise to eight main themes. Denial hinders mental health literacy, yet it is facilitated by acceptance. Health seeking action is a positive result of mental health literacy and mental health literacy is influenced by pre-existing knowledge and beliefs.

The recommendations aim to enhance mental health literacy, namely to provide adequate information through a variety of sources and providing this information to various levels of society including individuals, families and the general public.

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# ANNEXURE A: NORTH-WEST UNIVERSITY (POTCHEFSTROOM CAMPUS) ETHICS APPROVAL

NORTH-WEST UNIVERSITY
YUNIBESITI YA BOKONE-BOPHIRIMA
NOORDWES-UNIVERSITEIT

Private Bag X6001, Potchefstroom,
South Africa, 2520

Tel: (018) 299-4900
Faks: (018) 299-4910
Web: http://www.nwu.ac.za

**Institutional Research Ethics Regulatory Committee**
Tel: +27 18 299 4849
Email : Ethics@nwu.ac.za

**ETHICS APPROVAL CERTIFICATE OF STUDY**

Based on approval by **Health Research Ethics Committee (HREC)** on **02/11/2016** after being reviewed at the meeting held on **11/08/2016**, the North-West University Institutional Research Ethics Regulatory Committee (NWU-IRERC) hereby **approves** your study as indicated below. This implies that the NWU-IRERC grants its permission that provided the special conditions specified below are met and pending any other authorisation that may be necessary, the study may be initiated, using the ethics number below.

**Study title:** **Mental health literacy and information sources of hospitalised mental health care users with mood disorders.**

**Study Leader/Supervisor:** **Prof P Bester**
**Student:** **C French**

**Ethics number:** N W U - 0 0 0 8 2 - 1 6 - A 1
(Institution – Study Number – Year – Status)

Status: S = Submission; R = Re-Submission; P = Provisional Authorisation; A = Authorisation

**Application Type: Single study**
**Commencement date:** 2016-11-02 **Risk:** **Medium**

**Continuation of the study is dependent on receipt of the annual (or as otherwise stipulated) monitoring report and the concomitant issuing of a letter of continuation up to a maximum period of three years.**

**Special conditions of the approval (if applicable):**

- Translation of the informed consent document to the languages applicable to the study participants should be submitted to the HREC (if applicable).
- Any research at governmental or private institutions, permission must still be obtained from relevant authorities and provided to the HREC. Ethics approval is required BEFORE approval can be obtained from these authorities.

**General conditions:**

*While this ethics approval is subject to all declarations, undertakings and agreements incorporated and signed in the application form, please note the following:*

- *The study leader (principle investigator) must report in the prescribed format to the NWU-IRERC via HREC:*
  - *annually (or as otherwise requested) on the monitoring of the study, and upon completion of the study*
  - *without any delay in case of any adverse event or incident (or any matter that interrupts sound ethical principles) during the course of the study.*
- *Annually a number of studies may be randomly selected for an external audit.*
- *The approval applies strictly to the proposal as stipulated in the application form. Would any changes to the proposal be deemed necessary during the course of the study, the study leader must apply for approval of these amendments at the HREC, prior to implementation. Would there be deviated from the study proposal without the necessary approval of such amendments, the ethics approval is immediately and automatically forfeited.*
- *The date of approval indicates the first date that the study may be started.*
- *In the interest of ethical responsibility the NWU-IRERC and HREC retains the right to:*
  - *request access to any information or data at any time during the course or after completion of the study;*
  - *to ask further questions, seek additional information, require further modification or monitor the conduct of your research or the informed consent process.*
  - *withdraw or postpone approval if:*
    - *any unethical principles or practices of the study are revealed or suspected,*
    - *it becomes apparent that any relevant information was withheld from the HREC or that information has been false or misrepresented,*
    - *the required amendments, annual (or otherwise stipulated) report and reporting of adverse events or incidents was not done in a timely manner and accurately,*
    - *new institutional rules, national legislation or international conventions deem it necessary.*
- *HREC can be contacted for further information or any report templates via Ethics-HRECApply@nwu.ac.za or 018 299 1206.*

The IRERC would like to remain at your service as scientist and researcher, and wishes you well with your study. Please do not hesitate to contact the IRERC or HREC for any further enquiries or requests for assistance.

Yours sincerely

Prof LA Du Plessis
Digitally signed by Prof LA Du Plessis
Date: 2016.11.08 08:01:19 +02'00'

**Prof Linda du Plessis**
*Chair NWU Institutional Research Ethics Regulatory Committee (IRERC)*

## ANNEXURE B: REQUEST FOR PERMISSION FROM A PRIVATE MENTAL HEALTHCARE HOSPITAL IN NORTH-WEST

Private Bag X6001, Potchefstroom
South Africa 2520

Tel: 018 299-1111/2222
Web: http://www.nwu.ac.za

**Africa Unit for Transdisciplinary Health Research**
Tel: 018-299 2095

16 May 2016

**The Manager**

--------- Neuro-Clinic

94 Desmond Tutu Street

Klerksdorp

2571

(018) 462 3072

Dear Sir/Madam,

**THIS LETTER SERVES AS REQUEST FOR WRITTEN PERMISSION FROM THE MANAGER TO CONDUCT RESEARCH IN THE FOLLOWING FACILITY: --------- NEURO CLINIC.**

I am currently registered for a clinical master's degree in Community Psychiatric Nursing at the North-West University (Potchefstroom Campus). My research title is: *Mental health literacy and information sources of hospitalized mental healthcare users with mood disorders.*

I have been granted approval to undertake the project by the ethics committee of the North-West University (Potchefstroom Campus). Reference Number:_____. The aim of this research is to investigate the sources of information used by adult patients with mood disorders as well as

these patients' perceived mental health literacy about mood disorders. This research involves a semi-structured, individual interview that will be digitally voice-recorded and completion of a short check list. Data will be obtained by a researcher who has completed a comprehensive 960 hours in her clinical Master's degree in Community Psychiatric Nursing. An estimate of 8-15 participants will be included in this research, data collection will occur between the months of September and October 2016. Please find attached the proposal for the research.

Participation in the research will be entirely voluntary and patients are free to decline participation. If patients decline, they will not be negatively affected in any way. Patients are free to withdraw from the research at any time, even after initially agreeing to take part. The researcher will work through management, the psychiatrists (gatekeepers) and psychologists (mediators) in order to obtain access to the patients, the research will be explained to patients by their treating psychologist as trained by the researcher. Competency to consent assessment (McCat-CR) will be performed by the mediator (psychologist) when research is explained, and will be re-evaluated by the researcher before commencement of data collection. Passing the McCat-CR assessment accompanied by written informed consent will be required before commencement of data collection via semi-structured interviews and checklist.

The interested, consenting patients will be contacted by the researcher and appointment s will be scheduled as per patient and hospital request for up to one week prior to the interview and before discharge, depending on dates scheduled with the participant. The patient will be asked to take part in a semi structured interview that will occur within the hospital premises in a location suggested by management, this interview must take place in a quiet environment or separate room with a closed door in order to ensure privacy. Semi-structured interviews will be recorded and the patient will be asked to complete a brief checklist during or after the interview, the total duration of the data collection will not be more than 60 min. per participant. The time of the interview will be scheduled with patient and hospital staff according to the in-hospital program, no interviews will interfere with the hospital program and interviews will only be scheduled during the patient's "free / self" time.

**Potential risks involved**

This research is mainly focused on assessing mental health literacy and information sources of mental healthcare users hospitalized in your facility. The research does not expect of patients to share specifics related to their diagnosis and cannot lead to any direct physical or emotional harm, all information related to the hospital and the patients participating in this research will remain strictly confidential, the hospital will be named as "a private mental health hospital in North-West"

and patients will be referred to as “participants”, the researcher will make use of data coding to ensure confidentiality. Should there be any unforeseen emotional response during the interview, the researcher will immediately provide counselling and telephonically make an appointment with the patient’s treating psychologist for further management.

**Benefits of this research**

Participating in this research could assist your patients to become aware of the various information sources available and the ones they utilize in order to obtain information related to their mood disorder. Allowing your patients to participate in this research could assist the hospital in identifying gaps in patients mental health literacy, the researcher will make recommendations to you facility based on findings of this research. Once the researcher has collected and analyzed all data and results have been compiled, the researcher will in formal report provide the hospital with feedback and a letter of gratitude for your contribution and efforts will be provided to your facility

I, the researcher hereby requests:

1. Written and signed permission to perform this research in your facility.
2. Any questions may be directed to me or to my facilitating supervisors via e-mail.
3. Could you please allocate me to a direct contact person in terms of arrangements of appointments and delegation of the location of appointments?
4. Please provide me with a description of your chosen method of feedback regarding the research.
5. Would you like the researcher to keep you updated on progress for monitoring purposes?

Thanking you in anticipation.

Yours Sincerely


| | | |
|---|---|---|
| Prof P Bester | Ms A Marx | Ms C French |
| Director | Co-supervisor | Postgraduate Student |
| 082 298 2567 | 082 938 8703 | 083 612 2989 |
| _____ | _____ | _____ |

# ANNEXURE C: PERMISSION FROM PRIVATE MENTAL HEALTHCARE HOSPITAL TO CONDUCT RESEARCH IN THE FACILITY

Blinded for confidentiality

MS C French
Private Bag X6001
POTCHEFSTROOM
2520

20 October 2016

Dear Ms French

**PERMISSION TO CONDUCT RESEARCH AT**

Your letter dated 12 October 2016 refers.

Permission is hereby granted to conduct research at Neuro Clinic as explained in your application. The Directors of were also consulted and permission granted by them.

Research activities will be conducted in your off duty time and should not interfere with the treatment regimens of patients.

Your contact person will be , Deputy Nursing Services Manager at . You may also approach Clinical Psychologists at to assist you with the recruitment of suitable participants for the research project.

Feedback regarding recommendations of the research should be given by means of a verbal presentation to the EXCO members on a date, time and venue to be determined. Hard and electronic copies of the dissertation or final report must be submitted to the Human Resources Development Department on completion of the research project.

Wishing you success with your studies.

**HRD MANAGER**

**CHIEF EXECUTIVE OFFICER**

## ANNEXURE D: REQUEST TO PSYCHIATRISTS TO ACT AS GATEKEEPERS IN RESEARCH

Private Bag X6001, Potchefstroom
South Africa 2520

Tel: (018)299-1111/2222
Web: http://www.nwu.ac.za
celentefrench@hotmail.com

------- Neuro-Clinic

94 Desmond Tutu Street

Klerksdorp

2571

(018) 462 3072

Dear Dr.

**THIS LETTER SERVES AS A REQUEST FOR YOUR ASSISTANCE IN MY RESEARCH**

I am currently registered for a clinical master's degree in Community Psychiatric Nursing at the North-West University (Potchefstroom Campus). My research title is: *Mental health literacy and information sources of hospitalised mental healthcare users with mood disorders.* I have been granted approval to undertake the project by the ethics committee of the North-West University (Potchefstroom Campus). Reference Number: NWU-00082-16-S1. The aim of this research is to investigate the sources of information used by adult patients with mood disorders as well as these patients' perceived mental health literacy about mood disorders. This research involves a semi-structured, individual interview that will be digitally voice-recorded and completion of a short check list. Data will be obtained by the researcher who has completed a comprehensive 960 hours in her clinical Master's degree in Community Psychiatric Nursing. An estimate of 8-15 participants will be included in this research, data collection will occur between the months of September and October

2016. A weekly update on data collection progress will be given to you verbally, telephonically, or via e-mail.

Participation in the research will be entirely voluntary and candidates are free to decline participation. If candidates decline, they will not be negatively affected in any way. Participants are free to withdraw from the research at any time, even after initially agreeing to take part. The researcher will work through management, the Psychiatrists (gatekeepers) and Clinical Psychologists (mediators) in order to obtain access to the patients.

The researcher's request to you as Psychiatrist is to act as gatekeeper for this research, thus required of you will be:

- To inform the researcher telephonically, verbally, or via e-mail if you are interested in acting as gatekeeper for this research.
- To identify suitable candidates diagnosed with bipolar mood disorder,
- To make such candidates aware of the research and to inform them of what it is about. An information leaflet containing all information and contact details will be made available to you and a copy will be made available for interested participants, this will be kept in a file in the manager's office,
- Assessment of the MacCAT-CR standard of competency measure, the questionnaire and pre-determined questions will be provided to you,
- If deemed incompetent please exclude discretely and do not refer for consent,
- If the patient is interested and deemed competent according to the MacCAT-CR with a score of five or more out of seven, please refer to a Registered Nurse in the ward for obtaining of consent. The prospective participant should be given at least 24 hours to decide whether or not they want to participate and sign consent.

**Potential risks involved for participants**

This research is focused on assessing mental health literacy and information sources of mental healthcare users hospitalised in the facility. The research does not expect of participants to share specifics related to their diagnosis and cannot lead to any direct physical or emotional harm. All information of participants of this research will remain strictly confidential and the researcher will make use of data coding. Should there be any unforeseen emotional response during the interview, the researcher will immediately provide counselling and telephonically make an appointment with the patient's treating Clinical Psychologist for further management, and the

researcher will accompany the participant to the ward and hand over to the Registered Nurse on duty.

**Benefits of this research**

Participating in this research could assist your patients to become aware of various information sources available and the sources they use in order to obtain information related to their mood disorder. Allowing your patients to participate in this research could assist the hospital in identifying gaps in patients mental health literacy, the researcher will make recommendations to the facility based on findings of this research. Once the researcher has collected and analysed all data and results have been compiled, the researcher will in formal report provide the hospital with feedback and you will receive a letter of gratitude for your contribution and efforts.

Thanking you in anticipation.

Yours Sincerely


| | | |
|---|---|---|
| Prof P Bester | Ms A Marx | Ms C French |
| Supervisor | Co-supervisor | Postgraduate Student |
| 082 298 2567 | 082 938 8703 | 083 612 2989 |
| _____ | _____ | _____ |

# ANNEXURE E: REQUEST TO PSYCHOLOGISTS TO ACT AS MEDIATORS IN RESEARCH

Private Bag X6001, Potchefstroom
South Africa 2520

Tel: (018)299-1111/2222
Web: http://www.nwu.ac.za
celentefrench@hotmail.com

------- Neuro-Clinic

94 Desmond Tutu Street

Klerksdorp

2571

(018) 462 3072

Dear Clinical Psychologist

**THIS LETTER SERVES AS A REQUEST FOR YOUR ASSISTANCE IN MY RESEARCH**

I am currently registered for a clinical master's degree in Community Psychiatric Nursing at the North-West University (Potchefstroom Campus). My research title is: *Mental health literacy and information sources of hospitalised mental healthcare users with mood disorders.* I have been granted approval to undertake the project by the ethics committee of the North-West University (Potchefstroom Campus). Reference Number: NWU-00082-16-S1. The aim of this research is to investigate the sources of information used by adult patients with mood disorders as well as these patients' perceived mental health literacy about mood disorders. This research involves a semi-structured, individual interview that will be digitally voice-recorded and completion of a short check list. Data will be obtained by the researcher who has completed a comprehensive 960 hours in her clinical Master's degree in Community Psychiatric Nursing. An estimate of 8-15 participants will be included in this research, data collection will occur between the months of September and October

2016. A weekly update on data collection progress will be given to you verbally, telephonically, or via e-mail.

Participation in the research will be entirely voluntary and candidates are free to decline participation. If candidates decline, they will not be negatively affected in any way. Participants are free to withdraw from the research at any time, even after initially agreeing to take part. The researcher will work through management, the Psychiatrists (gatekeepers) and Clinical Psychologists (mediators) in order to obtain access to the patients.

The researcher's request to you as Clinical Psychologist is to act as mediator for this research, thus required of you will be:

- To inform the researcher telephonically, verbally, or via e-mail if you are interested in acting as mediator for this research.
- To identify suitable candidates diagnosed with bipolar mood disorder,
- To make such candidates aware of the research and to inform them of what it is about. An information leaflet containing all information and contact details will be made available to you and a copy will be made available for interested participants, this will be kept in a file in the manager's office,
- Assessment of the MacCAT-CR standard of competency measure, the questionnaire and pre-determined questions will be provided to you,
- If deemed incompetent please exclude discretely and do not refer for consent,
- If the patient is interested and deemed competent according to the MacCAT-CR with a score of five or more out of seven, please refer to a Registered Nurse in the ward for obtaining of consent. The prospective participant should be given at least 24 hours to decide whether or not they want to participate and sign consent.

**Potential risks involved for participants**

This research is focused on assessing mental health literacy and information sources of mental healthcare users hospitalised in the facility. The research does not expect of participants to share specifics related to their diagnosis and cannot lead to any direct physical or emotional harm. All information of participants of this research will remain strictly confidential and the researcher will make use of data coding. Should there be any unforeseen emotional response during the interview, the researcher will immediately provide counselling and telephonically make an appointment with the patient's treating Clinical Psychologist for further management, and the

researcher will accompany the participant to the ward and hand over to the Registered Nurse on duty.

**Benefits of this research**

Participating in this research could assist your patients to become aware of various information sources available and the sources they use in order to obtain information related to their mood disorder. Allowing your patients to participate in this research could assist the hospital in identifying gaps in patients mental health literacy, the researcher will make recommendations to the facility based on findings of this research. Once the researcher has collected and analysed all data and results have been compiled, the researcher will in formal report provide the hospital with feedback and you will receive a letter of gratitude for your contribution and efforts.

Thanking you in anticipation.

Yours Sincerely


| | | |
|---|---|---|
| Prof P Bester | Ms A Marx | Ms C French |
| Supervisor | Co-supervisor | Postgraduate Student |
| 082 298 2567 | 082 938 8703 | 083 612 2989 |
| _____ | _____ | _____ |

# ANNEXURE F: MACCAT-CR STANDARD OF COMPETENCY MEASURE

**MacCAT-CR standard of competency measure**

Questions are based on the research as it has been explained to the hospitalized patient, this assessment will be performed before consent is obtained, and it will be reviewed by the researcher before data collection. A score of five or more out of these seven questions will deem a patient competent to give informed consent to research.

| ***Area*** | ***Justification*** | ***Question*** | ***Shows applicable competency*** | |
|---|---|---|---|---|
| | | | ***Yes*** | ***No*** |
| ***Understanding:*** | ***The ability to understand and comprehend relevant information*** | ***'Could you explain to me what the research I have explained to you is about?'*** | | |
| | | ***'What do you understand of what is expected of you?'*** | | |
| ***Appreciation:*** | ***The ability to appreciate and recognize a situation and consequences of actions and applying it to one's own situation*** | ***How will participating in this research affect you?'*** | | |
| | | ***'Will taking part in this research affect your hospital stay?'*** | | |
| ***Reasoning*** | ***Ability to reason information in a rational manner.*** | ***'Please explain to me what will happen if you decide to withdraw from this research?'*** | | |
| ***Expressing a choice*** | ***Communicating a choice clearly and consistently.*** | ***'What effect will you taking part in this research have?'*** ***'Why would you like to take part in this research?'*** | | |
| ***Total score (a score of 5 or more indicates competency to consent to this research)*** | | | | |
| Do you find this patient competent to make decisions, able to communicate decisions, and able to express a choice? | | | | |

Date of assessment: _____Signature: _____

# ANNEXURE G: PARTICIPANT INFORMATION LEAFLET AND CONSENT FORM

HREC Stamp

NORTH-WEST UNIVERSITY
YUNIBESITI YA BOKONE-BOPHIRIMA
NOORDWES-UNIVERSITEIT
POTCHEFSTROOM CAMPUS

**PARTICIPANT INFORMATION LEAFLET AND CONSENT FORM FOR HOSPITALISED MENTAL HEALTHCARE USERS WITH MOOD DISORDERS.**

Research Title: *Mental Health Literacy and Information Sources of Hospitalised Mental Healthcare Users with Mood Disorders*

**REFERENCE NUMBER:** NWU-00082-16-A1

**PRINCIPAL INVESTIGATOR:** Petra Bester, Annemarie Marx & Celente French

**ADDRESS:** Blinded for confidentiality

**CONTACT NUMBER:** Blinded for confidentiality

You are hereby invited to take part in a research project that forms part of a Magister Curationis in Advanced Community Psychiatric Nursing at the Potchefstroom Campus of the North-West University. Please take some time to read the information presented here, which will explain the details of this project and ask the researcher any questions about any part of this project that you do not fully understand. It is very important that you are fully satisfied that you clearly understand what this research entails and how you could be involved. Also, your participation is **entirely voluntary** and you are free to decline to participate. If you decline to participate, this will not affect you negatively in any way. You are also free to withdraw from the research at any point, even if you do agree to take part.

This research has been approved by the Health Research Ethics Committee of the Faculty of Health Sciences of the North-West University (NWU) Potchefstroom (***see*** annexure A, p.145) and will be conducted according to the ethical guidelines and principles of the international Declaration of Helsinki and the ethical guidelines of the National Health Research Ethics Council. It might be necessary for the research ethics committee members or relevant authorities to inspect the research records.

**What is this research all about?**

This research will be done in the hospital and will involve recorded interviews and completion of a brief check list. Information will be collected by a trained researcher who has completed 960 hours in her clinical Master's degree in Community Psychiatric Nursing. The aim of this research is to look into the sources of information you use to get information about your disorder, and what your knowledge is regarding your mood disorder in order to identify gaps in knowledge.

**Why have you been invited to participate?**

You have been invited to take part in this research because you are currently admitted with a mood disorder (condition/illness) in the selected Private psychiatric hospital in North-West.

You have also complied with the following inclusion criteria:

- You are hospitalised and formally diagnosed by a psychiatrist (Psychiatric Doctor) for a mood disorder (condition/illness).
- You do not currently have thoughts of harming yourself or others, you are not severely depressed or excessively manic and you are in no way aggressive.
- Fully aware of time, place and person and you understand the reason for this research.
- You are not confused or not fully orientated.
- You are able to understand, recall and think about the information you received about the research.
- You are able to compare risks and benefits of taking part and you can communicate a choice to take part or not.
- You are prepared and able to sign the permission letter to take part in the research.
- Both males and females may take part in this research,
- You can understand and speak English or Afrikaans as first or second language,

- You are between the ages of 18 and 70 years.
- Your mood disorder is not related to or caused by a medical condition or drug use.

You will be excluded if:

- You are currently confused,
- You are older than 70 years or at risk for age related disorders such as Alzheimer's or dementia,
- You feel at risk of being endangered or hurt in any way by participating in this research,
- You feel very emotional, like you want to fight or cry.

**What will your responsibilities be?**

During an interview you will be asked a few questions about your mood disorder, this will take about 10-30 minutes. You will also be asked to complete a short check list to help the researcher determine what you understand about your disorder and where you get the knowledge that you have about your disorder. The check list will be done immediately after the interview is finished and will not take longer than 10minutes. All the above activities will occur within the hospital on the _____day of _____ 2016. The researcher will schedule a meeting with you, please note that you may not skip any groups or other hospital routines to take part in this research. The data collection process consists of the completion of a brief check list followed by an interview lasting for no longer than 60 min.

**Will you benefit from taking part in this research?**

- Taking part in this research holds some benefit for you to become aware of what you currently know about your mood disorder and what the main sources are where you got this information, it can also help you to identify alternative help seeking pathways after discharge,
- Taking part will help you to realise if you feel you know about your mood disorder or not,
- On the demographic information sheet you can state if you would like to receive feedback about the research and how, the researcher will send you feedback within three months after the research is complete.

**The indirect benefit will be:**

The hospital and the researcher can become aware of the level of knowledge patients have regarding their mood disorders. New knowledge could help to create programs or new methods that can help others to better understand their condition and learn about where to get information about their condition. Taking part could improve the experience and knowledge for other patient's in the future as this research will help to identify new methods of increasing patient's knowledge about their mood disorders. Understanding what you know about your mood disorder and where you get your knowledge from can help you to become more aware about your mood disorder and can improve the hospital's methods of educating patient's with mood disorders in the future. Out of the information you give, the researcher can notice gaps and make recommendations of new ways to educate patients.

**Are there risks involved in your taking part in this research?**

The research focuses on what you know about your mood disorder and where you came across the information. You will not be asked to reveal the specifics about your disorder and you will not be negatively affected by taking part. Taking part in the research can in no way physically hurt you, and your personal details and information will be kept strictly confidential (secret) at all times.

**The risks in this research are:**

| **Risks** | **Safety measures** |
|---|---|
| You could get bored or tired by long interviews. | The interview time will be kept to the minimal, maximum one hour expected for complete interviews. |
| Sharing your personal information might be uncomfortable for you | The researcher will avoid personal or unrelated information and focus on the research. The researcher will be able to notice if you seem uncomfortable, emotional, or exposed. |
| Feeling threatened or intimidated by the interview or interviewer. | The researcher will talk to you in a language that you understand and will treat you with respect and dignity throughout interviews. |
| The possibility that the interview might trigger an emotional response. | In case you become emotional during the interview, you can take a five minute break. If this not helpful or if you don't want to take a break, you may withdraw from the research, the researcher will stop the interview, provide counselling if needed and hand you over to the Registered Nurse on duty for further management proceedings.<br>The researcher will arrange that your psychologist comes to see you as soon as possible and will follow up on your condition to |

| | |
|---|---|
| | ensure that the problem was addressed, if not, this could be reported to the unit manager for further management. |
| Misunderstandings, questions, inability to sign permission or poor understanding of research. | Before interviews the researcher will ask some questions to check your ability to sign the permission form. The research will be explained to you again and your questions will be answered to make sure that you understand the research and you know that you can withdraw at any time. |
| The researcher is legally bound to report any information you disclose that could be harmful to yourself or others. | If this is the case, the researcher will be forced to stop the interview, advise you that she has an obligation to report the case and refer the case to your psychologist to manage further. |
| Potential risk of confidentiality being exposed by other patient's. | You already know the other participants because you are admitted in the same facility, during admission you have signed a form of confidentiality and group confidentiality which decreases all risk of social harm, unfairness, and stigmatization. All participants will be kept secret and participation in the research will also remain anonymous. You are already in a protected environment in the hospital and there are no probable risks in this area. |
| Possible financial risks | The research will cause no financial implication for you, interviews will be done at the hospital while you are still hospitalised, you are not required to travel, interviews will be done in your "off" time,. |
| | Participating in this research requires a maximum 60 minutes of your resting time. Interview appointments will in no way affect your hospital routine, group sessions, or other appointments. According to the ward routine resting periods are between 17:00 and 20:00 every day, and during weekends, thus most appointments will be scheduled during weekends (excluding meal times) |

| | |
|---|---|
| Possible personal risk | You will be treated as an individual with values, preferences, commitments, and informed consent will be obtained before interviews. The researcher will minimise risks by a valid research design, the semi-structured interviews will be done by the researcher, who is a trained professional, privacy and confidentiality will be protected at all times, you will be monitored throughout interviews for possible harmful effects, a timely treatment plan is available in case of harm. |

**What will happen in the unlikely event of some harm/form of discomfort occurring as a direct result of your taking part in this research?**

If you need to discuss anything after the interview, or if you feel emotional in any way, the researcher will give you counselling and call your psychologist to make an appointment for you if necessary, you will be accompanied back to the ward and handed over to the registered nurse on duty for further management.

**Who will have access to your details?**

Your information will be given a code and thus your personal particulars will not be used. The researcher will make sure that only a few people (researcher, supervisors, co-coder and translator) have access to your personal information. All information will be kept safe and locked at all times and people who have access to your information must sign a form of privacy in which they declare not to share or use any of your information for anything else than what you have signed for in this document. The findings of the researcher will be reported namelessly so that no one will know any of your details. Information will be kept safe and secure by keeping hard copies in locked cupboards in an office and electronic information and recordings will be protected by a password. As soon as your interview has been written down, the recordings will be deleted.

**What will happen with the information?**

This is a once off collection and the information will be assessed by the researcher, assisted by a co-coder who will also sign an agreement of confidentiality. The information collected will be used for this research only and five years after the research results have been published your personal information will be destroyed. The information you provide use with will be use to determine gaps in mental health literacy and to identify current and alternative sources or programs that can be used to increase patient's knowledge about their mood disorders. Understanding what you know

about your mood disorder and where you get your knowledge from can help you to become more aware about your mood disorder and can improve the hospital's methods of educating patient's with mood disorders in the future. Out of the information you give, the researcher can notice gaps and make recommendations of new ways to educate patients. The research results will be distributed by means of a presentation to the health practitioners of the selected hospital. You can indicate on your demographic questionnaire if you would prefer the results via e-mail/post after the research is complete. Even though you have been discharged from the facility, you can still ask to receive feedback and recommendations of the results. The researcher will complete the mini-dissertation according to article format and plan to submit the manuscript for publication.

**Will you be paid to take part in this research and are there any costs involved?**

No, you will not be paid to take part in the research. The researcher will see you in the hospital and there are no costs involved for you, but you will be taking part in this research during your "resting" time during visiting hours or over a weekend.

**Is there anything else that you should know or do?**

- Enquiries to the researcher: Celente French at 064 864 3720, Supervisor Prof P Bester at 082 298 3567, or co-supervisor Ms A Marx at 082 938 8703.
- You can contact the Health Research Ethics Committee via Mrs Carolien van Zyl at 018 299 2089; carolien.vanzyl@nwu.ac.za if you have any concerns or complaints that have not been adequately addressed by the researcher.
- Participants will receive a copy of this information and consent form for your own records.

**How will you know about the findings?**

On the demographic assessment form you will be asked to complete a section that asks if you would like to receive feedback regarding the research or not. Should you wish to receive feedback you will there be provided with a space to enter your details of the method you prefer, after the research has been completed. This means that even after discharge, you can still expect feedback if requested on demographic data sheet; the researcher can also be contacted for feedback arrangements in case of late requests after being discharged from the hospital.

**Declaration by participant**

By signing below, I ……..……. agree to take part in a research entitled: Mental *health literacy and information sources of mental healthcare users with mood disorders.*

**I declare that:**

- I have read this information and consent form and it is written in a language with which I am fluent and comfortable and able to communicate in.
- I have had a chance to ask questions and all my questions have been adequately answered (at least 24hours before giving consent and within one week before the interview is conducted, depending on dates scheduled with me).
- I understand that taking part in this research is **voluntary** and I have not been pressurised to take part, taking part is my own decision.
- I may choose to leave the research at any time and will not be penalised or prejudiced (discriminated or ill-treated) in any way,
- I may be asked to leave the research before it has finished, if the researcher feels it is in my best interests, or if I do not follow the research plan, as agreed to.

Signed at (place) .....…..…….. on (date) ……...…….. 2016

**.....** **.....**

Signature of participant Signature of witness

**Declaration by Registered Nurse obtaining consent**

I (name) ……..…… declare that:

- I explained the information in this document to ……..,
- I encouraged him/her to ask questions and took adequate time to answer them,
- I am satisfied that he/she adequately understands all aspects of the research, as discussed above,
- I did/did not use an interpreter.

- 

Signed at (place) .....…..…….. on (date) ……...…….. 2016

**.....** **.....**

Signature of Registered Nurse Signature of witness

**Declaration by the Researcher**

I (name) ……..…… declare that:

- I explained the information in this document to ……..,
- I encouraged him/her to ask questions and took adequate time to answer them,
- I am satisfied that he/she adequately understands all aspects of the research, as discussed above,
- I did/did not use an interpreter.

Signed at (place) .....…..…….. on (date) ……...…….. 2016

**.....** **.....**

Signature of Researcher Signature of witness

## ANNEXURE H: DEMOGRAPHIC DATA COLLECTION

Please tick the appropriate information:

**Demographic data:**

**Gender:**

| | |
|---|---|
| Male | Female |

| |
|---|
| Age: _____ |

**First Language:**

| | | | |
|---|---|---|---|
| English | Afrikaans | Setswana | Xhosa |

| |
|---|
| Other: please specify: _____ |

**Highest level of education:**

| | | | | |
|---|---|---|---|---|
| Grade 7 | Grade 12 | Diploma | Degree | Post- |

| |
|---|
| Other: please specify: _____ |

Would you like to receive feedback on the results of this research even after being discharged?

| | |
|---|---|
| Yes | No |

If yes, what is your preferred method of feedback? E-mail/post. Please provide details

_____

_____

_____

Participant code:

## ANNEXURE I: MAIN SOURCES OF INFORMATION CHECK LIST

As a mental healthcare user, what are the main sources you and your family utilize in order to obtain information related to mental health and your mental health condition? Please tick the appropriate boxes and specify when necessary.

| **Source** | **X (tick)** | **Please specify** |
|---|---|---|
| Magazines | | |
| Television programs | | |
| Internet | | |
| Newspapers | | |
| Academic journals | | |
| Brochures in consultation rooms | | |
| Psychiatrist | | |
| Psychologist | | |
| Other healthcare personnel | | |
| Books / self-help books | | |
| E-books | | |
| Seminars | | |
| Medication inserts | | |
| Pharmacist | | |
| Knowledgeable friends or family | | |
| Partner / Spouse | | |
| Radio | | |
| Other (Please specify) | | |

# ANNEXURE J: FIELD NOTES

**Field notes Participant 1**

**Descriptive notes**

The interview is conducted in a private office in the back-wing of the facility. The door was closed throughout the interview and an aircon maintains a cool temperature in the room with good ventilation. The unit is very busy and crowded due to full wards, the participant has been admitted for 2 weeks and is being discharged during next week.

**Personal notes**

Upon arrival to the unit the participant is fully prepared for the interview and she is aware of expectations of participating in the research. Due to being this being her first time to take part in any research she appears slightly anxious. Physically the participant appears poorly groomed and quite unkempt.

**Methodological notes**

She is anxious in the beginning of the interview but relaxes after the first few minutes and begins to interact more comfortably. Although she generally seems withdrawn and shy she becomes more open and interested in the research questions as it progresses further.

**Theoretical notes**

The participant's main focus is that she generally never knew that she had a mood disorder till she was admitted. She was also never interested in learning more about mood disorders and even after becoming aware of mood disorders in hospital, she feels that the knowledge she obtained from professionals is adequate. She shows little interest in exploring more options of gathering information as she feels that she knows what her diagnosis is and that is enough, she also has a view of taking her tablets because they are prescribed. She is however able to recall some of the indications and names of her medication. During the interview the participant becomes aware of her prior disinterest and discussing the topic of mood disorders and information sources has made her more open to think about different types of information sources that she could utilise post-discharge

**Field notes Participant 2**

**Descriptive notes**

The unit is extremely busy and the participant forgot about our scheduled appointment for the interview. At the time I arrived she had visitors with her and I waited for them to leave as they came

from far. The interview started 30 minutes later than scheduled and thus in order to prevent the interview from interrupting the participant's ward routine it had to be done in a rather limited space of time. My initial suggestion was to reschedule but she requested that we continue because she is being discharged tomorrow.

**Personal notes**

She initially apologises repeatedly for forgetting and seems anxious. As the interview formally begins, she becomes more calm and focused. The physical appearance of the patient is tremendously neat, it is clear that she is very perfectionistic about her grooming and concerned about her physical appearance. Initially the participant seemed anxious but later starts to become more comfortable and her responses to questions become more broadened.

**Methodological notes**

Full ward, visiting hours and participant forgetting about the interview posed challenges and interview had to start 30 minutes later than planned. To avoid interrupting the ward routine, the interview had to be completed in a short space of time.

**Theoretical** notes

Initially the participant said that she was always aware of mood disorders but she never truly thought that she would find herself in the situation of being the person to be diagnosed. The main focus of her answers lead towards the negative influence that a poorly-literate spouse has and how her spouse makes a "joke" of her diagnosis as a way of "supporting her". Although this participant's school literacy is only grade 8, she shows interest and she is actively involved in utilising electronic and professional sources available to her to learn more about her mood disorders.

**Field notes Participant 3**

**Descriptive notes**

Interview telephonically confirmed and venue arranged, upon arrival the office was readily available. Privacy was ensured, the room was cool and well lighted. Hospital was more quiet than usual and thus no distractions during the interview. Participant seems very down, makes little eye contact, talks quietly.

**Personal notes**

Professional nurse at a general hospital, living with depression and bipolar mood disorder for so long that she does not see any reason why she should have more knowledge of it. She feels that she is drinking her medication and that makes her fine, no other attempts of enhancing self-management. Severely overweight and that tells me that she is not watching what she is eating she is not exercising. Breadwinner with chronically ill husband and son, that has made her very neglectful towards herself. And definitely her circumstances play a very strong role here. She is working all the time, they are struggling financially, things are going very difficult but she is completely unmotivated and in denial towards all these symptoms.

**Methodological notes**

Challenging participant who has short, abrupt answers that are superficial. Additional probing was implemented in order to increase richer descriptions.

**Theoretical notes**

Mental health literacy does not necessarily enhance self-care, motivation and adherence. In the participant's view it is adequate for her to take her medication, she sees no reason why she has to do anything additional in order to manage her condition – poorly groomed, overweight, not eating healthy, no exercise. The participant is the breadwinner of her household, living with a chronically ill husband and son – yet she receives emotional support from them. Frequent readmission. Condition affected by financial and social stressors.

**Field notes Participant 4**

**Descriptive notes**

The day prior to interview the ward and patient were telephonically contacted to confirm interview. The interview took place in a consultation room that was quite close to other patient's and visitors, thus there was often a sound disturbance.

**Personal notes**

The participant is a registered nurse, she is very talkative and enjoys the interview. Although she had background knowledge of mental health, she denied symptoms within herself and was initially too scared to seek help due to fear of judgement. Participant makes jokes and laughs during the interview. Notes a gap in the way that information is conveyed, says mental health is neglected and Alzheimer and dementia is more "out there".

**Methodological notes**

At one point the interview was interrupted by an unexpected visitor, this distracted the participant briefly.

**Theoretical notes**

Although the participant has background knowledge of mental health and she is able to assist others, she denies symptoms within herself. Mental health is a neglected disease and should be put "out there" like cancer awareness campaigns. Stigma can take place in areas where you would generally seek support such as in the Church. Stigma is associated with judgment.

**Field notes Participant 5**

**Descriptive notes**

Today is a relatively calm day at the hospital. The participant took part in the groups until 1:00pm. The interview started at 3:30pm. The participant displays understanding about the research. The MCAT assessment was done beforehand. The interview took place in a pre-booked office.

**Personal notes**

The participant seems to feel that his knowledge about his health and condition is adequate now that he has learnt more about mood disorders and it's management from her psychologist and during group sessions.

**Methodological notes**

Hospitalisation has increased the knowledge of the participant to an extent where he feels that he does not need to seek for more information. The knowledge obtained from professionals is reliable and up to date, yet little insight is noted.

**Theoretical notes**

Prior to admission and even currently the participant still sees no need to learn more, he has little insight about the true causes and management of the mood disorder and is lead by his own belief that mood disorders are due to poor blood circulation to the brain. Black male participant who has no formal education, low scholastic literacy.

**Field notes Participant 6**

**Descriptive notes**

The interview took place at 7:00pm in a locked office with minimal distractions and good lighting. The hospital is currently full with two wards. The patient is currently lying in a room with two other males who get along very well with him and it seems that he has actually contributed towards their knowledge because he seems to take part a lot in teaching them things that is related to his work.

**Personal notes**

The participant is very open-minded about mental health. He talks about including the community, including individuals and the government, policies and so forth. This is because the participant is a professional individual. He works with people who also are illiterate and he faces the same challenges with them in his daily life at work.

**Methodological notes**

He did the pre-interview, the MacCAT score showed that the patient has five out of seven and he is able to give consent to take part in this research. At a stage, he did want to talk about his private reasons for being admitted and we moved away from that into the health literacy area and how it contributes to his disorder. The participant has diabetes, cholesterol and hypertension

**Theoretical notes**

The participant is of the opinion that certain communities, illiteracy, poverty and culture could influence mental health literacy. Individuals in rural communities have less access to technology and are generally more illiterate and thus they are left untreated. Participant knows his chronic treatment but he cannot relate the same to the mental health treatment and this is because the patient has only been on this treatment for about two weeks. He only became aware that he does not know his medication today when we spoke about it. Academically, he is very literate and he shows a lot of motivation and enthusiasm towards measures of enhancing the health of South Africans.

**Field notes Participant 7**

**Descriptive notes**

Interview took place at 7:00pm during resting time. Medication rounds are only at 8:00pm. The participant will be discharged from hospital tomorrow. The interview took place in a closed office

where privacy was created. There were no interruptions except for the traffic passing by the windows, but it did not influence the participant's concentration or contribution to the interview.

**Personal notes**

The participant was admitted to a psychiatric facility after being in and out of hospitals on multiple occasions with multiple causes. He chronically feels ill, tired and weak. During the interview the participant explained that the only reason why he agreed to be admitted is because of his wife who supports him and wants him to get better, his wife. On various previous occasions the participant was misdiagnosed by practitioners and he initially felt that this is just "another admission". he participant has felt sick and tired for a long time, yet even after being in and out of hospital no-one ever could determine the cause. Now that he is admitted and receiving psychiatric treatment his mood as well as his physical health has started to improve.

**Methodological notes**

The participant was mainly focused on and distracted by chronic symptoms and misdiagnosis rather than mental health and mental health literacy related questions. He has to be guided back to the research topic.

**Theoretical notes**

The influence of support from a spouse stands out in this interview. Being misdiagnosed decreased the participant's motivation and interest and contributed towards isolation, decreased self-care and family conflict.

**Field notes Participant 8**
**Descriptive notes**

On my arrival to the unit the participant was already waiting for me, sitting with notes in his hand. Interview conducted in a private pre-arranged office in the back-wing of the facility. No interruptions during interview.

**Personal notes**

The participant prepared for the interview and made notes in order to remember everything that he wants to say. Being a single dad places additional stress on him and he feels that he needs to be

driven by his kids and that he needs to set an example, he may not lose his temper and act inappropriately because that makes him a poor example for his children.

**Methodological notes**

The expected role that males play in the family, in society and in the workplace makes it hard for a male individual to accept that something is wrong and that he needs help. The participant pressures himself to strengthen his spiritual relationship with God as a way to help him cope with his mood disorder.

**Theoretical notes**

It is more difficult for a male to seek help for mental health and it is even more difficult for males to admit they have a problem. Being the breadwinner and the leader of the house creates the expectation that you must always be able to deal with anything. Being in hospital teaches you a variety of coping mechanisms.

**Field notes Participant 9**
**Descriptive notes**

The interview was also conducted within the hospital setting, in a closed office. There were no distractions while the interview was performed. And she really contributed well and did not feel at all threatened or affected negatively by the research interview.

**Personal notes**

The participant was very excited to participate and she was cooperative during the interview. It seems like she really tried to show that she does have knowledge and insight regarding the psychiatric condition but if you think about the fact that she is working within a psychiatric environment, she is exposed to symptoms often and knows exactly what they entail.

**Methodological notes**

Information can be obtained via computer or with the internet or whatever so she usually uses a lot of old sources, original booklets, brochures, and document that are left in the ward where she works. In service training has taught her a lot of what she knows about mental disorders.

**Theoretical notes**

Nurse in a psychiatric environment works with mental health on a daily basis, yet failed to notice symptoms in herself – this could be denial. The fact that she tried to still do her best at work, still do the best for her family, she completely had self-denial towards her own condition and her own progress. Help-seeking from fellow employees at work.

**Field notes Participant 10**

**Descriptive notes**

The interview is conducted in a pre-arranged private office with an aircon, generally there is a very calm atmosphere and the participant tries to the best of her ability to say as much as possible in response to the interview questions. The interview was very comfortable and the participant was very open and honest in raising her views. She is a coloured individual and is thus given a choice of language preference, she speaks Afrikaans fluently and thus the interview continues in Afrikaans. After confirming the MacCAT-CR the interview is conducted and no interruptions occurred during interviews.

**Personal notes**

The interview provided new insights towards another culture, not African, not white, but a rather "mixed" perspective. Generally the participant had very good insight and help-seeking began within the workplace where fellow employees were asked for help , possibly be due to poor family support. Breadwinner in the family and is generally the one that everyone turns to. initially in denial prior to admission.

**Methodological notes**

The participant is a nursing assistant in a psychiatric hospital, she knows how to recognise symptoms in others and how to help others but had difficulty in detecting and managing symptoms in herself. A strong sense of denial came through during this interview. The participant is coloured, yet she is aware of the African beliefs and traditions associated with mental illness as she has been exposed to such practices within her community.

**Theoretical notes**

Culture influences mental health literacy and cultural beliefs play a role in treatment seeking and attitudes towards mental healthcare users.

**Field notes Participant 11**

**Descriptive notes**

The interview was confirmed with the participant and unit telephonically a day in advance and upon my arrival to the unit the participant was excitedly waiting. The office that I have arranged for the interview was unfortunately occupied by a clinical psychologist and thus there was no longer an office available for us to work in, the participant suggested that we continue with the interview in his hospital room. The interview was conducted in a single room with good lighting and ventilation, the patient sat comfortably on his bed and I sat on a chair across him. Admitted for three weeks today.

**Personal notes**

The participant was very prepared and excited to talk about his ideas of “getting knowledge out there”. He is a well-known businessman in the community and he plays a vital role within the company he works for, he is wise and his ideas and opinions are realistic and logic. I really enjoyed this interview because it was a learning opportunity for me to sit and hear from an African man of such stature how strong the influence of culture can truly be. Beforehand, he was also in a lot of denial. He never recognised the symptoms of his condition and it seems that he is kind of blaming his culture for it. Saying that his culture has made him to not believe that there is something as depression or as bipolar mood disorder. And that also seems to me like he was inn self-denial but he came towards insight while he was at the hospital. He clearly says that he was never interested in reading up about mental health or learning anything about it because he did not think it was a problem. What he has learnt in the hospital, he really found valuable and he has made a lot of progress in terms of how he is going to go out there and help other people because he feels that there is a lot of people within his culture, who are illiterate in terms of mental health literacy.

**Methodological notes**

The competency assessment scale assessment is performed prior to starting the interview and first the participant starts a conversation on how interesting he finds this assessment tool and how he appreciates my “integrity” to “protect” people from participating in something that they do not fully understand.

**Theoretical notes**

This interview was very insightful as the participant speaks directly from a male, African, higher class businessman perspective. Yet he does not forget his roots and still talks about the culture that he grew up in, how mental illness is being stigmatised against. It makes me think of the term “mass denial”, how a certain culture altogether reject the unknown. And he feels a lot of neglect towards himself because he realises that he lead this condition to happen to him. It seems that the depression, he is kind of blaming himself for the depression, because he never noticed what was

going on and he never listened to his body when he saw the symptoms. He never went to seek help.

**Field notes Participant 12**

**Descriptive notes**

At the time of the interview no offices were available and it was visiting hours, thus the unit was very busy. The interview was conducted outside in a garden patio where we sat comfortably away from all the noise and people inside the facility. The participant was relieved to get away from all the visitors inside the facility as it was too overwhelming for her. She was comfortable and shared her views freely with little need for probing questions.

**Personal notes**

The participant is a registered nurse, she learnt about psychiatry in her second year and has built on that knowledge since diagnosis. Her has made her knowledgeable and she feels that there is not much more that she can learn as she has lived with bipolar mood disorder for a long time and she has been admitted more than once. Poor family support, disinterest, lack of understanding and “mocking” comments.

**Methodological notes**

Poor family support and talking about the onset of the mood disorder was a challenging topic for the participant, she became uncomfortable while talking about this. As the interview progressed she regained confidence and continued comfortably.

**Theoretical notes**

Knowledge could in some cases be negative because knowing more about her mood disorder creates feelings of guilt. The lack of family support encouraged support seeking from other sources: pastor, psychologist and friends. Informed about medication and the need to manage mood disorder and decrease destructive behaviour through therapy. Formal education, long term diagnosis and readmission contribute towards the knowledge of the participant to an extent where she feels “saturated”. She refers to formal terminology and formal names of medication.

## ANNEXURE K: PARTIAL EXERPT FROM A TRANSCRIPT

| | |
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| Participant | (Silence)… It… I think it is one of the easiest communication resources and a lot of people, they can get to those resources, because sometimes the Internet, people do not have money to use it. A brochure, you can just pick it up from the library. Even newspapers, they are available in libraries. And magazines, you can go to any shop and in a magazine or book, you can just open it without buying it. You understand, so it will be easier for people to reach that information. It is the accessible part, you know I don't… I am… I am a black person. You know black people, they really don't believe that the mood…depression. It is a sign of weakness to them. So, they don't have information of that. And I realised when I came here that a lot of my people or should I say Africans, they… they are really sick, they don't even know that. They think they are just normal but they don't even know. Even now, I am here, they don't think that I should be here. But I know the benefits of being here. |
| Researcher | It's a very interesting thing you are saying. You went away from the sources and you went into your culture. (Participant: yes) Could you be more specific and explain to me what exactly causes your culture to be like that? Why do you believe that? |
| Participant | OK. My culture (silence) … they don't believe in such things namely because they don't think – they read depression – they don't think there is that. Like if you are stressful and you avoid them. For them there is nothing wrong with you, you are just this child who is disrespectful to them and all that. You understand? There is a lot of oppression, especially to us when you are young because you cannot talk back to your elders; you cannot say "No". You must really, really pick your words very carefully because you will get a hiding. Not just a hiding with a "sambok" or something or a cane, like physical, you will say it is abuse, but we are already used to that. To that beating. So the other thing is (silence) … being weak is… being sick or … is a sign of weakness of you will be… people will be saying you are crazy or something. So even if people know there is something wrong, they are afraid to say something. (Researcher: Because of what the others might think? How does that influence you?) You know, I am… I am a very smart guy. I really… I am, am open minded and I don't really, I don't really care what people say. I mean, you understand, so. Even my parents, when they came here, they were like: "OK, you are in a holiday." So there is this other institution. When you mention this institution, you mention |

| | |
|---|---|
| | like you … he is out of his mind, he is really crazy. You understand? Not understanding that the institution has got a department also. It is not only for crazy people. It has got departments like this one. It is a lot like this one. So, that is what we experience. We grow up under these rules and we are not normal but we get used to it, until they get normal. |
| Researcher | The fact that your culture has such a big influence on how you actually… did that influence why you never thought that you had a problem? |
| Participant | Yes, even if I had a problem, I wouldn't ask for help. I wouldn't ask for help from my parents or my family, because I already know them. You understand? I already know them. (Researcher: So, if you feel you really need help?) That is when I go to the internet and … because it is personal…and not even that, they don't even believe the Internet. (Researcher: your family?) No, my culture. They don't even believe the Internet. |
| Researcher | So then, what do they believe is the cause of psychiatric conditions? You say they don't believe in depression and so, but what do you think is the cause of other psychiatric conditions? |
| Participant | OK. You are bewitched. Number one. Or you were born like that. That is the only thing. (Silence)… If you are like that, you were born like that or you are bewitched. |
| Researcher | So what do they do then, usually? |
| Participant | I guess there are some ceremonies that they do and you can get help from that, but I don't think that it's a long term … a long term solution, but I know they can cure epilepsy. I know they can cure if your nose is bleeding and if it's non-stop. You understand that? I know the other traditional medicals that we use that are very effective. Ja. They are very effective. Somehow they cure and the hospital cannot cure them. And they cure them. |
| Researcher | If you think about what you know about your mood disorder now, where have you learnt everything that you know? |
| Participant | I did not have any kind of knowledge. So... Everything that I know today, I had to learn here at the hospital. |

## ANNEXURE L: EDITORS LETTER

Blinded for confidentiality

Potchefstroom
North West
South Africa
16/08/2017

Blinded for confidentiality

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To whom it may concern

My name is Phillip Marange. I am a PhD student under AUTHeR (African Unit for Transidisciplinary Health Research) at the North-West University (Potchefstroom Campus). I assisted Celente French with scientific writing and reference editing her dissertation: **Mental health literacy and information sources of hospitalised mental healthcare users with mood disorders**. Regarding the afore mentioned aspects that I worked on; I recommend that she can now submit his work for marking.

Yours sincerely,

Phillip Marange

Signature