The relationship between patient, carer and staff perceptions of need in an assertive community treatment team in South Africa

By

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Declaration

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ABSTRACT

Background

The assessment of a patient's individual needs offers many benefits and it is essential for planning and implementing services and interventions. Need is a subjective concept and may be defined from several perspectives. Patient, carer and staff interests may differ, influencing their perspectives in defining needs. Traditionally, the staff perspective on needs has taken priority but the steady growth of the 'user movement' and 'recovery philosophy' has led to this being challenged.

This study aimed to establish patient, carer and staff perceptions of patient need, the extent to which these perceptions were homo- or heterogeneous, and what factors were associated with local perceived needs.

Methods

The study was informed by a systematic review of the literature focused on the individual needs of people with severe mental illness assessed from multiple perspectives. Patients, carers and staff on the Valkenberg Hospital assertive community treatment (ACT) service were assessed using the Camberwell Assessment of Need Short Appraisal Schedule to evaluate needs. Patient global functioning and current levels of psychopathological symptoms were assessed using the Global Assessment of Functioning scale and the Positive and Negative Syndrome Scale respectively. Kappa statistics were computed to assess agreement in the participants' perspectives.

Results

Seventy-three (73%) patients and 68 carers (97%) participated. The numbers of needs expressed by the participants in the study were in keeping with those expressed in high- and middle-income countries serviced by integrated and continuous systems of mental health care. Patients identified a mean of 4.9 needs, of which more were met (2.9) than unmet (2.0). The needs identified by patients were varied and encompassed multiple domains.

Patients identified more unmet needs in the psychosocial than the biomedical domains. There were no significant differences in the numbers of needs expressed by patients and carers. Staff identified significantly more total and met needs than both patients and carers. The three groups differed as to the domains of needs identified. There were discrepancies in the domains of 'information', 'benefits', 'intimate relationships', and 'sexual expression', which staff considered to be problems of lesser importance whilst patients identified these as serious need domains. The overall agreement on the presence of a need was poor to fair and there was no substantial or almost perfect agreement for any of the domains. Higher levels of dysfunction and psychopathological symptoms were found to be related to higher patient-rated needs. Patients living on their own, away from family, expressed fewer needs.

Conclusion

The study findings support the calls for adopting recovery-orientated practices within local mental health services. The needs expressed by patients are consistent with the principle of personhood and the domains identified can be framed using a dimensional model of recovery. The finding of a lack of consensus on the presence of a need emphasises the importance of using a multi-perspective paradigm and triangulating the different perspectives when determining needs. It suggests that person-centred care should be embraced, with needs and recovery defined by the individual patient and family, clinicians, and the wider community providing supports to the process.

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LIST OF ABBREVIATIONS

ACT	Assertive Community Treatment
CAN	Camberwell Assessment of Need
CAN C	Camberwell Assessment of Need clinical version
CAN M	Camberwell Assessment of Need mothers version
CAN R	Camberwell Assessment of Need research version
CANSAS	Camberwell Assessment of Need Short Appraisal Schedule
CSQ	Client Satisfaction Questionnaire
BANP	Bangor Assessment of Need Profile
BASIS-32	Behaviour and Symptom Identification Scale
CGI	Clinical Global Impression rating scale
DAS	Disability Assessment Schedule
DAQ	Dysfunctional Analysis Questionnaire
EM	Engagement Measure
GAF	Global Assessment of Functioning Scale
HoNOS	Health of the Nation Outcome Scales
IEQ	Involvement Evaluation Questionnaire
LQOLP	Lancashire Quality of Life Profile
MANSA	Manchester Short Assessment of Quality of Life Scale
NFCAS	Needs for Care Assessment
PANSS	Positive and Negative Syndrome Scale
PPASQ	Problems Perception and Adaptation Strategies Questionnaire
SANS	Scale of Assessment of Negative Symptoms
SAPS	Scale of Assessment of Positive Symptoms
SLDS	Satisfaction with Life Domain Scale
VSSS	Verona Service Satisfaction Scale
WHOQOL-100:	100 item World Health Organisation Quality of Life instrument

CHAPTER 1 INTRODUCTION

This chapter sets out the reasons for conducting this study and introduces key concepts in mental health need.

1.1 Motivation for study

South Africa has a high burden of psychiatric illness and its mental health care system is under resourced (Lund et al., 2012). Post apartheid, the planning of local mental health services has shifted conceptually towards community-based care (Department of Health, 1997; Department of Health, 2004); resource allocation, however, has not sufficiently followed policy directives, with available resources largely still residing within psychiatric hospitals (WHO, 2007). While the country has made strides in integrating mental health services into formal primary health care services, there remains a paucity of residential and day care services (Lund & Flisher, 2009; Petersen & Lund, 2011).

This lack of adequate community resources, in combination with the prevailing poor socio-economic circumstances, has contributed to a substantial increase in the so-called 'revolving door' phenomenon in state psychiatric facilities (Botha et al., 2008). Individuals are frequently admitted to psychiatric hospitals and remain well in the community for only short periods of time. In the Western Cape, the assertive community treatment (ACT) model of care has demonstrated success in addressing this phenomenon (Botha et al., 2010; Botha et al., 2014). ACT is a recognised evidence-based practice, the core features of which include small caseloads, crisis support, whole team approach, monitoring of medication, individualised care, majority of care at home, regular meetings and no discharge policy (Bond et al., 2001). Whilst the ACT service has been successful in engaging patients[1] with severe mental illness, reducing hospitalisation and increasing time spent in the community, it has proven to have less impact on social functioning (Smith & Newton, 2007; Burns, 2010).

Assessment of needs is an essential input and basis for planning services, and for planning and implementation of interventions for the individual patient (Hansson et al., 2003). Basing the care provided for individual patients on an assessment of their needs offers many benefits. These may include: improving the comprehensiveness of case formulations and care plans by integrating a broad range of health determinants; supporting clinician-patient discussions about care priorities, which is associated with improved treatment satisfaction and adherence to treatment; giving guidance about which part of the mental health system should treat the patient; and identifying the contribution of services outside the mental health sector (Slade et al., 2011; Lasalvia et al., 2005).

Need is a subjective concept and needs may be defined from several perspectives: *felt needs* as experienced by the patient; *expressed needs* as experienced and communicated by the patient; *normative needs* as judged by professionals; and *comparative needs* based on comparisons with some reference group (Brewin, 1993; Slade, 1994). Patients, their relatives, and mental health professionals may prioritise and relate to different sources of information in defining a need (Macpherson et al., 2008; Foldemo et al., 2004).

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[1] The term 'patients' in this study is used to describe the recipients of mental health services in preference to the term 'mental health care user' that was introduced in South Africa's Mental Health Care Act, 17 of 2002. In the Act, a mental health care user is defined as 'a person receiving care, treatment and rehabilitation services or using a health service at a health establishment aimed at enhancing the mental health status of a user, a state patient or mentally ill-prisoner…' The Act also includes prospective 'users', users' next of kin, persons authorised by law to act on behalf of users, administrators appointed in terms of the Act, and an executor of a deceased user's estate. In this study, 'patients' refer to the direct recipients of mental health services rather than 'mental health care users' to differentiate the direct recipients of care from the indirect recipients of care such as family or other supports who under the Act, could also be deemed 'mental health care users'.

The patient's view of need may be influenced by specific factors in a socio-cultural context, education and past experiences; whereas the professional's view may be influenced by professional values, cultural factors, ethics and personal values (Hansson et al., 2003).

Historically, differences in patient and staff perspectives on needs were acknowledged and recorded but supremacy was still given to the staff perspective (Hansen et al., 2002). However, the steady growth of the 'user movement' and the 'recovery philosophy' emphasising personal recovery has resulted in the prioritisation of staff perspectives on needs being increasingly challenged (Farkas, 2007; Parker, 2012). Many in the user movement advocate for a shift to a 'partnership model' between health professionals and patients; this model is based on mutual respect for each other's skills and competencies and recognition of the advantage of combining these resources to achieve beneficial outcomes (Tritter, 2009; Wallcraft et al., 2011; Lasalvia et al., 2012).

Backed by scientific evidence supporting optimism about outcome from serious mental illness (Warner, 2010; Hooper et al., 2007), mental health policies internationally are placing an emphasis on services that support personal recovery (Slade at al., 2008). Personal recovery differs from clinical recovery which is traditionally understood to mean an 'absence of disease or, cure' (Torgalsbøen, 2005). In clinical recovery, professionals diagnose and treat with the aim of curing or reducing symptoms. Personal recovery has been described as 'a deeply personal, unique process of changing one's attitudes, values, feelings, goals, skills and/or roles. It is a way of living a satisfying, hopeful and contributing life even with limitations caused by illness. It involves the development of new meaning and purpose in one's life as one grows beyond the catastrophic effects of mental illness' (Anthony, 1993). In personal recovery, there is an emphasis on life goals; collaboration between providers, patients, and their families; patient choice; diverse treatment options; and individually tailored services (Kidd et al., 2010; Slade et al., 2012; Slade et al., 2014).

In the context of limited mental health resources, increased engagement with patients in the community, and a mental health service striving to become recovery orientated, it is important to unpack the needs of Valkenberg Hospital ACT team patients. Using a multiple-perspective paradigm and triangulating the perspectives of patient, carer and ACT staff may deepen the understanding of the patient's needs, and thereby offering the opportunity to produce a more balanced and recovery-orientated care plan (Rose et al., 2006).

1.2 Aim

The aim of this study is to investigate the relationship among patient, carer and staff perceptions of patient needs in those treated by the Valkenberg Hospital ACT team.

1.3 Objectives

- To determine patient, carer and staff perceptions of patient needs.
- To measure the homogeneity and heterogeneity of patient, carer and staff perceptions of patient needs.
- To determine which socio-demographic and clinical factors are associated with needs in a South African setting.

CHAPTER 2 LITERATURE REVIEW

2.1 Introduction

This chapter presents a systematic review of the individual needs of people with severe mental illness. The review aims to summarise the studies to date that focus on the needs of people with severe mental illness from multiple perspectives. There will be an elucidation of the settings in which these studies were conducted, the particular focus of the studies, the needs assessment instruments and other tools commonly used, together with the methods of analysis commonly employed. The review will report on the needs rated by each group and will comment on whether these needs differ, highlight any clinical and sociodemographic factors associated with these expressed needs, and identify where research is lacking in this area of investigation. The findings of the review will inform the conduct of the new study looking at the relationship between patient, carer and staff perceptions of need in an ACT team in South Africa.

2.2 Scope and methodology of literature review

2.2.1 Search strategy

The review of this topic was conducted using two approaches:

- A key word search of the PubMed, Scopus, Google Scholar and selected EBSCOhost databases. The selected EBSCOhost data bases included Academic Search Premier, Africa Wide, CINAHL, PsycARTICLES, PsycINFO and SocINDEX. The databases were selected after consultation with two experienced librarians at the University of Cape Town Faculty of Health Sciences library. The search was restricted to articles published in English and the key words used were combinations of 'mental health needs', 'assessment of need', 'severe mental illness', and 'assertive community treatment'.

- A hand search of the reference lists of these publications for further relevant articles.

2.2.2 Inclusion criteria

The following were used as inclusion criteria during the search:

1 Quantitative studies published from 1993 to March 2015 – this period covered post-apartheid South Africa.

2 Studies published in peer-reviewed journals.

3 Studies focusing on the assessment of needs.

4 Studies assessing needs from more than one perspective (i.e. patient and staff; patient and carer; staff and carer; patient, staff and carer).

5 Studies using an established needs assessment instrument.

6 A study population describing patients diagnosed with a serious mental illness, predominantly a psychotic illness.

2.2.3 Exclusion criteria

The following were used as exclusion criteria during the search:

1 Studies based on samples solely with children, adolescents, the elderly, those with intellectual disability, a forensic population, or a military population.

2 Studies with a focus on substance misuse, disasters, migrants and refugees.

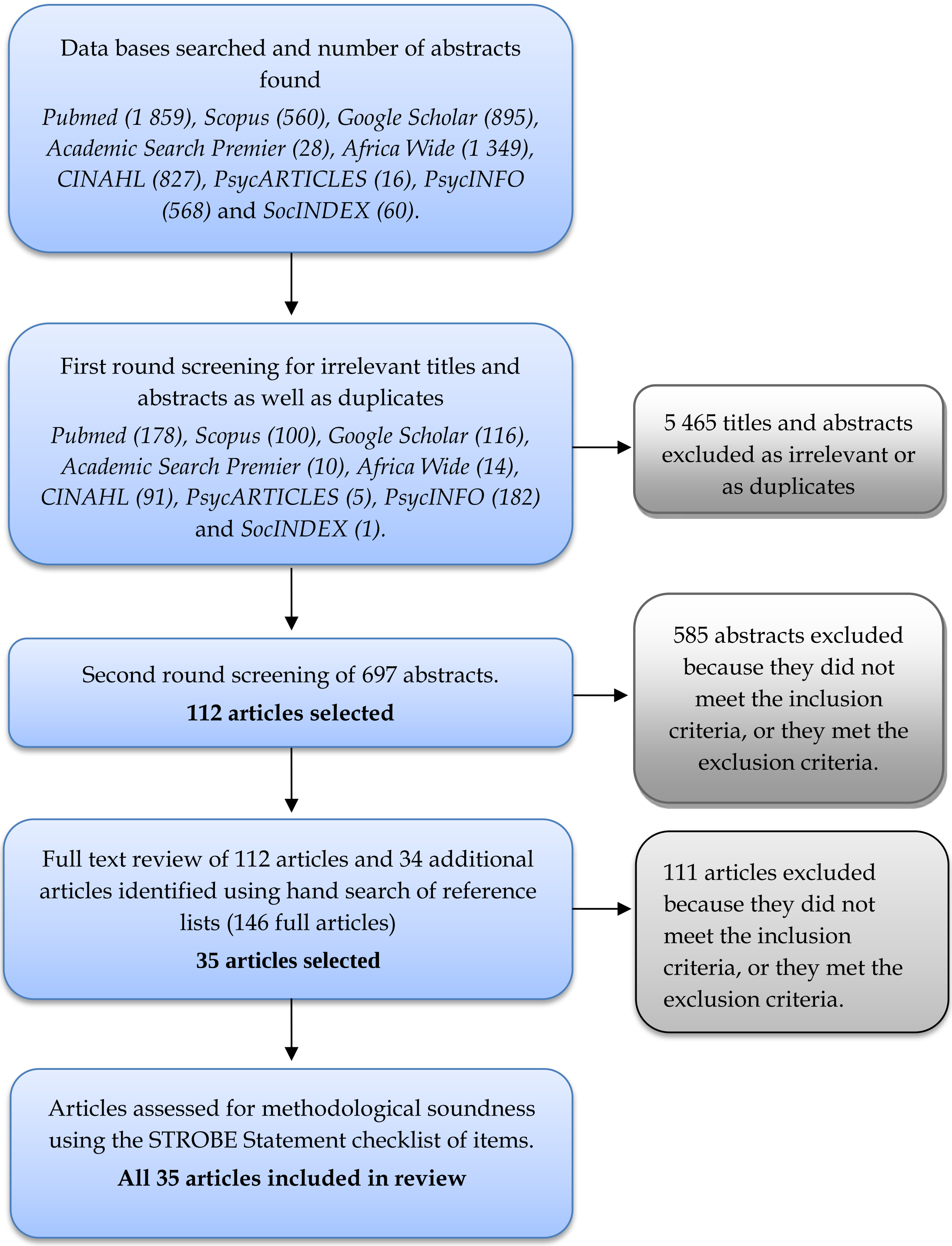
2.2.4 Identification of studies

As depicted in Figure 1 below, 6 162 publications were initially identified from the selected databases. After a screening of the titles and abstracts, the number of publications was narrowed to 112 potentially relevant publications. A further 34 potentially relevant publications were identified using the hand search. Following a review of the 146 full publications, 35 were found that met the set criteria.

2.2.5 Assessment of quality of studies

The 35 publications meeting the set criteria were assessed for methodological soundness using the Strengthening the Reporting of Observational Studies in Epidemiology (STROBE) Statement checklist of items as a guide (Von Elm et al., 2007). The STROBE statement is a checklist of 22 items considered essential for good reporting of observational studies. These items relate to an article's title and abstract, the introduction, methods, results and discussion sections, and other information. All 35 studies were deemed methodologically sound and are included in the literature review.

A flowchart of the selection process is included below as Figure 1 and summaries of the included studies are presented in Tables 1 to 4.



Data bases searched and number of abstracts found

Pubmed (1 859), Scopus (560), Google Scholar (895), Academic Search Premier (28), Africa Wide (1 349), CINAHL (827), PsycARTICLES (16), PsycINFO (568) and *SocINDEX (60).*

First round screening for irrelevant titles and abstracts as well as duplicates

Pubmed (178), Scopus (100), Google Scholar (116), Academic Search Premier (10), Africa Wide (14), CINAHL (91), PsycARTICLES (5), PsycINFO (182) and *SocINDEX (1).*

5 465 titles and abstracts excluded as irrelevant or as duplicates

Second round screening of 697 abstracts.

112 articles selected

585 abstracts excluded because they did not meet the inclusion criteria, or they met the exclusion criteria.

Full text review of 112 articles and 34 additional articles identified using hand search of reference lists (146 full articles)

35 articles selected

111 articles excluded because they did not meet the inclusion criteria, or they met the exclusion criteria.

Articles assessed for methodological soundness using the STROBE Statement checklist of items.

All 35 articles included in review

Figure 1: Selection process for inclusion of studies

2.3 Results of literature review

2.3.1 Description of studies

Eight studies were published prior to 2000, 22 studies were published between 2000 and 2010, and 5 studies were published after 2011.

The majority of the 35 included studies were undertaken in Europe (N=24). Eleven of these studies were conducted in England (Phelan et al., 1995; Carter & Crosby, 1996; Slade et al., 1998; Slade et al., 1999a; Macpherson et al., 2003; Najim & McCrone, 2005; Howard et al., 2007; Macpherson et al., 2007; Macpherson et al., 2008; Lambri et al., 2012; Macpherson et al., 2013); three in Sweden (Arvidsson, 2001; Foldemo & Bogren, 2002; Foldemo et al., 2004); two in Italy (Lasalvia et al., 2000; Lasalvia et al., 2012); two as part of a multicentre study of the five Nordic countries (Hansson et al., 2001; Hansson et al., 2003); and one as part of a multicentre study of community services in Spain, the Netherlands, England, Sweden, Germany and Switzerland (Wiersma et al., 2009). Other European countries where a single study was undertaken include the Netherlands (Wiersma et al., 1998), Spain (Ochoa et al., 2003), Denmark (Middelboe et al., 1998), Wales (Carter, 2003) and Romania (Popescu & Miclutia, 2009).

The remaining 11 studies in this field incorporated five Australian studies (Issakidis & Teesson, 1999; Gallagher & Teeson, 2000; Trauer & Tobias, 2004; Cleary et al., 2006a; Cleary et al., 2006b), two from Israel (Grinshpoon et al., 2008; Werner, 2012), two from Canada (Comtois et al., 1998; Fleury et al., 2006) and one each from India (Kulhara et al., 2010) and Kuwait (Zahid & Ohaeri, 2013). No published studies meeting the inclusion criteria were conducted in African countries.

Looking at the studies selected using the World Bank classification of defining countries through their per capita income (World Bank, n.d.), the vast majority of studies were conducted in high-income countries; only one was conducted in a middle-income country (Popescu & Miclutia, 2009) and one in a low-income country (Kulhara et al., 2010).

All but two of the studies looked at needs in urban settings. The latter two studies investigated needs in urban and semi-rural communities (Wiersma et al., 2009; Najim & McCrone, 2005).

As noted, the review focused on studies measuring levels of need from differing perspectives: 80% (n=28) of the studies measured needs from the patients and professional staff perspectives only (Box I); only 9% (n=3) of the studies measured the patients and carers perspectives of needs (Box II), and 11% (n=4) of studies measured needs from the perspectives of the patients, their carers and professional staff (Box III).

Macpherson et al., 2013; Wiersma et al., 2009; Popescu & Miclutia, 2009; Phelan et al., 1995; Carter, 2003; Wiersma et al., 1998; Issakidis & Teeson, 1999; Lasalvia et al., 2000; Slade et al., 1998; Werner, 2012; Lambri et al., 2012; Howard et al., 2007; Hansson, 2003; Carter & Crosby, 1996; Zahid & Ohaeri, 2013; Fleury et al., 2006; Slade et al., 1999a; Macpherson, 2003; Ochoa et al., 2003; Hansson et al., 2001; Najim & McCrone, 2005; Foldemo & Bogren, 2002; Middelboe et al., 1998; Gallagher & Teeson, 2000; Arvidsson, 2001; Trauer & Tobias, 2004; MacPherson et al., 2007; Comtois et al., 1998.

Box I: Studies assessing patient and staff perspectives on needs

Kulhara et al., 2010; Cleary et al., 2006a; Cleary et al., 2006b.

Box II: Studies assessing patient and carer perspectives on needs

Grinshpoon et al., 2008; Macpherson et al., 2008; Lasalvia et al., 2012; Foldemo et al., 2004.

Box III: Studies assessing patient, carer and staff perspectives on needs

In terms of the location where the studies were conducted, 66% (n=23) looked at the needs of patients following up with community mental health services. A further 10 studies (28%) looked at needs from patients both in the community and in hospital (Arvidsson, 2001; Carter & Crosby, 1996; Cleary et al., 2006a; Howard et al., 2007; Issakidis & Teeson, 1999; Lambri et al., 2012; Phelan, 1995; Slade et al., 1998; Werner, 2012; Wiersma et al., 1998), whilst only two studies (6%) focused solely on hospital inpatients (Cleary et al., 2006b; Grinshpoon et al., 2008). The proportional location of the studies is depicted in Figure 2.

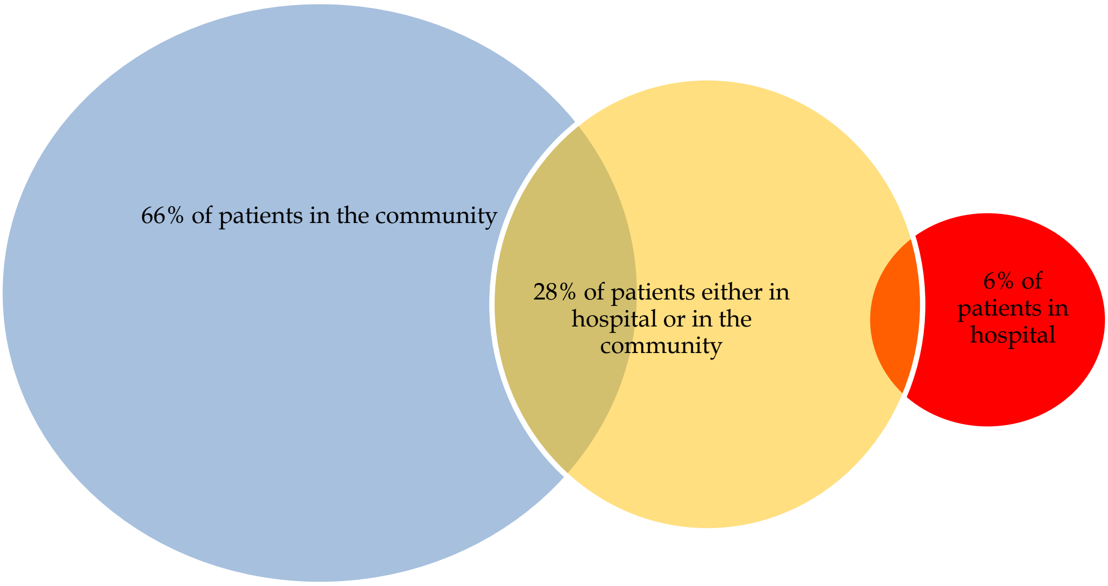


Figure 2: Follow-up locations of patients in included studies

Only four studies (11%) reported on needs in the context of assertive community treatment, three of which reported on work conducted by the same research group: Macpherson et al. (2013) evaluated the outcomes for service users during their first year of treatment in three English ACT teams.

Macpherson et al. (2008) focused on the assessment of needs within an ACT team in an English city, whilst Macpherson et al. (2007) studied the factors associated with changing patient needs in the same English ACT team. Gallagher and Teeson (2000) trialled routine measurement of need, disability and outcome in mental health services within an Australian city where they compared standard case management with assertive case management.

Just over a third of studies focused on the associations of various factors with needs (n=13). Studies reported on the association of needs with caregiver burden (n=2) (Cleary et al., 2006a; Cleary et al., 2006b), service satisfaction (n=2) (Lasalvia et al., 2012, Middelboe et al., 1998), quality of life (n=4) (Foldemo & Bogren 2002; Hansson et al., 2003; Lambri et al., 2012; Slade et al., 1999a), and insight into mental illness (n=1) (Carter 2003). A further four studies focussed on the assessment of needs in relation to socio-demographic or socio-clinical factors (Kulhara et al., 2010; Ochoa et al., 2003; Slade et al., 1998; Zahid & Ohaeri, 2013).

Eight studies (23%) focused on the perceptions of needs and the changes in needs following a set period of time or following a specific intervention (Foldemo & Bogren, 2002; Macpherson et al., 2013; Macpherson et al., 2007; Trauer and Tobias, 2004; Wiersma et al., 1998; Wiersma et al., 2009; Carter & Crosby, 1996; Phelan et al., 1995).

Four of the studies assessing needs from multiple perspectives (11%) focused on the development or translation of valid and reliable needs assessment tools (Carter & Crosby, 1996; Howard et al., 2007; Phelan et al., 1995; Popescu & Miclutia, 2009).

In summary, the majority of the studies were published between 2000 and 2010 and were predominantly conducted in urban settings in high-income countries. There were no published studies from any African countries nor were any studies conducted exclusively in rural settings. The studies tended to measure needs from the perspective of healthcare professionals and patients receiving treatment in community mental health services. Only 11%

(n=4) of the studies measured needs from the perspectives of patients, their carers and professionals, and similarly only four out of 35 studies reported on needs in the context of ACT. Relatively few studies focused on the association of needs and even fewer reported on changes in need over a given period of time or following an intervention.

2.4 Methodological issues

2.4.1 Characteristics of study samples

In this field, 74% studies made use of a cross sectional study design (n=26), with the remaining 26% being cohort studies (n=9).

Non-probability sampling methods were employed in 97% of studies. These included case identification without randomisation (46%), case identification with randomisation (17%), convenience sampling (17%) and purposive sampling (17%). Only one study made use of clustered probability sampling (3%).

The four studies focusing on needs from three perspectives tended to have smaller sample sizes than studies focused on two perspectives. The studies focusing on patient-carer-staff perspectives had sample sizes ranging from 32 to 115 patients, 32 to 120 carers, and 27 to 78 staff. Studies focused on patient-staff perspectives had sample sizes ranging from 20 to 420 patients and 20 to 370 staff, whilst those focused on patient-carer perspectives had samples of 100 to 400 patients and 35 to 100 carers.

The cross sectional study design and the non-probability sampling strategy favoured in the reviewed studies resulted in common limitations. There was limited ability to establish causal relationships; many of the findings were not generalizable to other settings (Lasalvia et al., 2012; Lambri et al., 2012); selection bias tended to be a potential problem; and the small sample sizes limited the power of the studies and illustrated the practical difficulties in obtaining a sample including more than one perspective (Cleary et al., 2006a; Cleary et al., 2006b). Cohort studies tended to be limited by the absence of a control group, as well as being limited in study power due to relatively short follow-up periods (Macpherson et al., 2007), low rates of participation (Trauer & Tobias, 2004), and small sample sizes (Foldemo & Bogren, 2002).

2.4.2 Study instruments

Instruments used in the reviewed literature fell into four broad groups: (i) needs assessment instruments such as the Camberwell Assessment of Need (CAN), (ii) measures of psychopathology and disability such as the Positive and Negative Syndrome Scale (PANSS), the Brief Psychiatric Rating Scale (BPRS), the Global Assessment of Functioning Scale (GAF), the self-report Insight Scale for psychosis (IS) and the Engagement Measure (EM) (iii) measures of patient-centred outcomes such as the Verona Service Satisfaction Scale (VSSS), Lancashire Quality of Life Profile (LQoL) and the Interview Schedule for Social Interaction, and (iv) measures of caregiving consequences such as the Involvement Evaluation Questionnaire (IEQ).

The most frequently used needs assessment instrument was the CAN and its variants, with 31 out of 35 studies making use of it. The clinical version (CAN-C) was the most frequently used CAN variant (n=16), followed by the brief version (CANSAS) (n=11), the research version (CAN-R) (n=3) and the mothers version (CAN-M) (n=1). Only two studies relied on the Bangor Assessment of Need Profile (BANP) and an equally small number (n=2) employed the Needs for Care Assessment Schedule (NFCAS).

The needs assessment instruments only reported on needs limited to areas covered by the instruments; other needs may have been present but were not addressed by the instruments (Kulhara et al., 2010). Differing needs instrument problem areas did not fully correspond with each other and there were differences in the concepts of need (Wiersma et al., 1998; Wiersma et al., 2009). The CAN was the instrument most favoured in the literature. It has the advantage of assessing need from multiple perspectives; furthermore, it is brief, simple to use and can be completed by staff members from a range of professional backgrounds without formal training (Phelan et al., 1995). The

CAN has been recommended for use in routine and research settings (Macpherson et al., 2007; Gallagher & Teeson, 2000) and it is considered preferable for transcultural and international comparison (Lasalvia et al., 2012; Kulhara et al., 2010; Wiersma et al., 1998). Compared to assessments made by researchers, patient and clinician, CAN assessments may yield ratings that are more clinically relevant and more valid over time (Wiersma et al., 2009; Macpherson et al., 2007).

A number of studies compared needs with measures of disability and psychopathology. The instrument most often used to measure disability was the GAF (n= 14).Less frequently used were the Health of the Nation Outcome Scales (HoNOS) (n=3), the Disability Assessment Schedule (DAS) (n=2), the Clinical Global Impression rating scale (CGI) (n=2), the Dysfunctional Analysis Questionnaire (n=1) and the 36 Item Short Form (n=1). The instruments most often used for measuring psychopathology were the BPRS (n=6) followed by the PANSS (n=2). Two studies included the less established Scale of Assessment of Positive Symptoms (SAPS), the Scale of Assessment of Negative Symptoms (SANS) and the Behaviour and Symptom Identification Scale (BASIS-32) to determine the levels of psychopathology.

The relationship between needs and insight was investigated twice using the IS, and the EM was also used twice to determine the association of needs and engagement.

Patient-centred outcome measures in the reviewed literature consist of measures of satisfaction, quality of life and social networks. Three studies assessed patient satisfaction in the context of an assessment of needs. The instruments used were the Verona Service Satisfaction Scale (VSSS), the Satisfaction with Life Domain Scale, and the Client Satisfaction Questionnaire (CSQ). Six of eight studies assessing quality of life made use of the LQoL, whilst the remaining two studies used the 100 item World Health Organisation Quality of Life instrument and the Manchester Short Assessment of Quality of Life Scale (MANSA). The relationship between needs and social networks was investigated in two studies using the Interview Schedule for Social Interaction.

The last group of instruments described in this review are those that measure caregiving consequences. Two studies used the Involvement Evaluation Questionnaire (IEQ) to investigate the relationship between needs and care-giver burden, whilst an Indian study used locally adapted instruments, the Social Support Scale and the Objective Burden Interview Scale, to assess caregiving consequences.

2.4.3 Methods of analysis

All the studies expressed need in terms of frequencies and percentages for categorical data such as the domain of needs, and means, and standard deviations for continuous data such as the total number of met and unmet needs.

The level of agreement between raters on the presence of a need and whether the need had been met was more frequently ascertained using Cohen's Kappa coefficient (n= 19) than the percentage of complete agreement (n=6). The chi-square test was the most commonly used test when categorical data was compared (n=13). These analyses compared domains of need among patients, staff and carers, and in comparing change over a 1-year period in individual patients-rated unmet needs. Only one study used Fisher's exact test to test for differences in need domains among staff, patients and family members.

T-tests were used to compare the mean met, unmet and total need as rated by each respondent group (n=12). They were also used to compare the concurrent validity of the CAN and HoNOS (n=1). Similar analyses using ANOVA with or without *post hoc* tests were done in seven studies. Non-parametric tests such as the Mann-Whitney-U test, the Kruskal-Wallis test and the Wilcoxon signed-rank test were used in six studies to compare data that were not normally distributed.

Fourteen studies made use of correlation analysis; these included Spearman's rank correlation to assess the strength of the relationship between baseline and follow-up need ratings, and the Pearson Product moment correlation to assess the relationship between need and various sociodemographic and clinical variables. Correlations between summary scores were also calculated to indicate inter-rater and test–retest reliability in the development of the CAN.

Regression models were fitted in eight studies, with six studies using multiple regression models. In three studies, multiple regression analyses were performed to explore the influence of sociodemographic and clinical variables on the different types of patient and staff rated needs. Two other studies using multiple regression analyses explored the relationship of met and unmet needs and quality of life.

2.5 Substantive findings

2.5.1 Socio-demographic and clinical profile

The majority of the studies reported on mean or median ages (n=26) and gave ranges of 34 to 56 years. Of the 21 studies that commented on gender, 19 had a preponderance of males with percentages ranging from 50–77%. Over half the studies commented on marital status (n=18), and in most cases the sample was single, having been never married. The percentages ranged from 48–94%.

Figures for unemployment ranged from 19% to 89%. These figures were variably defined. For example, Lasalvia et al. (2012) and Kulhara et al. (2010) reported the working status as either ‘working’, ‘unemployed’, and ‘a housewife, student, retired’. In other studies, this last grouping was recorded as ‘unemployed’.

Howard et al. (2007) also reported on a category of ‘medically retired’, whilst Ochoa et al. (2003) reported that 66% of the sample fell into the category of ‘on permanent sick leave’.

There was no clear trend in respect of the type of accommodation noted in the reviewed literature, with wide variations in the percentages of people who lived in the family home, their own or rented home, another home, or in supported accommodation.

Almost half (n=17) of the reviewed studies specifically identified patients with schizophrenia and psychotic disorders as the focus patient population. The remaining 18 of the 35 studies reported on a heterogeneous group with 'severe mental illness'. In these studies, schizophrenia or a psychotic illness was the most reported diagnosis. This tended to be followed sequentially by bipolar disorder, depression or anxiety disorder. Four articles reported on the frequency of personality disorders with the percentages ranging from 4-7%.

Mean duration of illness was reported in 15 samples and this ranged from 5 to 29 years. The GAF gave an assessment of overall functioning in 13 of the samples and the range of the mean scores was between 45 and 60. This indicated moderate to serious symptoms or moderate to severe difficulty in social, occupational or school functioning. Only four articles reported on the level of psychopathology using the BPRS, and mean scores ranged from 14 to 44, indicating mild to moderate illness.

Only three of the 32 studies that included professional staff perspectives reported on the professions of the staff involved. In these three studies, staff were largely psychiatric nurses (41–46%), followed by social workers and lastly, psychiatrists.

Four out of the seven studies that included the perspectives of carers reported on the mean ages of the carers, and these ranged from 47 to 66 years. In all the samples of carers, more than half were parents.

2.5.2 Levels of needs

In the literature, the numbers of total needs reported by each group varied widely with patients reporting total needs ranging from 3.3 to 9.5, carers 6.0

to 10.8, and staff 3.3 to 14.0. There was no trend as to which group rated more needs. This was the case for total, met and unmet needs. Having a carer did not change the number of needs perceived by the patient (Kulhara et al., 2010; Cleary et al., 2006a; Cleary et al., 2006b; Macpherson et al., 2008; Grinshpoon et al., 2008; Lasalvia et al., 2012; Foldemo et al., 2004). Reasons for the varying levels of needs included differences in study inclusion criteria (Foldemo et al., 2004); differing service provisions in differing countries with relatively better resources in high-income countries (Arvidsson, 2001; Werner, 2012); and differing cultural contexts with variability in accommodation, carer presence and type, and differences in care culture, resulting in demands of life being modest and adaptation to the disability relatively high (Zahid & Ohaeri, 2013; Kulhara et al., 2010; Arvidsson, 2001).

The four studies conducted in ACT teams all reported relatively higher numbers of total needs compared to studies conducted in standard community services. This was the case for needs as assessed by patients, their carers and staff (Macpherson et al., 2013; Macpherson et al., 2008; Macpherson et al., 2007; Gallagher & Teeson, 2000). In-patients were found to have more unmet needs than community-based patients (Cleary et al., 2006a). Staff and patients in semi-rural settings rated fewer needs than those in inner-city areas (Najim & McCrone, 2005; Fleury et al., 2006). Fewer needs were reported in samples with a higher proportion of patients with non-psychotic disorders (Middelboe et al., 1998; Lasalvia et al., 2000; Macpherson et al., 2003).

Both studies from middle- and low-income countries that employed the CAN concluded that there are higher needs reported, particularly unmet needs, as compared to high-income countries (Popescu & Miclutia, 2009; Kulhara et al., 2010). Any help received in middle- and low-income countries tended to be from informal sources.

2.5.3 Domains of needs

On the whole, the three groups differed widely on the individual need domains identified. In general, there were more ratings of no need in the 22 CAN areas assessed by all three groups than there were ratings of met or unmet needs. There was no discernible trend regarding which domains had the most met or unmet needs.

The patients, carers and staff tended to identify most total needs in the domains of psychotic symptoms, psychological distress, company, daytime activities, money, and looking after the home (Hansson et al., 2001; Middelboe et al., 1998; Slade et al., 1998; Zahid & Ohaeri, 2013; Issakidis & Teeson, 1999; Fleury et al., 2006; Lasalvia et al., 2000; Arvidsson, 2001; Macpherson et al., 2003; Werner, 2012; Ochoa et al., 2003; Wiersma et al., 1998; Kulhara et al., 2010; Macpherson et al., 2008; Lasalvia et al., 2012). This was the same for high-, middle- and low-income countries (Kulhara, 2010; Popescu & Miclutia, 2009).

Purported reasons for the disparity in domains of needs identified included patient symptoms restricting their ability to see their own needs; less reliable staff and carer responses due to less knowledge of patient circumstances, particularly in areas such as sexual expression and intimate relationships; staff reluctance to rate a need as unmet rather than met due to concern about potential perceptions of their professional competence; and different expectations of what constitutes a problem as a result of sociocultural, educational and professional backgrounds (Slade et al., 1999a; Arvidsson, 2001; Ochoa et al., 2003; Lasalvia et al., 2000; Slade et al., 1996; Hansson et al., 2001).

Different categories of staff also answered the CAN differently, with psychiatrists tending to report only serious health problems (physical health, psychotic symptoms, psychological distress, safety to self, safety to others, alcohol, drugs) and social workers and other professionals identifying serious problems in domains of basic needs (accommodation, food, daytime activities), functioning (looking after the home, self-care, child care, education, money) and services (information, transport, telephone, benefits) (Fleury et al., 2006). Keyworkers may also have had a better understanding of their patients compared to researchers, resulting in differences in ratings (Macpherson et al., 2003).

Staff tended to identify more need areas relating to medical issues, while patients tended to report more needs in areas of everyday life (Lasalvia et al., 2000). The domains of information, benefits, intimate relationships and sexual expression were considered by staff to be problems of lesser importance because they are not directly related to schizophrenia, which explained the inadequate help or insufficient services available to meet these needs. Patients identified serious need in these four domains, however, and this resulted in high levels of discrepancies in these domains (Middelboe et al., 1998; Fleury et al., 2006; Issakidis & Teeson, 1999).

The cohort studies reviewed demonstrated a trend for change in the nature and amount of needs over a period of time, with or without an intervention (Macpherson et al., 2013; Wiersma et al., 2009; Macpherson et al., 2007; Carter & Crosby, 1996; Wiersma et al., 1998; Phelan et al., 1995; Foldemo & Bogren, 2002; Trauer & Tobias, 2004; Howard et al., 2007). There was no consistency as to which of patient or staff rated needs changed and to which of total, met, or unmet needs changed. Needs changed across a variety of domains, rather than in one specific area.

Only one of the cohort studies investigated the effect of an intervention on the levels of needs (Wiersma et al., 2009). After one year of a novel intervention aimed at improving communication, both patient and staff-rated total needs remained stable but unmet needs decreased significantly. Sensitivity to change of unmet needs was quite high with the finding that from both the perspectives, about two-thirds of all unmet needs made a transition to no or met need, and more than half of all unmet needs at follow up were new.

2.5.4 Agreement on needs

On the whole, levels of agreement on the presence of a need were poor between the patients, carers and staff. Only three studies out of 35 reported high levels of agreement (Phelan et al., 1995; Arvidsson, 2001, Macpherson et al., 2003).

This trend of poor agreement was present in studies done in different settings and differing populations, and using differing study design and methodology. There were no trends relating to which pairing had better agreement.

There was less discrepancy in the domains with a defined service response such as accommodation (supported housing), telephone (telephone card provision) and benefits (benefits entitlement). Needs in areas such as sexual expression and intimate relationships have a less defined service response and so tended to have more discrepancies (Issakidis & Teeson, 1999; Slade et al., 1996; Slade et al., 1998; Lasalvia et al., 2000).

2.5.5 Associations of needs

A number of correlates of unmet needs were reported in the reviewed literature. Five studies examined the relationship between needs and quality of life and the consistent finding was that the presence of unmet needs, particularly those expressed by the patient, is associated with a worse overall quality of life (Hansson et al., 2001; Ochoa et al., 2003; Hansson et al., 2003; Slade et al., 1999a; Lambri et al., 2012). Unmet needs have also been associated with worse psychopathology (Hansson et al., 2001; Ochoa et al., 2003; Zahid & Ohaeri, 2013; Kulhara et al., 2010).

Higher disability as rated by the GAF and the HoNOS scores has been associated with greater needs (Werner, 2012; Ochoa et al., 2003; and Issakidis & Teesson, 1999), whilst lower global functioning scores predicted poorer agreement in patient and staff ratings of needs (Lasalvia et al., 2000).

The three studies focused on the association of needs and diagnosis varied on need. Trauer & Tobias (2004) reported less need in those with schizophrenia as compared to mood disorder and personality disorders, whilst Cleary et al. (2006b) reported the opposite findings in their in-patient sample. Macpherson et al. (2003) found that patient ratings of unmet need did not differ significantly according to diagnosis.

The association between social network and needs was investigated in two studies. Hansson et al. (2001) found that the presence of patient-rated unmet needs was associated with a worse social network, and Kulhara et al. (2010) reported patients and caregivers with poor social support to have had a higher number of unmet needs and total needs.

Need and its association with caregiver burden was investigated in three studies focused on patient and carer perspectives on needs (Kulhara et al., 2010; Cleary et al., 2006a; Cleary et al., 2006b). In these studies, carer rated unmet need was significantly related to the burden felt by the carers, and carers of in-patients reported more burden than those of community-based patients. Carers were more burdened than patients perceived them to be.

Carter (2003) was the only study to investigate insight and its association with needs. It found that patients who had more insight rated themselves as having significantly more total needs. No significant correlation was found in total staff rated need scores. Staff members rated need independently of measures of insight.

There was no consistency as to the association of needs with sociodemographic variables such as age, gender, employment status and marital status. Macpherson et al. (2003) reported that patient ratings of unmet need did not differ significantly according to accommodation type, age, or ethnicity and similarly Zahid & Ohaeri (2013) found needs were not significantly associated with gender, age, education, marital status or duration of illness. However, Werner (2012) reported that age was found to be negatively associated with patients' reported unmet needs and that men reported a higher number of unmet needs than women. Kulhara et al. (2010) reported that correlation analysis suggested that more needs were expressed by males, patients who had a longer duration of illness and those belonging to non-nuclear families. They also that found male patients reported significantly more needs as being met compared to female patients, and that caregivers of younger patients expressed fewer unmet and total needs. Lasalvia et al. (2000) found that a higher number of service contacts and patient unemployment predicted a higher number of staff-rated needs. The needs (total, met and unmet) of severely mentally ill patients were found by patients and staff to be greater in an inner-city area compared to a rural one, and the finding of less agreement between patients and staff in the inner-city suggested that more stable staff-patient relationships existed in the rural area (Najim & McCrone, 2005).

Box IV displays the studies focused on the perceptions of needs and its associations.

Needs and association with caregiver burden – Kulhara et al., 2010; Cleary et al., 2006a; Cleary et al., 2006b

Needs and insight to mental illness – Carter, 2003

Needs and quality of life – Lambri et al., 2012; Ochoa et al., 2003; Hansson et al., 2003; Foldemo & Bogren, 2002; Hansson et al., 2001; Slade et al., 1999a

Needs and social networks – Kulhara et al., 2010; Hansson et al., 2001

Needs and relations with clinical factors – Zahid & Ohaeri, 2013; Werner, 2012; Kulhara et al., 2010; Cleary et al., 2006b, Trauer & Tobias, 2004; Macpherson et al., 2003; Ochoa et al., 2003; Hansson et al., 2001; Lasalvia et al., 2000; Issakidis & Teesson, 1999

Needs and relations with socio-demographic – Zahid & Ohaeri, 2013; Werner, 2012; Kulhara et al., 2010; Najim & McCrone, 2005; Macpherson

Box IV: Studies focused on the perceptions of needs and its associations

2.6 Discussion

The literature review reveals that although a significant body of literature on needs in mental health exists, relatively little of it focuses on the needs of the severely mentally ill taken from multiple perspectives. The 35 publications selected represent a relatively small number of studies published in this field, even taking into account the inclusion criteria. The majority of these were published after the year 2000 suggesting that this remains a topical area of interest. The selected studies have tended to look at needs from the perspectives of the patients and professional staff members, with little inclusion of family or other carers who often bear the costs of care and experience high levels of burden and distress (Kulhara et al., 2010; Cleary et al., 2006b). The literature demonstrates that combining the three perspectives of the patient, carer and staff is a complex task but that it is an effort worth pursuing, since it may provide a more comprehensive and articulated view on how patients and staff interaction works within 'real-world' mental health services (Lasalvia et al., 2012).

The reviewed studies were largely conducted in urban settings of high-income countries with participants living with chronic severe mental illness and following up with standard community services. This makes it difficult to generalise the finding of these studies and highlights the gap in the literature for studies done in settings such as African countries, low- and middle-income countries, rural settings, non-severe mental illness, first presentation psychosis, in-patient samples and ACT team samples.

The CAN, together with its variants, was the needs assessment instrument of choice. It was shown to have good psychometric properties in diverse settings and it allows for international and cross cultural comparisons to be made (Zahid & Ohaeri, 2013; Kulhara et al., 2010; Popescu & Miclutia, 2009). The CANSAS was employed as frequently as the more extended versions of the CAN, suggesting its utility both as a clinical and as a research instrument.

There were relatively few studies that explored the association of needs with clinical and socio-demographic factors. These studies employed a wide range of instruments, which precluded comparison of results across papers and settings. The studies demonstrated that in spite of there being no consistency regarding the association of needs with diagnosis and demographic variables, a number of clinical variables were consistently found to be associated with needs. The most consistent findings were that unmet need, particularly need expressed by patients, was associated with worse quality of life and worse psychopathology (Zahid & Ohaeri, 2013; Kulhara et al., 2010; Ochoa et al., 2003; Hansson et al., 2003). Higher disability was also associated with worse needs and higher disagreement in patient and staff ratings (Werner, 2012; Lasalvia, 2000). These associated factors may be targets for future interventions aimed at ameliorating needs.

The review highlighted that disagreement among patients, carers and staff opinions represented the rule rather than the exception in mental health services. Discrepancies were found not only on the numbers of needs, nature (met or unmet) and domains of needs, but also in the poor agreement on the presence of a need. These discrepancies exist even when using methods of analysis controlling for chance. Differences in needs exist in studies conducted in different countries; in in-patient versus community samples; in urban and non-urban samples; and in assertive outreach and case management models. This emphasises the uniqueness of each population's needs and the importance of incorporating the perspectives of all stakeholders involved. It suggests that becoming aware of the patterns of disagreement about patient needs is a necessary starting point from which service providers can work to increase consensus. Attempts to increase consensus must, however, be accompanied by a reorientation in the service philosophy, i.e. by viewing patients as 'treatment leaders' and not as passive treatment recipients (Lasalvia et al., 2012).

The review has highlighted a number of gaps in the literature. Due to the uniqueness of each study population, it is important to have locally specific and relevant research studies. More studies need to be conducted in varied settings: middle- and low-income countries, non-European settings, rural settings, in-patient settings, and ACT populations. There is a need for studies with better defined populations of people with serious mental illness and for more studies focused on the needs of individuals with psychotic disorders specifically. Most of the literature has looked at needs from the perspective of patients and staff members, meaning that additional publications focused on needs from the carer perspective are required.

This review has a number of limitations. There was only one reviewer and the publications reviewed were limited to those published in English. Few publications met the inclusion criteria. An adequate quality assessment tool for observational studies could not be found and the quality of the selected studies was assessed using the STROBE statement checklist. This tool was designed as a guide for good reporting on observational studies rather than for use specifically as a quality assessment tool. As such, the quality of some of the publications may be questionable: the publications tended to employ a cross sectional and cohort study design; there were low numbers of participants who tended not to be blinded; and the study populations were largely heterogeneous. This made it difficult to comment on causality.

Despite these limitations, the study has assisted in achieving the aims of the review. The review has revealed the requirement for additional studies incorporating all stakeholders' perspectives on needs and for studies conducted in diverse settings including low-income countries and assertive outreach teams. It has highlighted the discrepancies and disagreement that exist in the perceptions of needs and the uniqueness of each study population's needs. There has been guidance on the study methodology and methods of analysis that can best be used to allow for comparison across different settings and the review has given direction as to the factors associated with needs which may be explored in the local setting.

Finally, this review highlights the need for a study to examine the relationship between patient, carer and staff perceptions of need in an assertive community treatment team in South Africa.

Table 1: Summary of cohort studies focused on needs from multiple perspectives

No.	Author	Country & World Bank Classification	Study design & Sampling methodology	Population studied	Needs assessment tool	Other tools	Methods of analysis	Summary of findings
1	***Macpherson et al., 2013***	England High income country	Cohort study Case identification without randomisation	49 patients 49 key worker ratings Schizophrenia and Bipolar disorder Urban setting Out-patient setting ACT setting	CANSAS (patient and keyworker)	HoNOS EM	Frequencies & percentages Wilcoxon's signed rank sum tests	**Prevalence of needs** • Staff identified more needs than patients at baseline and at 6- and 12-month follow-up by an assertive outreach team. • Mean staff-rated met need increased significantly over an initial 6-month period of treatment but not over 12 months. • There was no significant change in mean patient-rated needs at 6- and 12-month follow up. • The proportions of met and unmet needs rated by staff and patients at baseline and 12 months did not change significantly. **Agreement on needs** *No comment made* **Associations of needs** *No comment made*
2	***Wiersma et al., 2009***	Netherlands Sweden Germany Switzerland High income countries	Cohort study Cluster randomisation sampling	294 patient ratings 302 clinician ratings Schizophrenia or related psychotic disorder Urban and mixed urban-rural setting Out-patient setting	CANSAS (patient and clinician)	PANSS MANSA CSQ Clinicians' job satisfaction	Frequencies & percentages Spearman correlations Cohen's Kappa Chi-square tests	**Prevalence of Needs** • Clinicians identified more total, met and unmet needs than patients at baseline and at 1 year following a novel intervention at improving communication. • The total number of met needs remained stable but unmet needs decreased significantly over time according to patients and clinicians. • Sensitivity to change of unmet needs was high: about two-thirds of all unmet needs changed to no or met need, and more than half of all unmet needs at follow up were new. **Agreement on needs** • Poor agreement on total and unmet needs at baseline and on 1-year follow up. **Associations of needs** *No comment made*
3	***Macpherson et al., 2007***	England High income country	Cohort study Purposive sampling	79 patients & keyworker ratings	CANSAS (patient & keyworker)	Engagement measure (EM)	Frequencies & percentages Wilcoxon	**Prevalence of needs** • Keyworkers identified more total, met and unmet needs than patients at baseline and at 6-month follow-up by an assertive

No.	Author	Country & World Bank Classification	Study design & Sampling methodology	Population studied	Needs assessment tool	Other tools	Methods of analysis	Summary of findings
				Urban setting Out-patient setting ACT setting			matched pairs signed rank tests Regression analysis	outreach team. • Over 6-month period patient-rated unmet need reduced and met need increased. • Patient's needs changed across a variety of domains, rather than in one specific area. • There was no change in keyworker ratings of need. **Agreement on needs** *No comment made* **Associations of needs** • Only diagnosis and accommodation type played an important role in changing patient-rated met or unmet need.
4	***Howard et al., 2007***	England High income country	Cohort study Case identification without randomisation	36 patient and staff ratings Women with severe mental illness Pregnant or with children 16 years of age or younger Urban setting In- and out-patient setting	CAN-M Included 7 domains new or modified from original CAN (pregnancy care, sleep, safety to child and others, violence and abuse, practical demands of childcare, emotional demands of childcare, language-culture-and religion.		Frequencies & percentages Spearman's correlations Concordance correlation coefficients Paired t tests Cohen's Kappa Regression analyses	**Prevalence of needs** • Patients reported significantly more total and unmet needs than staff. • No significant change in patient- or staff-rated total needs after a 2-week period. **Agreement on needs** *No comment made* **Associations of needs** • There was moderate correlation between the staff rated total need and the GAF symptom and disability sub-scores.
5	***Trauer & Tobias, 2004***	Australia High income country	Cohort study Convenience sampling	188 patient & keyworker ratings Predominantly Schizophrenia Urban setting Out-patient	CANSAS (patient and keyworker)	BASIS-32	Frequencies & percentages Pearson's correlations ANOVAs	**Prevalence of needs** • Keyworkers identified more total, met and unmet needs than patients at baseline. • At 6-month follow up there were no significant differences between the mean counts of needs, irrespective of type of need or informant.

No.	Author	Country & World Bank Classification	Study design & Sampling methodology	Population studied	Needs assessment tool	Other tools	Methods of analysis	Summary of findings
				setting				**Agreement on needs** *No comment made* **Associations of needs** • Patient and keyworker assessments of needs were highly correlated for the whole group and for each of the main diagnostic groups (Schizophrenia, mood disorders, and personality disorder). • Keyworkers did not identify significantly different numbers of needs according to main diagnosis, but patients did. Patients with schizophrenia identified the least needs and those with personality disorders the most.
6	***Foldemo & Bogren, 2002***	Sweden High income country	Cohort study Case identification without randomisation	17 patient and keyworker ratings Schizophrenia Urban setting Out-patient setting	CAN C (patient and keyworkers)	QLS-100 GAF CGI Insight scale of Birchwood	Frequencies & percentages Wilcoxon's signed rank sum tests. Spearman correlations	**Prevalence of needs** • Staff identified more domains where patients had needs than the patients themselves. • Keyworkers identified more total needs than patients at baseline and at 5-year follow-up. **Agreement on needs** • The need ranking with keyworkers and patients showed a strong positive correlation at baseline and at 5-year follow-up. **Associations of needs** • Significant correlation found between CAN and GAF, as well as CAN and CGI both at baseline and at follow up.
7	***Wiersma et al., 1998***	Netherlands High income country	Cohort study Case identification without randomisation	50 patients and staff ratings Non-affective functional psychosis Urban setting In- and out-patient setting	CAN C (patient rated) Needs for Care Assessment Schedule (NFCAS)- staff rated		Frequencies & percentages Percentage agreement	**Prevalence of needs** • Staff NFCAS conducted at 15 years after first onset of psychosis and again at 17 years. • Patient CAN conducted only at 17 years after first onset psychosis. • Patients identified more total, met and unmet needs than staff at 2-year follow-up. • There was very high stability in staff-rated need domains over the 2-year period. • There was instability in staff-rated number of needs over time and there were relatively more new unmet need at follow up and less improvement to no need.

No.	Author	Country & World Bank Classification	Study design & Sampling methodology	Population studied	Needs assessment tool	Other tools	Methods of analysis	Summary of findings
								Agreement on needs • There was a high level of agreement on the number of unmet needs but poor agreement as to the nature of the needs. **Associations of needs** • There was no significant difference between change in need status and gender and age; unmarried patients and in-patients had significantly more unmet needs.
8	***Carter & Crosby, 1996***	United Kingdom High income countries	Cohort study Case identification without randomisation	57 patient & keyworker ratings Major mental illness Urban Long stay in- and out-patients	BANP (patient and staff)		Frequencies & percentages Percentage agreement Cohen's Kappa	**Presence of needs** • Staff reported significantly needs than patients. **Agreement on needs** • Mean percentage agreement on the presence of a need was fair whilst the mean Kappa agreement was poor. • After 1 month, test-retest agreement on the presence of a need was fair for patient ratings, and moderate to very good for staff ratings. • Test-retest agreement for individual need items was fair to good for patient ratings, and moderate to good for staff ratings. **Associations of needs** *No comment made*
9	***Phelan et al., 1995***	England High income country	Cohort study Case identification with randomisation	49 patients & 60 keyworker ratings Severe mental illness Urban In- and out-patients	CAN R (patient and staff)		Frequencies & percentages Percentage agreement Cohen's Kappa Pearson correlation coefficient	**Presence of needs** • Patients and keyworkers identified similar numbers of total needs. • The groups differed on the domains of needs identified. • Staff rated needs as met for most areas. • Unlike in other areas, up to a quarter of keyworkers did not know whether a need existed for sexual expression and welfare benefits. **Agreement on needs** • Percentage agreement and Kappa coefficient revealed good agreement on the presence of a need initially and substantial agreement 1 week later. • Correlation studies revealed moderate agreement between summary scores of needs initially and 1 week later. **Associations of needs** *No comment made*

Table 2: Summary of cross-sectional studies focused on needs from patient and carer perspectives

	Author	Country & World Bank Classification	Study design & Sampling methodology	Population studied	Needs assessment tool	Other tools	Methods of analysis	Summary of findings
1	***Kulhara et al., 2010***	India Low income country	Cross sectional study Convenience sampling	100 patients and carer ratings Schizophrenia Urban setting Out-patient setting	CAN C (patient and carer)	SAPS SANS DAQ Social support scale Objective Burden Interview Scale	Frequencies & percentages Pearson's correlations Spearman correlations Cohen's Kappa	**Prevalence of needs** • Patients expressed more total, met and unmet needs than carers. • Indian patients reported a higher number of needs than reported in studies from the West but the most reported areas of needs were similar. **Agreement on needs** • There was poor agreement for most CAN domains. **Associations of needs** • More needs were expressed by males, patients who had a longer duration of illness and those who belonged to non-nuclear families. • Significantly more males than females reported needs as being met. • Carers of younger patients expressed less unmet and total needs. • Patients and carers with poor social support had more unmet needs and total needs. • Total needs and unmet needs expressed by carers had correlation with severity of psychopathology. • Total needs and unmet needs as expressed by both groups had positive correlation with burden and level of dysfunction.
2	***Cleary et al., 2006a***	Australia High income country	Cross sectional study Case identification without randomisation	407 patient and 50 carer ratings Patients discharged from in-patient services Urban setting In and out-patient setting	CANSAS (patient and carer)	IEQ	Frequencies & percentages Pearson chi-square test ANOVAs Cohen's Kappa Pearson's correlations	**Prevalence of needs** • No significant differences in the number of needs identified by patients and carers but ratings differed significantly regarding the types of need. **Agreement on needs** • Agreement on the presence of needs ranged from poor to moderate. **Associations of needs** • Having a carer was not associated with differences in the number of needs expressed by patients. • Unmet need was significantly related to burden from the carer's perspective.

	Author	Country & World Bank Classification	Study design & Sampling methodology	Population studied	Needs assessment tool	Other tools	Methods of analysis	Summary of findings
								- In-patients had more unmet needs than community-based patients.
3	***Cleary et al., 2006b***	Australia High income country	Cross sectional study Purposive sampling	200 patient, and 35 carer ratings Severe mental illness Urban setting In-patient setting	CANSAS (patient and carer)	IEQ	Frequencies & percentages Pearson chi-squared tests Cohen's Kappa ANOVA Paired t-tests Pearson's correlations	**Prevalence of needs** - No significant differences in the number of needs identified by patients and their carers but significant differences regarding the types of need **Agreement on needs** - Low level of agreement between patient and carer ratings of need. **Associations of needs** - Having a carer was not associated with differences in the number of needs expressed by patients. - In-patients with Schizophrenia had most met needs, those with affective disorders had most unmet needs and in-patients with other diagnoses had the lowest total of needs.

Table 3: Summary of cross-sectional studies focused on needs from patient, carer and staff perspectives

	Author	Country & World Bank Classification	Study design & Sampling methodology	Population studied	Needs assessment tool	Other tools	Methods of analysis	Summary of findings
1	***Lasalvia et al., 2012***	Italy High income country	Cross sectional study Case identification without randomisation	115 patient, 27 staff, and 120 family member ratings. Non-affective psychosis Urban setting Out-patient setting	CAN C (patient, staff and family)	VSSS	Frequencies & percentages Chi-square tests Fisher's exact tests t- tests ANOVAs Percentage agreement Cohen's Kappa 22 CAN items grouped into 5 conceptual domains	**Prevalence of needs** • Patients, staff and parents reported similar numbers of needs. • Patients identified significantly fewer needs in the basic and functioning domains than staff or family. **Agreement on needs** • Levels of agreement were low between the 3 groups. • Patients and family showed more areas of discrepancies in both needs and service satisfaction. **Associations of needs** *No comment made*
	Macpherson et al., 2008	England High income country	Cross sectional study Purposive sampling	78 patients and keyworker ratings 32 carer ratings Urban setting Out-patient setting ACT setting	CANSAS (Patient, carer and staff)		Frequencies & percentages t-tests Cohen's Kappa	**Prevalence of needs** • Similar levels of need were rated by patients with and without a carer. • Staff and carers reported higher levels of need than patients. • Carers rated higher needs in care of the home and self-care than patients and staff. **Agreement on needs** • Agreement between patient-staff ratings was higher than that between patients-carers and staff-carer ratings. • The agreement between the groups varied across domains, and was generally lower in domains self-care or safety to others **Associations of needs** *No comment made*

	Author	Country & World Bank Classification	Study design & Sampling methodology	Population studied	Needs assessment tool	Other tools	Methods of analysis	Summary of findings
3	***Grinshpoon et al., 2008***	Israel High income country	Cross sectional study Convenience sampling	52 patient, staff and carer ratings Schizophrenia or Schizoaffective disorder Urban setting In- patient setting	CAN C (patient, carer and staff)		Frequencies & percentages Chi-square tests t-tests ANOVAs 22 CAN items grouped into 5 conceptual domains	**Prevalence of needs** • Patients reported fewer total needs than family. • 16 of the 22 CAN items were similar between the three groups and the items that differed significantly, did so between patients and staff. • Patients rated lower needs in the 'functioning' and 'health' domains than both staff and relatives. **Agreement on needs** *No comment made* **Associations of needs** *No comment made*
4	***Foldemo et al., 2004***	Sweden High income country	Cross sectional study Purposive sampling	32 patient, 44 parent and 31 staff ratings Schizophrenia Urban setting Out-patient setting	CAN C (patient, parent, staff)	GAF CGI Insight Scale	Mean values and standard deviations Spearman's correlations Mann-Whitney U-tests	**Prevalence of needs** • Parents and staff rated more total, met, and unmet need than the patients. • The correlation between parent and staff need ratings was stronger than that between patient-staff and patient-parent ratings. • Parents and staff rated significantly higher severity of needs than patients in the areas of 'looking after the home' and 'daytime activities'. • Patients and parents generally reported more needs in areas of everyday life and the staff tended to identify more needs in areas related to medical issues. **Agreement on needs** *No comment made* **Associations of needs** *No comment made*

Table 4: Summary of cross-sectional studies focused on needs from patient and staff perspectives

	Author	Country & World Bank Classification	Study design & Sampling methodology	Population studied	Needs Assessment tool	Other Tools	Methods of Analysis	Summary of Findings
1	*Zahid & Ohaeri, 2013*	Kuwait High income country	Cross sectional study Convenience sample	130 patient and staff ratings Schizophrenia Urban setting Out-patient setting	CAN C (patients & staff)	LQoL BPRS GAF	Frequencies & percentages Cohen's Kappa Spearman's correlation Chi-square tests	**Prevalence of needs** • Staff identified significantly more total, met, and unmet needs than patients. • Most needs were found to be met by both groups. **Agreement on needs** • Agreement on the presence of a need was fair to moderate in all domains, except for alcohol and drugs were agreement was poor. • There was poorer agreement on presence of unmet needs. **Associations of needs** • Higher levels of needs were significantly associated with severity of psychopathology and negative affect, and not participating in outdoor activities
	Lambri et al., 2012	England High income country	Cross sectional study Case identification with randomisation	110 patient and staff ratings Severe mental illness Urban setting In-and out-patient setting	CAN R (patient and staff)	SF-36 LQoL BPRS	Frequencies & percentages Regression analyses	**Prevalence of needs** • Staff reported more met needs than patients in all housing settings, except in low-supported housing. • Met needs tended to increase from low-supported accommodation through rehabilitation settings which had more staff in support; however, unmet needs varied far less across housing type. **Agreement on needs** • There was lack of agreement in all-need scores between patients and staff in all housing settings. **Associations of needs** A greater quality of life score was predicted by lower patient-rated unmet needs and greater SF-36 mental scores.
	Werner, 2012	Israel High income country	Cross sectional study Convenience sample	206 patient and 112 staff ratings Serious mental illness In- and out-patient setting Urban and semi	CANSAS (Patient and staff	GAF	Frequencies & percentages Pearson's correlations Independent t-tests	**Prevalence of needs** • There were no significant differences in total needs but staff found more met need and patients more unmet need. **Agreement on needs** • Overall agreement on the presence of needs was poor to moderate. **Associations of needs** *No comment made*

	Author	Country & World Bank Classification	Study design & Sampling methodology	Population studied	Needs Assessment tool	Other Tools	Methods of Analysis	Summary of Findings
				urban setting			ANOVAs Cohen's Kappa	
	Popescu & Miclutia, 2009	Romania Middle income country	Cross sectional study Case identification without randomisation	58 patient and staff ratings Schizophrenia Urban setting Out-patient setting	CAN- C (patient and staff)		Cohen's Kappa Percentage agreement Cronbach's alpha t-tests	**Prevalence of needs** • Staff rated more total needs than patients. • More unmet needs were reported compared to other European countries. **Agreement on needs** • There was poor agreement on the presence of a need. **Associations of needs** *No comment made*
	Fleury et al., 2006	Canada High income country	Cross sectional study Case identification with randomisation	165 patients 165 staff Severe mental health problems Urban, semi urban and rural setting Out-patient setting	CAN C (patient and staff)		Frequencies & percentages Kappa coefficient	**Prevalence of needs** • Similar numbers of needs were identified by patients and staff but the domains of needs differed. • For both patients and staff, more unmet needs were found in areas regarded as social needs. **Agreement on needs** • Overall agreement on between patients and staff was moderate. **Associations of needs** Service districts with greatest degree of agreement were also the ones where patients considered that local services best met their needs.
	Najim & McCrone, 2005	England High income country	Cross sectional study Case identification with randomisation	50 patients in semi-rural setting, 127 patients in deprived inner city, 177 corresponding staff ratings Severe mental illness Out-patient setting	CANSAS (patient and staff)	GAF	Frequencies & percentages t-tests Chi-squared tests Cohen's Kappa	**Prevalence of needs** • Similar numbers of needs identified by patients and staff but the domains of needs differed. **Agreement on needs** • Overall agreement on needs was low in both areas although it was marginally better in semi-rural area. **Associations of needs** Total, met, and unmet needs were fewer in semi-rural setting than inner-city area according to both staff and patients.

	Author	Country & World Bank Classification	Study design & Sampling methodology	Population studied	Needs Assessment tool	Other Tools	Methods of Analysis	Summary of Findings
	Carter, 2003	Wales High income country	Cross sectional study Purposive sampling	160 patient and keyworker ratings Serious mental illness Urban setting Out-patient setting	BANP (patient and staff)	The Insight Scale	Frequencies & percentages t-tests	**Prevalence of needs** • Keyworkers reported more total needs compared to patients. • Patient under-reporting of need was more probable than over-reporting. **Agreement on needs** *No comment made* **Associations of needs** • Patients who had more insight rated significantly more total need. • Non-significant relationship found between keyworker perceptions of patient need and insight.
	Hansson et al., 2003	Denmark Sweden Norway Finland Iceland High income countries	Cross sectional study Case identification without randomisation	418 patient and 300 staff ratings Schizophrenia Urban setting Out-patient setting	CAN C (patient and staff)	LQOLP BPRS GAF Interview Schedule for Social Interaction	Frequencies & percentages Pearson's correlations T-tests ANOVAs Multiple regression analyses	**Prevalence of needs** • Staff rated significantly more total needs but not significantly more met or unmet needs. **Agreement on needs** *No comment made* **Associations of needs** • More unmet needs as rated by staff and patients were associated with a worse quality of life. • Unmet need in CAN domains of social relationships, accommodation, psychotic symptoms, social benefits, and childcare was associated with a worse quality of life.
	Ochoa et al., 2003	Spain High income country	Cross sectional study Case identification with randomisation	231 patient and staff ratings Schizophrenia Urban and semi urban setting Out-patient setting	CAN C (patient and staff)	PANSS GAF DAS QOL	Frequencies & percentages Cohen's Kappa Multiple linear regression	**Prevalence of needs** • Staff rated more total and unmet needs a compared to patients. • Main discrepancies arose in areas of company, daytime activities, psychotic symptoms and self-care. **Agreement on needs** • Agreement on the presence of needs was fair and it was substantially lower in the evaluation of unmet needs. **Associations of needs** • People with more severe clinical symptoms and higher disability were found to have more unmet needs. • Patients with a worse quality of life had more unmet needs.

	Author	Country & World Bank Classification	Study design & Sampling methodology	Population studied	Needs Assessment tool	Other Tools	Methods of Analysis	Summary of Findings
	Macpherson et al., 2003	England High income country	Cross sectional study Case identification with no randomisation	225 patient and 25 staff ratings Functional psychosis Urban setting Out-patient setting	CANSAS (patient and staff)		Frequencies & percentages Mann-Whitney tests Kruskal-Wallis tests Cohen's Kappa	**Prevalence of needs** • Staff and patients rated similar levels of total, met and unmet needs but in different domains. • Unmet need rated most highly in social and relationship domains by patients and staff. **Agreement on needs** • Levels of agreement on needs were substantial in all domains except risk to others, in which it was fair. **Associations of needs** • Staff, but not patients, rated significantly more unmet need in non-Caucasian groups.
	Arvidsson, 2001	Sweden High income country	Cross sectional Case identification without randomisation	372 patient and staff ratings Severe mental illness Urban setting In- and out-patient setting	CAN C (patient and staff)	GAF	Paired sample t-tests Pearson's correlations Cohen's Kappa	**Prevalence of needs** • Staff reported more total, met and unmet need than patients. • For domains of 'sexual expression' and 'intimate relationships' there were significantly more ratings of 'unknown' as compared to the other domains. **Agreement on needs** • There was good agreement between patients and staff on the presence of each need and whether the need was met or not. **Associations of needs** *No comment made*
	Hansson et al., 2001	Denmark Sweden Norway Finland Iceland High income countries	Cross sectional study Case identification with no randomisation	300 patient and staff ratings Schizophrenia Urban setting Out-patient setting	CAN C (patient and staff)	LQOLP BPRS Interview Schedule for Social Interaction	Frequencies & percentages Cohen's Kappa Wilcoxon matched pairs signed-rank tests Spearman's correlations Regression	**Prevalence of needs** • Staff rated more total need than patients. **Agreement on needs** • There was moderate agreement on the presence of a need and fair agreement on unmet needs. • There was substantial disagreement on whether the patient was given the right kind of help or support. **Associations of needs** • Patient-rated unmet needs were associated with a worse overall quality of life and a worse social network. • Staff-rated unmet needs were associated with worse psychopathology and a worse social network.

	Author	Country & World Bank Classification	Study design & Sampling methodology	Population studied	Needs Assessment tool	Other Tools	Methods of Analysis	Summary of Findings
							analyses.	
	Lasalvia et al., 2000	Italy High income country	Cross sectional study Case identification without randomisation	247 patient and staff ratings Severe mental illness Urban setting Out-patient setting	CAN C (patient and staff)	BPRS DAS GAF	Frequencies & percentages Chi-squared tests Paired t-tests ANOVAs Percentage agreement Cohen's Kappa Multiple regression analyses. 22 CAN items grouped into 5 conceptual domains	**Prevalence of needs** • There were no significant differences found in the total needs but staff found more met need and patients more unmet need. **Agreement on needs** • There was poor agreement on both the presence of a need and on whether need had been met or not. **Associations of needs** • Higher disability predicted a higher number of patient-rated needs. • Higher disability, higher number of service contacts, and patient unemployment predicted a higher number of staff-rated needs. • Lower global functioning predicted higher disagreement in patients and staff ratings of needs.
	Gallagher & Teeson, 2000	Australia High income country	Cross sectional study Case identification without randomisation	283 patient and case manager ratings Serious mental illness Urban setting Out-patient setting ACT setting	CAN C (patient and staff)	HoNOS	Independent t-tests Pearson correlations. Paired t-tests	**Prevalence of needs** • Staff rated more needs than patients. • Patients of both standard and assertive case management groups rated themselves as having similar levels of need. • Staff rated the assertive case management patients as having significantly more needs than those in standard case management. **Agreement on needs** *No comment made* **Associations of needs** • Staff CAN ratings correlated highly with HoNOS scores. • Patient ratings of need correlated only moderately with staff ratings of need.
	Issakidis &	Australia	Cross sectional	78 patient and case manager	CANSAS	HoNOS	Frequencies &	**Prevalence of needs**

	Author	**Country & World Bank Classification**	**Study design & Sampling methodology**	**Population studied**	**Needs Assessment tool**	**Other Tools**	**Methods of Analysis**	**Summary of Findings**
	Teesson, 1999	High income country	study Case identification without randomisation	ratings Severe mental illness Urban setting In- and out-patient setting			percentages Cohen's Kappa coefficient Pearson correlations	• Staff reported significantly more total needs than patients. • The need areas identified by the two groups were similar. **Agreement on needs** • The level of agreement on the presence of a need was poor overall. **Associations of needs** • Patient rated needs were moderately correlated with staff ratings of disability on the HoNOS. • Staff ratings of disability and unmet needs were highly correlated, whereas ratings of disability and met need were moderately correlated.
	Slade et al., 1999	England High income country	Cross sectional study Case identification with randomisation	137 patient and 212 staff ratings Functional psychosis Urban setting Out-patient setting	CAN C (patient and staff)	GAF LQoL	Frequencies & percentages Pearson correlations Regression analysis	**Prevalence of needs** • Patients rated significant more total needs and unmet needs than staff. **Agreement on needs** *No comment made* **Associations of needs** • Increasing age and a psychotic diagnosis other than schizophrenia were associated with a higher quality of life. • There was a very strong positive relationship between patient ratings of met needs, but only a moderate positive relationship between ratings of unmet needs. • Patient ratings of unmet need and quality of life were more reliable than ratings by staff. • Both patient rated unmet and met needs were negatively associated with quality of life.
	Slade et al., 1998	England High income country	Cross sectional study Case identification with randomisation	137 patient and staff ratings Functional psychosis Urban and peri-urban In and out-patients	CAN C (patient and staff)	GAF	Frequencies & percentages t-tests Cohen's Kappa 22 CAN items grouped into 5 conceptual	**Prevalence of needs** • Patients rated significantly more total and unmet needs than staff but no significant difference in met needs. **Agreement on needs** • On average there was moderate agreement on the presence of a need and the presence of a met need for a particular domain, but only fair agreement on unmet need for a particular domain. • Areas with specific service response tended to have the best agreement and areas with less well-defined service responses tended to have the

	Author	**Country & World Bank Classification**	**Study design & Sampling methodology**	**Population studied**	**Needs Assessment tool**	**Other Tools**	**Methods of Analysis**	**Summary of Findings**
							domains	poorest agreement. **Associations of needs** • Need was not significantly associated with any patient sociodemographic characteristics.
	Comtois et al., 1998	Canada High income country	Cross sectional study Convenience sampling	47 patient and staff ratings First episode Schizophrenia spectrum disorder Urban and peri-urban Out-patients	NFCAS (staff) PPASQ (patient)		Frequencies & percentages Percentage agreement Cohen's Kappa	**Prevalence of needs** • Patients and staff rated different areas of needs. • Patients expressed more problems in the areas of interpersonal relationships and daily living, whereas staff was more concerned with impairments and deficits associated with the disorder and its treatment. **Agreement on needs** • Percentage agreement on average was good but the Kappa agreement was poor for all items that could be matched. **Associations of needs** *No comment made*
	Middelboe et al., 1998	Denmark High income country	Cross sectional study Purposive sampling	45 patient and 39 staff ratings Predominantly schizophrenia Urban Out-patients referred to housing service	CAN R (patient and staff)	BPRS GAF SLDS	Frequencies & percentages Pearson's correlation Cohen's Kappa	**Prevalence of needs** • Patients and staff rated similar numbers of needs but different areas of needs. • For both patients and staff needs were most prevalent in the areas of psychological and social functioning. • Staff rated 2-fold higher unmet needs within the areas 'psychological distress', 'psychotic symptoms', 'alcohol', and 'drugs' possibly reflecting the patients poor insight into their illness. **Agreement on needs** • There was a generally low level of agreement on the presence of a need. **Associations of needs** *No comment made.*

CHAPTER 3 METHODS

3.1 Study design

A quantitative descriptive study using a survey method was conducted.

3.2 Study population and sampling

Valkenberg hospital is one of three specialist psychiatric hospitals drawing patients from greater Cape Town and the Western and Southern Cape. Patients who follow up at Valkenberg Hospital, largely suffering from severe mental illness, represent a cross-section of cultures and languages. Patients range between 18 and 60 years, and are of both genders.

Patients who are frequently readmitted to hospital or who have prolonged hospital stays are referred to the Assertive Community Treatment (ACT) team. The ACT team is a specialist team that follows an assertive model of providing care, which includes treatment within the community, a high level of multidisciplinary staff support, a high patient to staff ratio, an emphasis on practical activities of daily living, and a team approach to case management so that clients have access to a number of staff. ACT patients typically suffer from chronic or relapsing psychosis; have poor social functioning; a history of poor compliance with treatment; and disengagement from standard services. Many have a dual diagnosis and live in unsuitable accommodation or under stressful living conditions (Botha et al., 2008).

A convenience sampling method was used for this study. All 100 patients and their carers on the Valkenberg ACT team caseload were approached by ACT clinicians to participate in the study. All patients met the existing ACT team inclusion criteria of being an adult between 18 to 65 years of age diagnosed with Schizophrenia, Schizo-Affective Disorder or Bipolar Affective Disorder type I (American Psychiatric Association, 2000), and having significant psychosocial impairment. Prior to being accepted by the ACT team, patients would have had either three or more admissions within 12 months, or five or more admissions in 18 months; or they had to restart clozapine two or more times in the preceding 12 months; or they would have had a prior prolonged admission of more than 6 months.

The carer was a person identified by the patients as being significantly involved in their psychosocial wellbeing. They had to be family or a close friend spending a minimum of 12 hours per week helping and supporting the patient. The ACT team staff component consisted of two psychiatric nurses, two social workers, a medical officer and a psychiatrist.

The study aimed to achieve a sample size in excess of 80 patients and 50 carers in keeping with published studies conducted by ACT teams (Botha et al., 2008; Macpherson et al., 2007; Macpherson et al., 2008).

3.3 Instruments

The CANSAS was selected as the most appropriate need assessment tool (Phelan et al., 1995) because of its good psychometric properties with demonstrated reliability and validity both locally (Flisher et al., 2012; Joska & Flisher, 2007) and internationally (Ponizovsky et al., 2014; Slade et al., 1999b). The CANSAS is a structured interview schedule covering both objective and subjective perspectives of need by recording patient, carer and staff views separately. Needs are defined as deficits in function, physical environment, mental or physical health. Unmet needs occur where these deficits are perceived to be partially provided for or not fully provided for by available services. It assesses needs in 22 health and social domains: accommodation, food, self-care, looking after the home, daytime activities, physical health, psychotic symptoms, information about condition and treatment, psychological distress, safety to self and others, abuse of alcohol, abuse of drugs, company, intimate relationships, sexual expression, childcare, access to telephone, education, transportation, budgeting and benefits. Ratings of need are made on a 3-point severity scale (0, ‘no problem’, indicating no need; 1, ‘no or moderate problem due to help given’, indicating a met need; 2 ‘serious problem’, indicating an unmet need; 9 ‘not known’). No additional domains were added.

Current levels of psychopathological symptoms were quantified using the PANSS (Kay et al., 1987). The PANSS is a 30-item scale with 16 general psychopathology symptom items, 7 positive-symptom items and 7 negative-symptom items. Each item is scored on the same 7-point severity scale, resulting in a range of possible scores from 30 to 210. The positive- and negative-symptom item groups are often scored separately with a possible range of 7–49. A patient with schizophrenia entering a clinical trial typically scores 91 and usual PANSS scores are 60 to 80 for stable outpatients and rarely exceed 80 to 150 for inpatients (Opler et al., 2006). The PANSS was selected for this study because it has been used internationally in studies correlating need and psychopathology (Ochoa et al., 2003; Grinshpoon & Ponizovsky, 2008), and locally in an ACT population (Botha et al., 2010).

The individual's overall current level of functioning was rated using the GAF (American Psychiatric Association, 2000). The GAF assesses overall psychological, social, and occupational functioning, excluding impairment due to physical or environmental factors. It is rated on a scale of 1–100, where 1 indicates lowest functioning and 100 the highest. A score of 50 or less indicates serious symptoms (e.g. suicidal ideation, severe obsessional rituals, frequent shoplifting) or any serious impairment in social, occupational or school functioning (e.g. no friends, unable to keep a job). The GAF is considered a reliable and valid measure of psychiatric disturbance and is the single most widely used rating scale to assess impairment in patients with psychiatric disorders (American Psychiatric Association, 2000; Piersma & Boes, 1997).

3.4 Procedure

Recruitment of participants

ACT team staff members were approached to take part in the study by the principal investigator and ACT team consultant psychiatrist at the planning stages of the study and again after commencing study. Staff members were provided with an information sheet detailing the study and all the staff members gave informed consent to participate.

Patients and carers were then approached by staff members to take part in the study between September 2012 and March 2013. Patients and carers were provided with an information sheet detailing the study and informed consent was obtained from those willing to take part. A record of all patients and carers approached was documented. The information sheet and informed consent forms used for the study are included in the appendices.

Data collection

Staff members were trained in the use of the CANSAS, PANSS, GAF and other study instruments by a member of the University of Cape Town Department of Psychiatry and Mental Health who was experienced in the use of these tools.

All data collection took place during routine clinical contacts. An attempt was always made to complete the data collection during one home visit but when a follow up visit was necessary it was arranged to coincide with the next scheduled clinical visit. At the follow up visit, the patient and carer were again approached for consent. This was given on all occasions.

The staff CANSAS assessment of patient needs was randomly completed by one of the staff members. Because the Valkenberg ACT team did not have specific case coordinators, every staff member knew the patients as well as the other. The patient and carer CANSAS was administered in the form of a structured interview by staff members. It was emphasised that the CANSAS should represent the independent view of the patient and carer and that no undue influence should be exerted. The ACT team was composed of staff who were fluent in the three dominant languages in the Western Cape. When an interpreter was required, interpretation into Afrikaans/Xhosa was done by one of the staff members trained in the CANSAS. The time taken to complete the CANSAS did not exceed 20 minutes.

The clinical measures were collected by the staff, which included the PANSS and the GAF. The time taken to complete the two instruments did not exceed 40 minutes.

Demographic and historical clinical information was obtained from the patient's clinical folder and entered on to a pro-forma. Demographic information included age, gender, occupation, education, marital status, accommodation type, residential suburb, the carer type and carer age. Clinical information included the DSM IV TR primary and substance diagnoses, age at onset of illness, and the duration of time following up with the ACT team.

3.5 Data management and analysis

All collected data was stored in a secure room in the UCT Department of Mental Health and Psychiatry.

The data was checked and thereafter entered into SPSS (version 20) for analysis by the principal investigator. A statistician from the department of Statistics at UCT was consulted to assist in the data analysis. The statistician gave guidance on which tests to employ and how best to interpret the results.

Mean and standard deviations were computed, deriving ranges for continuous variables and frequencies, and percentages for ordinal and nominal variables. Means and interquartile ranges were computed for data that was not normally distributed. Kruskal-Wallis tests and *post hoc* Bonferroni correction were used to compare mean met, unmet and total need as rated by patients, carers, and ACT staff. Cohen's Kappa statistic was used to compare perceptions on the presence of a need. The Kappa statistic controls for chance agreement, with values greater than 0.7 representing excellent agreement, values below 0.4 poor agreement and values between 0.4 and 0.7 fair to very good agreement (Cohen, 1960; Landis & Koch, 1977). The relationships between needs and various socio-demographic and clinical characteristics were explored using non-parametric tests. These included Mann-Whitney tests, Kruskal-Wallis tests with Bonferroni correction and Spearman's rank correlation.

3.6 Ethical and legal considerations

Ethical approval was obtained from the University of Cape Town Human Research Ethics Committee.

There was minimal risk associated with participating in this study. Potential benefits of participating were that the patients and carers were able to express their needs to the team involved in their care. The knowledge emanating from the study will be used to plan for a better clinical service to a historically vulnerable and neglected group.

All the participants received the Participant Information Sheet, which was available in English, Xhosa and Afrikaans. All participants were also given a detailed explanation of the information sheet in the language of their choice after which a consent form was signed by those willing. It was emphasised that the decision to participate or not to participate would not influence their clinical care. All the ACT team staff members obtaining the consent had research and clinical experience in the informed consent procedure. Participants did not receive any compensation for their participation. Plans were put in place to discuss any clinical concerns likely to have an impact on a participant with the study supervisor and to notify the relevant clinician. No clinical concerns were raised during the course of the study.

Confidentiality of the data was assured by having the completed data sheets collected from the ACT staff on the same day that they were collected and by ensuring that only the principal investigator had access to the raw data. Any written or verbal reports or presentations of this information will retain the patient's anonymity.

The results of the project will be made available to the relevant authorities and the scientific community through presentations and publications. Participants will be informed of the results at the regular Family Psycho-Education Days hosted by the ACT team.

CHAPTER 4 RESULTS

4.1 Characteristics of sample

4.1.1 Participants

From September 2012 to March 2013, all 100 patients on the ACT team case load were approached to participate in the study. A total of 73 patients gave their consent to participate in the study. Of the 27 patients who did not consent, 18 patients declined the invitation to take part, four patients were assessed as being too ill and unable to give informed consent, four patients were in prison at the time of the study, and one patient was missing and not locatable.

Of the 73 patients agreeing to take part in the study, two refused carer participation and one patient did not have a carer due to living alone. Seventy carers were approached for consent, two of whom declined participation. In all, 68 carers agreed to participate.

All six staff members of the ACT team, comprising two social workers, two psychiatric nurses, a psychiatric medical officer and a psychiatrist, consented to take part.

The data collected from consenting patients, carers and staff is presented below: Ratings of 'unknown' were not included in the calculations and they were not taken as being synonymous with 'no need'.

4.1.2 Socio-demographic characteristics

Patients

There were more males (61.2%) than females (38.4%) in the sample of 73 patients interviewed. The median age was 46.0 years with an interquartile range of 34.0–51.0 years. Most participants were single, never having married (83.6%); 11% percent were divorced or separated; 4.1% had a deceased spouse; and a minority were currently married (1.4%).

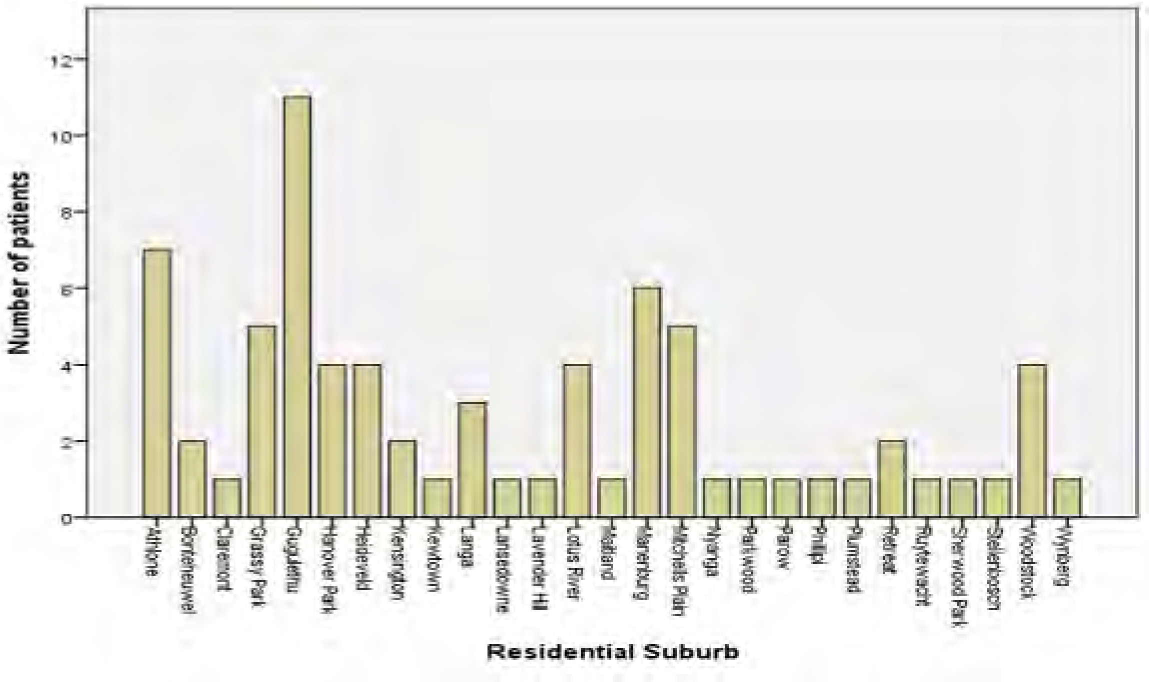
Few of the patients had university education (4.1%); 37% of patients had achieved a high school educational level between grades 11 and 12, and 21.9% between grades 8 and 10. Slightly more than a third (37%) had a primary school educational level of less than grade 8.

The majority of patients were unemployed and receiving a disability grant (89%).

Table 5: Employment status of patients

	Frequency (n)	Percentage (%)
Professional/technical/artisan employed	3	4.1
Non-professional employed	1	1.4
Unemployed, receiving disability grant	65	89.0
Unemployed, not receiving disability grant	4	5.5
Total	**73**	**100.0**

The patients lived in a total of 27 residential suburbs, primarily on the Cape Flats, an area designated for non-whites under apartheid. These suburbs consist of formal and informal housing, including low-cost housing and shacks. The areas continue to be characterised by high rates of poverty, unemployment, overcrowding and gang activity (Spinks, 2001; Crankshaw, 2012). Most patients lived in Gugulethu (15%), followed by Athlone (10%), Manenburg (9%), Mitchell's Plain (7%), and Grassy Park (7%). The residential suburbs are depicted in Graph 1.

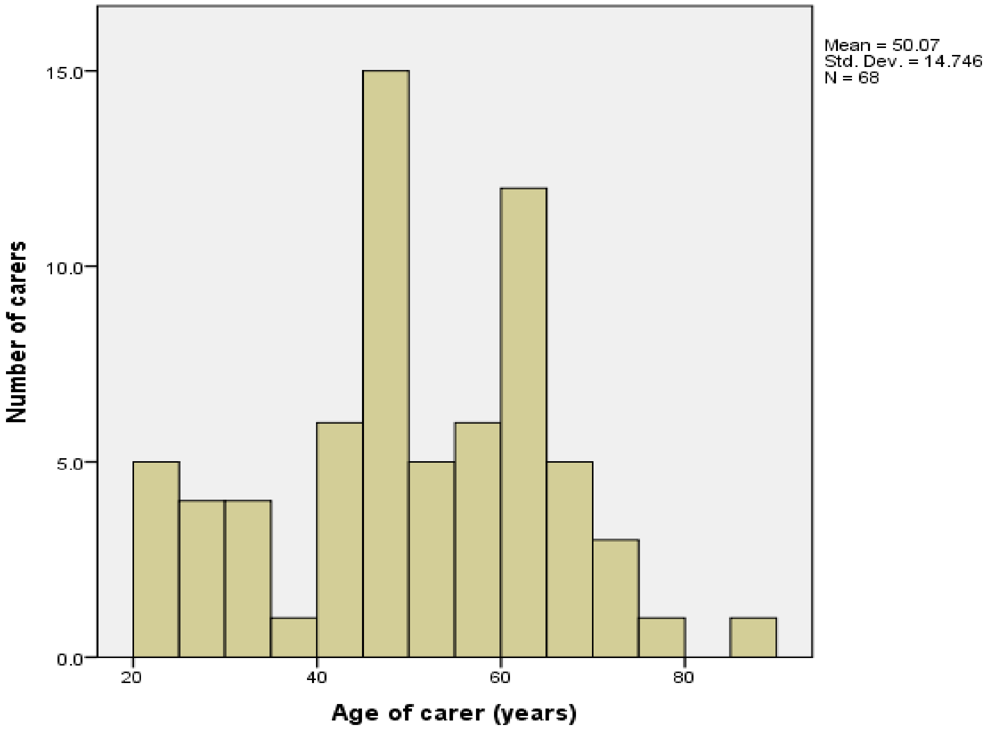


Graph 1: Residential suburbs of patients

Of the patients, 9.6% lived alone, in their own house and 65.8% lived with family, either inside the family house (52.1%) or in a building outside the family house (13.7%). A further 23.2% of patients were tenants away from family, living either inside the main house (16.4%) or in a building outside the main house (6.8%). One patient (1.4%) was homeless with no fixed abode

Carers

A total of 68 carers took part in the study, with a median age of 49.0 years and an interquartile range of 42.3–63.0 years. Graph 2 depicts the age of the carers.



Graph 2: Age of carers

The majority of carers were family members, with 37.0% being a parent, 31.5% other family, and 2.7% a spouse. In 21.9%, the type of carer identified was 'other', which was not a relative. Five patients (6.8%) did not identify a carer.

4.1.3 Clinical characteristics of patients

The median age of onset of psychiatric illness was 21.0 years, with an interquartile range of 18.0–24.0 years. The majority of patients had a primary DSM-IV TR diagnosis of Schizophrenia (58.9%), followed by Schizo-affective disorder (34.2%) and Bipolar Mood Disorder I (6.8%).

The median duration of patients following up with the ACT team was 44.0 months, with an interquartile range of 21.5–57.5 months. The minimum duration of time following up with the ACT team was 2 months and the maximum 66 months.

The most common drugs of abuse used by patients were alcohol, cannabis and methamphetamines. Slightly more than half (54.8%) the patients met the criteria for a substance use disorder, of which half (27.4%) had a diagnosis of a combination of cannabis, methamphetamine and alcohol abuse or dependence. The remaining 45.2%

(n=33) did not report using any drugs of abuse. Overall, 40 patients (54.8%) abused a substance, 9 (22.5%) female and 31 (77.5%) male. There was a significant difference in the proportion of substance abusers by gender (chi square = 11.99, p = .017).

Table 6: Patient substance misuse

	Total number (%)	Number of males (%)	Number of females (%)
Cannabis abuse/dependence only	10 (13.7%)	9 (90%)	1 (10%)
Methamphetamine abuse/dependence only	3 (4.1%)	3 (100%)	0 (0.0%)
Alcohol abuse/dependence only	7 (9.6%)	4 (57.1%)	3 (43.9%)
Combination of one or more of cannabis, methamphetamine, alcohol abuse/dependence	20 (27.4%)	15 (75%)	5 (25.0%)
No substance misuse	33 (45.0)	14 (42.4%)	19 (57%)
Total	**73**	**45**	**9**

The patients were found to have low levels of psychopathology, with a median score for the PANSS of 48.0 with an interquartile range of 38.5–62.5.

While none of the patients was assessed on the GAF as having gross psychiatric symptoms or gross impairment of personal, social and psychiatric functioning (score under 20), approximately a third (32.9%) were living with serious symptoms or impairment in most (score 21–30) or several (score 31–40) of these areas of functioning.

Half of the sample (52%) was living with serious symptoms or impairment in one area (score 41–50) or moderate symptoms or impairment in several (score 51–60) areas of personal social and occupational functioning. Only 15% were functioning fairly well (score 61–70), with mild symptoms or some difficulty in social or occupational functioning.

Table 7: Patient Global Assessment of Functioning (GAF) score

GAF score	Number (%)
21–30	7 (9.6%)
31–40	17 (23.3%)
41–50	19 (26.0%)
51–60	19 (26.0%)
61–70	11 (15.1%)
Total	**73 (100%)**

4.2 Ratings of needs

4.2.1 Patient-rated needs

The mean number of total needs of the patients involved in the study was 4.9 (S.D 3.5, range 0–17). This reflects a mean met needs of 2.9 (S.D 1.8, range 0–9) and a mean unmet needs of 2.0 (S.D 2.5, range 0–13). Needs are defined as deficits in function, physical environment, mental or physical health. Unmet need occurs where these deficits are perceived to be not fully or only partially provided for by available services.

The CANSAS ratings by the patients are presented in Table 8.

Table 8: Patients assessments of levels of needs for 22 items of the CANSAS (n=73)

Needs domain	No need n (%)	Met need n (%)	Unmet need n (%)	Unknown n (%)	Total need n (%)
Physical health	48 (65.8%)	19 (26.0%)	6 (8.2%)	0	25 (34.2%)
Psychotic symptoms	45 (61.6%)	21 (28.8%)	7 (9.6%)	0	28 (38.4%)
Alcohol	68 (93.2%)	4 (5.5%)	1 (1.4%)	0	5 (6.9%)
Drug	60 (82.2%)	11 (15.1%)	2 (2.7%)	0	13 (17.8%)
Safety to self	66 (90.4%)	5 (6.8%)	2 (2.7%)	0	7 (9.5%)
Safety to others	67 (91.8%)	5 (6.8%)	1 (1.4%)	0	6 (8.2%)
Psychological distress	47 (64.4%)	19 (26.0%)	7 (9.6%)	0	26 (35.6%)
Accommodation	56 (76.7%)	9 (12.3%)	8 (11%)	0	17 (23.3%)
Food	60 (82.2%)	10 (13.7%)	3 (4.1%)	0	13 (17.8%)
Daytime activities	49 (67.1%)	13 (17.8%)	11 (15.1%)	0	24 (32.9%)
Company	54 (74.0%)	12 (16.4%)	7 (9.6%)	0	19 (26.0%)

Needs domain	No need n (%)	Met need n (%)	Unmet need n (%)	Unknown n (%)	Total need n (%)
Intimate relationships	55 (75.3%)	3 (4.1%)	15 (20.5%)	0	18 (24.6%)
Sexual expression	52 (71.2%)	4 (5.5%)	15 (20.5%)	2 (2.7%)	19 (26.0%)
Information	49 (67.1%)	14 (19.2%)	8 (11.0%)	2 (2.7%)	22 (30.2%)
Telephone	55 (75.3%)	6 (8.2%)	11 (15.1%)	1 (1.4%)	17 (23.3%)
Transport	63 (86.3%)	5 (6.8%)	5 (6.8%)	0	10 (13.6%)
Benefits	52 (71.2%)	9 (12.3%)	11 (15.1%)	1 (1.4)	20 (27.4%)
Money	49 (67.1%)	16 (21.9%)	8 (11.0%)	0	24 (32.9%)
Self-care	66 (90.4%)	6 (8.2%)	1 (1.4%)	0	7 (9.6%)
Child care	65 (89.0%)	3 (4.1%)	5 (6.8%)	0	8 (10.9%)
Education	57 (78.1%)	9 (12.3%)	6 (8.2%)	1 (1.4%)	15 (20.5%)
Looking after home	63 (86.3%)	7 (9.6%)	3 (4.1%)	0	10 (13.7%)

For all the need domains, patients rated more ‘no need’ than met or unmet needs.

Patients rated the most total needs as being in the domains of ‘psychotic symptoms’ (38.4%), ‘psychological distress’ (35.6%), ‘physical health’ (34.2%), ‘daytime activities’ (32.9%) and ‘money’ (32.9%).

The domains with the most unmet needs were identified by the patients as being ‘sexual expression’ (20.5%), ‘intimate relationships’ (20.5%), ‘telephone’ (15.1%), ‘benefits’ (15.1%) and ‘daytime activities’ (15.1%).

Most met needs were in the domains of ‘psychotic symptoms’ (28.8%), ‘physical health’ (26.0%), ‘psychological distress’ (26.0%), ‘money’ (21.9%) and ‘information’ (19.2%).

Overall there were few ratings of ‘unknown’ by the patients and they were in the domains of ‘information’ (2.7%), ‘sexual expression’ (2.7%), ‘education’ (1.4%), ‘telephone’ (1.4%) and ‘benefits’ (1.4%).

4.2.2 Carer-rated needs

The mean number of total needs as rated by the carers was 6.1 (S.D 3.6, range 0–15). This reflects a mean met needs of 3.5 (S.D 2.2, range 0–9) and a mean unmet needs of 2.6 (S.D 2.3, range 0–11). The CANSAS ratings by the carers are presented in Table 9.

Table 9: Carer assessments of levels of needs for 22 items of the CANSAS (n=68)

Needs domain	No need n (%)	Met need n (%)	Unmet need n (%)	Unknown n (%)	Total need n (%)
Physical health	49 (72.1%)	15 (22.1%)	3 (4.4%)	1 (1.5%)	18 (26.5%)
Psychotic symptoms	26 (38.2%)	18 (26.5%)	24 (32.9%)	0	42 (54.4%)
Alcohol	51 (75.0%)	5 (7.4%)	11 (16.2%)	1 (1.5%)	16 (23.6%)
Drugs	50 (73.5%)	8 (11.8%)	10 (14.7%)	0	18 (26.5%)
Safety to self	60 (82.2%)	5 (7.4%)	3 (4.4%)	0	8 (11.8%)
Safety to others	37 (54.4%)	25 (36.8%)	6 (8.8%)	0	31 (45.6%)
Psychological distress	50 (73.5%)	16 (23.5%)	2 (2.9%)	0	18 (26.4%)
Accommodation	53 (77.9%)	7 (10.3%)	8 (11.8%)	0	15 (22.1%)
Food	56 (82.4%)	9 (13.2%)	3 (4.4%)	0	12 (17.6%)
Daytime activities	34 (50.0%)	22 (32.4%)	12 (17.6%)	0	34 (50.0%)
Company	47 (69.1%)	12 (17.6%)	7 (10.3%)	2 (2.9%)	19 (27.9%)
Intimate relationships	46 (67.6%)	4 (5.9%)	16 (23.5%)	2 (2.9%)	20 (29.4%)
Sexual expression	33 (48.5%)	2 (2.9%)	11 (16.2%)	22 (32.4%)	13 (19.1%)
Information	54 (79.4%)	9 (13.2%)	1 (1.5%)	4 (5.9%)	10 (14.7%)
Telephone	58 (85.3%)	3 (4.4%)	5 (7.4%)	2 (2.9%)	8 (11.8%)
Transport	60 (88.2%)	3 (4.4%)	5 (7.4%)	0	8 (11.8%)
Benefits	54 (79.4%)	8 (11.8%)	3 (4.4%)	3 (4.4%)	11 (16.2%)
Money	34 (50.0%)	14 (20.6%)	20 (29.4%)	0	34 (50.0%)
Self-care	41 (60.3%)	23 (33.8%)	4 (5.9%)	0	27 (39.7%)
Child care	58 (85.3%)	4 (5.9%)	4 (5.9%)	2 (2.9%)	8 (11.8%)
Education	61 (89.7%)	4 (5.9%)	2 (2.9%)	1 (1.5%)	6 (8.8%)
Looking after home	32 (47.1%)	23 (33.8%)	13 (19.1%)	0	36 (52.9%)

In the majority of the need domains, carers rated more ‘no need’ than met and unmet needs. The only domains in which met and unmet needs outnumbered no needs were ‘psychotic symptoms’, ‘looking after the home’ and ‘sexual expression’.

Carers rated the most total needs as being in the domains of ‘psychotic symptoms’ (54.4%), ‘looking after home’ (52.9%), ‘money’ (50.0%), ‘daytime activities’ (50.0%) and ‘safety to others’ (45.6%).

The most carer-rated unmet needs were in the domains of 'psychotic symptoms' (32.9%), 'money' (29.4%), 'intimate relationships' (23.5%), 'looking after home' (19.1%) and 'daytime activities' (17.6%).

Most carer-rated met needs were in the domains of 'safety to others' (36.8%), 'self-care' (33.8%), 'looking after home' (33.8%), 'daytime activities' (32.4%) and 'psychotic symptoms' (26.5%).

A relatively high percentage of carers rated the domain of sexual expression as unknown (32.4%).

4.2.3 Staff-rated needs

The mean number of total needs as rated by ACT staff members was 7.3 (S.D 2.7, range 1–13), which reflects a mean met needs of 4.7 (S.D 1.9, range 1–10) and a mean unmet needs of 2.6 (S.D 2.2, range 0–8). The CANSAS ratings by the staff are presented in Table 10.

Table 10: Staff assessments of levels of needs for 22 items of the CANSAS (n=68)

Needs domain	No need n (%)	Met need n (%)	Unmet need n (%)	Unknown n (%)	Total need n (%)
Physical health	45 (61.6%)	22 (30.1%)	6 (8.2%)	0	28 (38.2%)
Psychotic symptoms	18 (24.7%)	38 (52.1%)	17 (23.3%)	0	55 (75.4%)
Alcohol	44 (60.3%)	9 (12.3%)	16 (21.9%)	4 (5.5%)	25 (34.2%)
Drugs	41 (56.2%)	10 (13.7%)	21 (28.8%)	1 (1.4%)	31 (42.5%)
Safety to self	65 (89.0%)	8 (11.0%)	0	0	8 (11.0%)
Safety to others	29 (39.7%)	37 (50.7%)	6 (8.2%)	1 (1.4%)	43 (58.9%)
Psychological distress	65 (89.0%)	6 (8.2%)	2 (2.7%)	0	8 (10.9%)
Accommodation	49 (67.1%)	18 (24.7%)	6 (8.2%)	0	24 (32.9%)
Food	68 (93.2%)	4 (5.5%)	1 (1.4%)	0	5 (6.9%)
Daytime activities	13 (17.8%)	32 (43.8%)	28 (38.4%)	0	60 (82.2%)
Company	22 (30.1%)	35 (47.9%)	14 (19.2%)	2 (2.7%)	49 (67.1%)
Intimate relationships	34 (46.6%)	5 (6.8%)	20 (27.4%)	14 (19.2%)	25 (34.2%)
Sexual expression	14 (19.2%)	2 (2.7%)	14 (19.2%)	43 (58.9%)	16 (21.9%)
Information	72 (98.6%)	0	0	1 (1.4%)	0
Telephone	58 (85.3%)	3 (4.4%)	5 (7.4%)	2 (2.9%)	8 (11.8%)

Needs domain	No need n (%)	Met need n (%)	Unmet need n (%)	Unknown n (%)	Total need n (%)
Transport	65 (89.0%)	3 (4.1%)	5 (6.8%)	0	8 (10.9%)
Benefits	60 (82.2%)	11 (15.1%)	2 (2.7%)	0	13 (17.8%)
Money	34 (46.6%)	23 (31.5%)	15 (20.5%)	1 (1.4%)	38 (52.0%)
Self-care	37 (50.7%)	33 (45.2%)	3 (4.1%)	0	36 (49.3%)
Child care	64 (87.7%)	2 (2.7%)	7 (9.6%)	0	9 (12.3%)
Education	65 (89.0%)	7 (9.6%)	1 (1.4%)	0	8 (11.0%)
Looking after home	34 (46.6%)	34 (46.6%)	5 (6.8%)	0	39 (53.4%)

In the majority of need domains, staff rated more areas of 'no need' than met and unmet needs. The domains in which there were more met and unmet needs than 'no need' were 'psychotic symptoms', 'safety to others', 'daytime activities', 'company', 'intimate relationships', 'sexual expression', 'money' and 'looking after the home'.

Staff rated the most total needs as being in the domains of 'daytime activities' (82.2%), 'psychotic symptoms' (75.4%), 'company' (67.1%), 'safety to others' (58.9%) and 'looking after home' (53.4%).

The domains with the most unmet needs were identified by the staff as being 'daytime activities' (38.4%), 'drugs' (28.8%), 'intimate relationships' (27.4%), 'psychotic symptoms' (23.3%) and 'alcohol' (17.6%).

Most staff-rated met needs were in the domains of 'psychotic symptoms' (52.1%), 'safety to others' (50.7%), 'company' (47.9%), 'looking after home' (46.6%) and 'self-care' (45.2%).

There were high staff ratings of 'unknown' for the domains 'sexual expression' (58.9%), 'intimate relationships' (19.2%) and 'alcohol' (5.5%).

4.2.4 Patient- versus carer-rated needs

Upon using the Kruskal-Wallis test and Bonferroni correction, the differences in needs as rated by patients and carers was found to be non-significant for total number of needs (H(2)= 5.53, $p > 0.0167$), met needs (H(2)= 2.77, $p > 0.0167$), and unmet needs (H(2)= 3.92, $p > 0.0167$).

Table 11: Mean number of needs as rated by patients and carers

	Mean total needs	Mean met needs	Mean unmet needs
Patients	4.9	2.9	2
Carers	6.1	3.5	2.6

Patients and carers both felt that there were 'no problems' present in the majority of the needs domains. Carers rated more needs than patients although the differences in the means were all non-significant statistically. Both groups felt that most of the needs were met as compared to unmet.

The patients and carers both rated highest total needs in the domains of 'psychotic symptoms' and 'daytime activities'. Carers expressed more of these needs to be unmet whilst patients rated more needs in these domains as being met.

Both groups found significant unmet needs in the domains of 'intimate relationships' and 'daytime activities'. A high percentage of carers rated the domain of sexual expression as unknown (32.4%) and yet for patients, this domain had the highest percentage of unmet needs (20.5%).

4.2.5 Patient- versus staff-rated needs

Staff identified more needs than patients but both felt that more needs were met than unmet.

Table 12: Mean number of needs as rated by patients and staff

	Mean total needs	Mean met needs	Mean unmet needs
Patients	4.9	2.9	2
Staff	7.3	4,7	2.6

Significant differences were detected in patient and staff ratings of total number of needs (H (2) = 28.37, $p < 0.0167$) and met needs (H (2) = 32.05, $p < 0.0167$). There was no significant difference found in the patient and staff ratings of unmet need (H (2) = 5.24, $p > 0.0167$).

Staff and patients were alike in having more domains with 'no problem' than domains with met or unmet needs.

Both groups rated highest total needs in the domains of 'psychotic symptoms' and 'daytime activities'. Patients also found high total needs for 'physical symptoms', 'psychological distress' and 'money', which staff did not find. Staff rated higher total needs for 'company', 'looking after the home' and 'safety to others' than patients.

Staff and patients rated high unmet needs in the domains of 'daytime activities' and 'intimate relationships'. Staff differed from patients in finding high unmet needs for 'drugs' and 'alcohol', whilst patients found high unmet needs for 'sexual expression' and 'benefits', which staff did not find.

4.2.6 Carer- versus staff-rated needs

Staff identified more needs when compared to carers, although both groups rated more needs as met than unmet.

Table 13: Mean number of needs as rated by carers and staff

	Mean total needs	Mean met needs	Mean unmet needs
Carers	6.1	3.5	2.6
Staff	7.3	4,7	2.6

The differences in the needs as rated by carers and staff were significant for both met needs (H (2) = 12.86, $p< 0.0167$) and total number of needs (H (2) = 6.737, $p< 0.0167$) but non-significant for unmet needs (H (2) = 0.03, $p> 0.0167$).

Like staff, carers tended to rate 'no problem' in the majority of domains.

Both groups rated high total needs for 'daytime activities', 'psychotic symptoms', 'looking after the home' and 'safety to others'. Although the mean number of unmet needs was similar between carers and staff, different domains of needs were reported by the groups. The two groups were similar in rating high unmet needs for 'daytime activities', 'psychotic symptoms' and 'intimate relationships'. They differed in the domains of 'alcohol' and 'drugs' where staff identified high unmet needs, which the carers did not identify, and in the domains of 'money' and 'looking after the home' where carers identified high unmet needs, which the staff did not.

Both groups rated relatively high percentages of 'unknown' for the domain of 'sexual expression'.

4.3 Agreement on the presence of needs

Cohen's Kappa statistic was used to compare the CANSAS ratings of the patients, carers and clinicians. This has been specifically linked by Landis & Koch (1977) to level of agreement as follows: 0–0.2 'poor agreement'; 0.2–0.4 'fair agreement'; 0.4–0.6 'moderate agreement'; 0.6–0.8 'substantial agreement'; 0.8–1.0 'almost perfect agreement'.

Table 14: Agreement between patients, carer and staff CANSAS ratings using Cohen's Kappa coefficient

Needs domain	Patient versus staff agreement	Patient versus carer agreement	Staff versus carer agreement
Physical health	0.11	0.27	0.23
Psychotic symptoms	0.05	0.19	0.29
Alcohol	0.07	0.21	0.40
Drugs	0.22	0.26	0.30
Safety to self	0.20	0.49	0.31
Safety to others	0.09	0.07	0.16
Psychological distress	0.18	0.16	0.41
Accommodation	0.11	0.16	0.07
Food	0.21	0.20	0.42
Daytime activities	0.19	0.30	0.21
Company	0.15	0.16	0.25
Intimate relationships	0.21	0.30	0.23
Sexual expression	0.08	0.16	0.11
Information	-0.01	-0.03	-0.02
Telephone	0.26	0.28	0.24
Transport	0.57	0.69	0.59
Benefits	-0.14	0.11	0.17
Money	0.31	0.33	0.27
Self-care	0.10	0.11	0.40
Child care	0.48	0.32	0.21

Needs domain	Patient versus staff agreement	Patient versus carer agreement	Staff versus carer agreement
Education	0.34	0.29	0.23
Looking after home	0.15	0.12	0.09

Agreement varied widely across the different domains in all three 2-way comparisons. Overall agreement was 'poor' to 'fair'. Out of the 66 total domains, there were 30 ratings of 'poor' agreement, 27 of 'fair' agreement and 9 ratings of 'moderate' agreement. No domains showed 'substantial' or 'almost perfect' agreement.

The domain of transport had the highest levels of agreement for all three 2-way comparisons. In all three 2-way comparisons, there was a negative Kappa coefficient in the domain 'information', which suggested that there may have been active disagreement in perceptions in this domain. There may also have been disagreement between patients and staff in the domain of 'benefits'.

The lowest level of agreement was between ratings made by patients and staff, for whom 14 domains had 'poor' agreement, and 6 domains 'fair' agreement. In only two domains (childcare and transport) was agreement moderate.

Ratings made by patients and carers had better agreement than those between patients and staff. For patients and carers, there were 10 domains with 'poor' agreement, 10 domains with 'fair' agreement and 2 domains (transport and safety to self) with moderate agreement.

The highest level of agreement was between ratings made by staff and carers, for whom there were 5 domains of 'moderate' agreement, 11 domains of 'fair' agreement and 6 domains of 'poor' agreement.

4.4 Associations of patient-rated needs

Table 15 below depicts the associations of patient-rated needs and socio-demographic and clinical characteristics.

Table 15: Associations of patient-rated needs

	Total unmet needs	Total needs
Socio-demographic characteristic		
Patient age[1]	-0.20 *NS*	-0.17 *NS*
Gender[2]	548.5 *NS*	587.5 *NS*
Marital Status[2]	280.5 *NS*	275.5 *NS*
Education[3]	1.67 *NS*	1.80 *NS*
Type of accommodation[4]	5.27 *NS*	10.91 **
Type of carer[5]	0.86 *NS*	1.77 *NS*
Age of carer[1]	0.18 *NS*	0.15 *NS*
Clinical characteristics		
Primary diagnosis[2]	577.5 *NS*	524.0 *NS*
Substance diagnosis[2]	477.50 **	441.0 **
PANSS total score[1]	0.46 **	0.49 **
PANSS negative scale[1]	0.44 **	0.43 **
PANSS positive scale[1]	0.32 **	0.36 **
PANSS general scale[1]	0.42 **	0.44 **
GAF[2]	617.0 *NS*	420.5 **
Age at of illness onset [1]	-0.13 *NS*	-0.10 *NS*
Duration in ACT team[1]	0.05 *NS*	0.07 *NS*

NS non-significant

** Significant

1. Spearman's correlation. Significant at the 0.01 level (2-tailed)
2. Mann-Whitney U test. Significant at the 0.05 level (2-tailed)
3. Kruskal-Wallis test with Bonferroni correction. Significant at the 0.025 level (2-tailed)
4. Kruskal-Wallis test with Bonferroni correction. Significant at the 0.01 level (2-tailed)
5. Kruskal-Wallis test with Bonferroni correction. Significant at the 0.0167 level (2-tailed)

4.4.1 Associations of needs and socio-demographic characteristics

There were no significant relationships observed between patient-rated unmet and total needs, and most of the socio-demographic characteristics collected. These included patient age, gender, marital status, education, carer type, and carer age.

The only significant difference detected was in the total needs expressed by patients residing in different types of accommodation ($H (5) = 10.907$, $p< 0.05$). Mann-Whitney tests were used to follow up this finding. A Bonferroni Correction was applied and all effects were reported at a 0.010 level of significance. Patients residing in their own house independent from family expressed significantly fewer total needs than those who lived inside a family house (U =51.00, Z= -2.59, r= -0.30). There were no significant differences in the unmet needs expressed by patients residing in different types of accommodation (H (5) = 5.277, p> 0.01).

4.4.2 Associations of needs and clinical characteristics

No significant relationships were observed between patient-rated unmet and total needs and the patient primary diagnosis, age at illness onset and duration in the ACT team.

Patient-rated unmet needs did not differ significantly between those who had serious symptoms on the GAF scale (score ≤ 50) (median =1.00) and those with mild or moderate symptoms on the GAF scale (score > 51) (median =1.00), U=617.0, z=-0.32, ns, r=-0.04. However, patient-rated total needs differed significantly between those with serious symptoms on the GAF scale (median=5.00) and those with mild or moderate symptoms (median= 3.00), U=420.5, z=-2.54, p<0.05, r=-0.30.

Both patient-rated unmet needs and total needs were significantly correlated with the PANSS total score, and with the positive, negative and general scales making up the PANSS total score. The total score on the PANSS was significantly correlated with both patient-rated unmet needs, r =.46, p < 0.01 and also patient rated total needs, r = .49, p< 0.01. The PANSS negative scale score significantly correlated with both patient-rated unmet needs, r =.44, p < 0.01 and also patient rated total needs, r = .43, p< 0.01. The PANSS positive scale score significantly correlated with both patient-rated unmet needs, r =.32, p < 0.01 and also patient rated total needs, r = .36, p< 0.01. The PANSS general scale score significantly correlated with both patient-rated unmet needs, r =.42, p < 0.01 and also patient rated total needs, r = .44, p< 0.01.

Patient-rated unmet needs differed significantly between patients who did not use substances (median=0.0) and those who admitted to using substances (median = 2.0), U=477.5, z=-2.08, p <0.05, r=-0.24. Similarly patient-rated total needs also differed significantly between those who did not use substances (median= 3.0) and those that used substances (median= 4.0), U=441.0, z=-2.45, p<0.05, r=-0.29.

CHAPTER 5 DISCUSSION

This study was carried out on patients with severe mental illness being followed up by an ACT team from an urban and specialist psychiatric hospital in the Western Cape Province of South Africa. The study aimed to investigate the relationship between patient, carer and staff perceptions of patient needs in patients treated by the Valkenberg Hospital ACT team. Specifically, the study aimed to establish the following:

1 Patient, carer and staff perceptions of patient needs.

2 The extent to which these perceptions were homogeneous or heterogeneous.

3 The socio-demographic and clinical factors associated with local perceived needs.

This chapter will elucidate the key findings of the study and their implications for the development and delivery of services to patients treated within an ACT service.

5.1 Patient, carer and staff perceptions of patient needs

Taken as a whole, the findings of this study support the calls for adopting recovery-orientated practices within South African Mental Health Services (Parker, 2012) and within ACT Services (Kidd et al., 2010; Salyers & Tsemberis, 2007, Morse et al., 2015). The recovery philosophy's fundamental components include hope, self-direction, empowerment, holistic, nonlinear, strengths based, peer support, and individualised and person-centred recovery supports (Leamy et al., 2011; Slade et al., 2012). Recovery-based supports focus on self-determined life goals; collaboration between patients, providers and their families; patient choice; a diversity of treatment options; and individually tailored services (Kidd et al., 2010).

Discussion of the findings of this study are therefore framed within a recovery approach, specifically, the dimensional model of recovery proposed by Whitley and Drake, 2010. The model proposes five dimensions of recovery: clinical recovery, related to experiencing improvement in symptoms; existential recovery, that is, having a sense of hope, empowerment, agency, and spiritual wellbeing; functional recovery, or obtaining societal roles and responsibilities that enable participation in everyday life, including employment, education and stable housing; physical recovery, pursuing better health and a healthy lifestyle; and social recovery, experiencing enhanced and meaningful relationships with family, friends, and the wider community. The model also identifies lay, professional and systemic resources that promote each recovery dimension.

5.1.1 Patient-rated needs

Even though the patients reported socioeconomic and clinical characteristics universal to severe mental illness (Botha et al., 2014; Kulhara et al., 2010; Wiersma et al., 2009; Macpherson et al., 2008), the needs they expressed were varied, encompassed multiple domains and were unique to the local setting. These needs are consistent with the recovery principle ‘personhood’ which recognises that people with a mental illness have the same wants and needs as everyone else (Anthony, 2004).

Patients identified a mean of 4.9 needs, of which more were met (2.9) than unmet (2.0). These numbers of total needs and the presence of more met than unmet needs are in keeping with needs expressed by patients in high- and middle-income countries serviced by integrated and continuous systems of mental health care (Wiersma et al., 2009; Popescu & Miclutia, 2009; Ochoa et al., 2003; Slade et al., 1996; Slade et al., 1998; Wiersma et al., 1998). The domains with most unmet needs were more psychosocial than biomedical and included ‘sexual expression’, ‘intimate relationships’, ‘daytime activities’, ‘telephone’ and ‘benefits’, which demonstrates that the local service is similar to other mental health services internationally where patients experience the service as being less able to assist with the more psychosocial needs compared to needs that are more biomedical (Middelboe et al., 1998; Fleury et al., 2006; Issakidis & Teeson, 1999).

Patients expressed high needs in the domain of ‘psychotic symptoms’ which fall within the clinical dimension of recovery (Whitley & Drake, 2010). High needs in this domain are in keeping with the literature describing the persistence of psychopathological symptoms in those receiving treatment for severe mental illness (Tandon et al., 2010; Suzuki et al., 2011). They are also consistent with both western and non-western literature which found the most consistently reported area of needs by the patients to be psychotic symptoms (Foldemo & Bogren, 2002; Ochoa et al., 2003; Kulhara et al., 2010; Zahid & Ohaeri, 2013). The finding speaks to the need for ACT services to adopt evidence-based interventions when attempting to improve psychopathological symptoms. Interventions suggested by the literature include patient education, collaborating with carers, making more use of atypical oral and long-acting depot antipsychotics, and employing cognitive behaviour therapy for selected individuals (Pinninti et al., 2010; NICE, 2014). The finding also alludes to the need for the service to adopt evidenced psychosocial interventions focused on the reduction of symptoms and effects of the illness itself which are congruent with recovery values. Psychosocial interventions that are congruent with recovery values include, for example, shared decision making in medication use (Deegan et al., 2008), illness management and recovery (Mueser et al., 2006), and wellness action recovery planning (Copeland, 2002).

The high needs in the 'psychological distress' domain reported by patients are consistent with the reviewed literature focused on needs, irrespective of country income level (Ochoa et al., 2003; Foldemo et al., 2004; Kulhara et al., 2010). Needs in this domain fall within the existential dimension of recovery and they allude to the importance of including a central focus on support that can foster spiritual and emotional wellbeing, hope and a sense of empowerment in an individual's recovery process (Whitley & Drake, 2010). These supports should include multidisciplinary mental health teams, family, and the wider community such as peers and traditional and religious leaders (Campbell-Hall et al., 2010; Dein et al., 2010; Williams & Tufford, 2012; Kleintjes et al., 2013; Chinman et al., 2014; Brooke-Sumner et al., 2014). Mueser et al (2013) highlight the current low interest by clinical psychologists, yet the potentially important role they can play, given their profession, specific knowledge and skills in contributing to evidence-based practice in the domain of existential recovery. They suggest that improved competencies in recovery-informed practices in the field of psychology will assist persons in recovery to cultivate a richer and more positive self-experience across a range of recovery dimensions (Pinninti el al., 2010; Dickerson & Lehman, 2011; Mueser et al., 2013). I would argue for the extension of this proposal to include all professional and lay mental health workers. Specifically, there should be a greater investment in reconfiguring training, and institutional culture and support to multi-disciplinary professionals within the health, social service and non-governmental sector to expand its focus from 'sick role management to life role enablement' (Kleintjes et al., 2010; Davidson & White, 2007).

Patients in this study were similar to those from middle- and low-income countries in reporting high rates of unemployment, low education levels and in communicating higher numbers of need in the domains of 'daytime activities' and 'money' (Popescu & Miclutia., 2009; Kulhara et al., 2010). The findings refer to the association between poverty and social deprivation with mental ill health described in middle- and low-income countries (Lund et al., 2011) and they reflect the limited inter-sectoral collaboration that exists in South Africa's mental health services (Skeen et al., 2010). The findings highlight the need for the ACT service to incorporate a focus on functional recovery in supporting patients in recovery (Whitley & Drake, 2010). People with mental illness are like everyone else in their aspirations and in their need for quality education, meaningful work, a decent place to live and friendship (Anthony, 2004). In helping people meet these aspirations, it is important that skilled clinicians such as occupational therapists and social workers are included as part of ACT services (Rosen et al., 2007). Occupational therapists can assist individuals directly and improve clinical and functional independence outcomes such as daily time use; they can influence the service to consider more broadly the meaning of community adjustment, wellbeing and recovery; and they can be actively involved in the creation of occupational resources and opportunities within the social networks of ACT patients, the local mental health system and the broader community context (Krupa et al., 2002; Van Niekerk, 2009). Social workers are well equipped to provide an environment rich with what Anthony (1993) terms recovery 'triggers'. This includes information that people with psychiatric disabilities do recover; information on the range of services and treatments available; access to books, films and groups about possible life option; and links to peers in recovery. However varied the services offered, recovery is unlikely to happen through the mental health system alone. Social workers are ideally suited to help patients' recovery by helping them to connect or reconnect with resources such as family, friends, work, school, churches and supported housing that are outside the mental health system (Carpenter, 2002; Loumpa, 2012).

Patients in this study reported high unmet needs in the domain of 'sexual expression' which falls within the dimensions of physical and social recovery. This is in contrast to carers and staff who largely rated the domain as being 'unknown'. This discrepancy typifies the hesitancy and lack of comfort in discussing sexual matters in people with mental illness (Quinn et al., 2011; Higgins et al., 2008; Dobal & Torkelson, 2004). Studies exploring sexual and relationship issues in people with severe mental illness have found participants to be forthcoming with their responses with major themes revolving around establishing and maintaining relationships, sexual concerns and issues, stigma and self-esteem, family planning and parenting, formal and informal supports and views about prescribed medication (McCann, 2010a; McCann, 2010b; Deegan, 2001). People with severe mental health problems may be at greater risk of sexual exploitation, sexual abuse and being victimised due to low self-esteem, lack of education on risk behaviour and their disadvantaged social and economic status, which may place them in contact with high-risk populations and subject them to 'survival sex pressures' (Remafedi et al., 1998; Skegg et al., 2003).

The study findings call for openness and dialogue on matters of sexuality amongst patients and mental health staff. Staff members require guidance on how to talk about sexuality, how to address problematic sexual behaviour, the need to become aware of their personal sexual values and the need to have good knowledge on sexually transmitted disorders. Sex education for patients should include information about anatomy and physiology, contraception, prevention of sexually transmitted diseases and the effects of medication on sexual functioning, with an emphasis on sexual rights as well as information on sexual abuse (McCann, 2010b; Deegan, 2001).

Within the physical dimension of recovery, the domain of 'physical health' was reported to have high needs by patients. This finding is consistent with the well-documented evidence that people with mental illness have higher rates of physical health problems (Chwastiak et al., 2006), unmet physical health needs (Colton & Manderscheid, 2006), and earlier mortality relative to the general population (Laursen, 2011). It is also in keeping with the serious, chronic and life-threatening physical illnesses reported among persons serviced by ACT teams (Shattell et al., 2011). Currently, local mental health services focus exclusively on meeting the mental health needs of patients – patients with physical care needs are referred out to the general health services. Even though these patients are at greater risk of suffering from the common diseases such as diabetes, hypertension and HIV, they are expected to have sufficient insight and ability to navigate the complex and fragmented general health system on their own (Chopra et al., 2009). The finding of high needs in the domain of 'physical health' challenges this dualism in the management of physical and mental health. It suggests that ACT medical and nursing staff should take the lead in scrutinising and modifying proven guidelines on the management of physical illnesses in those with severe mental illness for local use (Weiss et al., 2009; Cuddeback & Shattell, 2010). These guidelines should focus on screening and risk factor identification, monitoring and management of common physical illnesses, prevention of complications, and role clarification for the professionals involved (Robson & Gray, 2006; Ehrlich et al., 2013).

High rates of substance misuse were observed in patients in this study. These rates were higher than those found in the local general population (Van Heerden et al., 2009; Dada et al., 2013) and were similar to rates reported in literature focused on dually diagnosed populations (Drake & Mueser, 2000; Horsfall et al., 2009). In spite of this, only the staff in this study perceived high needs in domain of substance use in contrast to both patients and carers. This may be a consequence of the pervasive substance misuse found in local communities and the community's resignation that substance misuse and its consequences is a 'problem that no one can solve' (Dada et al 2013, Watt et al 2014). Poor motivation to change commonly occurs in people with co-occurring substance misuse and severe mental illness, and points to the need for tailored strategies targeting substance misuse (DiClemente et al 2006). These strategies should include employing an integrated approach so that both the mental health problems and substance use problems are given attention; making use of motivational interventions such as motivational interviewing to promote health behaviour change; using cognitive behaviour therapy as it is efficacious for both primary substance misuse disorders and psychotic symptoms; and employing family education and interventions (Dixon et al., 2009; Barrowclough et al., 2010). There is also evidence for the effectiveness of group counselling, contingency management and long-term residential placement in the management of dual diagnosis patients (Drake et al., 2008). Common elements of recovery have been described in the management of substance misuse and mental illness, including becoming an empowered citizen, overcoming stigma and promoting positive views of recovery, assuming control, hope, understanding and accepting self, community involvement, and establishing and maintaining mutual relationships (Davidson et al., 2008). Increasingly dual diagnosis services are being encouraged to adopt a recovery orientation and the findings of the study suggest the same (Davidson & White, 2007; Gagne et al., 2007).

5.1.2 Carer-rated needs

Carers expressed similar numbers, types and domains of needs as carers in the literature from middle- and high-income countries. This again highlights the universality of the impairments imposed by severe mental illness and the impact on family supports (Foldemo et al., 2004; Macpherson et al., 2008; Kulhara et al., 2010; Lasalvia et al., 2012).

The mean total number of needs reported by carers was 7.3, out of which nearly two-thirds were met. Carers and patients were similar in identifying no needs in most of the domains and there was also no significant difference in the numbers of needs they identified. This is in keeping with the reviewed literature focused on the needs of patients and their carer's in which patients tended to report similar or fewer needs than carers (Foldemo et al., 2004; Cleary et al., 2006a; Cleary, 2006b; Grinshpoon et al., 2008; Macpherson et al., 2008; Kulhara et al., 2010; Lasalvia et al., 2012).

Similarly to patients, carers identified the highest unmet needs in the area of psychosocial needs, although differences existed in the psychosocial need domains identified. Carers differed from patients in expressing high unmet need in 'looking after the home' and 'money'. High needs in these domains seem understandable and may reflect a responsibility that is particularly felt by carers in the local context of socio-economic deprivation and limited residential and day care services (Lund & Flisher, 2009; Stats SA, 2014). Carers also differed from patients in key needs domains such as 'psychotic symptoms', 'safety to self', 'safety to others' and 'sexual expression', which demonstrates that carer opinions are not a proxy for patient opinions and that there are intimate and important topics that carers understand differently. This study differs from the only other study from India, a low-income country, where patients and carers expressed significantly higher numbers of needs and where the needs were mostly unmet (Kulhara et al., 2010). One reason for this difference may be that this study was conducted in the Western Cape province of South Africa, which is more similar to European countries with respect to its service structure and resource availability than it is to northern India (Lund et al., 2008). This study was also conducted in an ACT service that is better able to meet needs by providing for more integrated and continuous care than is generally found in community services (Botha et al., 2014). Patients in this study were also diagnosed primarily with schizophrenia, and they may have been less likely to identify need than other samples of patients with other diagnoses (Trauer & Tobias, 2004).

5.1.3 Staff-rated needs

Staff expressed similar numbers and domains of needs as those documented in the literature from middle- and high-income countries (Issakidis & Teesson, 1999; Macpherson et al., 2008; Popescu & Miclutia, 2009; Werner, 2012; Zahid & Ohaeri, 2013). Staff rated a mean of 7.3 needs of which substantially more were met than unmet.

The study findings on staff assessment of needs support the notion that the pattern of needs is influenced by the type of service, and the cultural and socio-economic circumstances (Wiersma, 2009; Zahid & Ohaeri, 2013). The higher needs that may have been anticipated in a low-income country may have been negated by the assertive community treatment service model that has proven to be effective in the local setting (Botha et al., 2014). Also in this study, patients, carers and staff all expressed fewer needs as compared to other studies focused on the needs of patients in ACT teams (Gallagher & Teeson, 2000; Macpherson et al., 2007; Macpherson et al., 2008; Macpherson et al., 2013). This may have been as result of a degree of cynicism in the participants resulting in fewer needs being expressed, as suggested by Carter (2003). Carter postulates that clients may underestimate needs because of being poorly motivated to express their needs, or they may believe that they cannot determine outcomes with regard to their general state of affairs. In the resource-poor setting of the current study, with its long history of underfunding and underperformance by available services, there may have been a feeling of helplessness and hopelessness with participants expecting little from the available service and thus rating fewer needs.

This study replicated the widely noted tendency for patient, carer and staff assessments of the levels and domains of needs to differ. Staff identified significantly more total and met needs compared to both patients and carers. Staff ratings had the highest ratings in the 'unknown' category and they tended to identify needs as present in most areas, unlike patients and carers who tended to find no needs present in most domains. Similarly to the literature, staff identified more need areas related to clinical recovery, while patients tended to report more needs in areas related to personal recovery (Lasalvia et al., 2000). There were discrepancies in the domains of information, benefits, intimate relationships and sexual expression, which staff considered to be less important problems, whilst patients identified these as serious need domains (Middelboe et al., 1998; Teeson & Issakidis, 1999; Fleury et al., 2006). These discrepancies suggest that staff training and orientation remains focused on clinical rather than personal recovery (Torgalsbøen, 2005; Kidd et al., 2010). Staff may be sensitive to needs in the clinical recovery dimension but may not be as sensitive to needs in other recovery dimensions. Again, these discrepancies highlight the value of ongoing assessments of the knowledge of and attitudes toward recovery-orientated practices among ACT staff and the need for ongoing reorientation and training in the recovery philosophy (Bedregal et al., 2006; Farkas, 2007).

5.2 Agreement on needs

The poor agreement on the presence of a need between participants in this study is in keeping with the reviewed literature. Only three of the 35 studies reported high levels of agreement (Phelan et al., 1995; Arvidsson, 2001; Macpherson et al., 2003).

Levels of agreement were highest between staff and carer ratings whilst agreements were lowest between patients and staff. The differences in the need domains identified and the poor agreement on the presence of needs is likely due to a number of reasons: patients may be under-reporting their needs due a lack of insight (Carter, 2003); staff and carers may hold negative stereotypes of patients perceived dangerousness and unpredictability, which causes them to overestimate certain needs (Lauber et al., 2006); the groups have different and competing priorities which may lead them to use different thresholds for what constitutes a need (Macpherson et al., 2008; Le Boutillier et al., 2015); and there may be limited communication between the three groups as is suggested by the finding of a negative kappa in the domain of information in this study and as has been described between staff and carers in mental health settings (Dixon et al., 2001; Krupnik et al., 2005).

These findings on agreement add robustness to the evidence that the perceptions of needs do not overlap and that mental health services should routinely involve patients and their relatives when planning and evaluating psychiatric interventions (Foldemo et al., 2004; Grinshpoon et al., 2008; Macpherson et al., 2008; Lasalvia et al., 2012). They further highlight the importance of adopting care that is person-centred, being ‘respectful of and responsive to individual patient preferences, needs, and values and ensuring that patient values guide all clinical decisions’ (Heidenreich, 2013).

5.3 Associations of patient-rated needs

Consistent with the literature, this study found that higher levels of dysfunction and psychiatric symptoms are related to higher needs (Lasalvia et al., 2000; Ochoa, 2002; Hansson et al., 2001; Kulhara, 2010; Werner, 2012; Zahid & Ohaeri, 2013). This again highlights the importance of managing psychopathological symptoms when supporting individuals on the recovery path. It reiterates the need to adopt evidence-based interventions (Pinninti et al., 2010; NICE, 2014) and the importance of incorporating psychosocial interventions that are congruent with recovery values (Copeland, 2002; Mueser et al., 2006; Deegan et al., 2008). Recovery supports should always keep in mind that the treatment of psychopathological symptoms may help personal recovery, but it can also hinder it, especially if it is the dominant focus and is associated with coercive practices (Slade et al., 2014).

The findings of the study emphasise the importance of individuals obtaining and maintaining secure housing, which is well recognised in the literature on ACT (Bond et al., 2001; Nelson et al., 2007) as well as in the literature on recovery (Anthony, 2004; Farkas, 2007; Whitley & Drake 2010). In this study, the majority of the patients resided in their family home and the carers were typically family members of a similar age to themselves. This is consistent with the only reviewed study from a low-income country (Kulhara et al., 2010) but it differs from studies conducted in high-income countries where proportionally more patients resided in supported accommodation and where fewer family members were identified as carers (Cleary, 2006b; Macpherson et al., 2008; Wiersma et al., 2009).

The study also identified patient accommodation type as the only socio-demographic variable associated with need in the local context. Accommodation type has previously been identified as a factor associated with changing patient need in an ACT service (Macpherson et al., 2007). The findings highlight the importance of the local service having supports that can assist with needs in the functional dimension of recovery (Whitley & Drake, 2010) and they support the calls for the upscaling of community-based psychosocial rehabilitation services as set out in South Africa's Mental Health Care Act 17 of 2002 and in its associated Mental Health Policy Framework and Strategic Plan (Department of Health, 2004; Lund et al., 2012; South African Department of Health, 2012).

The study findings also highlight the need to build in supports for carers of those with severe mental illness. These supports should be recovery orientated (Glynn et al., 2006; Mueser et al., 2006), should include peer support (Macleod et al., 2011; Kleintjes et al., 2013), and should include family therapy adapted for local challenges (Asmal et al., 2014).

5.4 Limitations of study

There are a number of limitations to this study. The case control design precludes the evaluation of causality. The sample size is small with limited power, having been constrained by the ACT service model. The sample is also drawn from one clinical setting within one psychiatric hospital, thus limiting the ability to generalise the findings to other populations, such as first episode psychosis, non-ACT patients or patients from other ACT teams.

The English language version of the CANSAS was used in this study. The Afrikaans and Xhosa language versions of the CANSAS were not obtainable at the time of the study and there may therefore have been difficulties in the interpretation and understanding of the instrument.

Patients and carers who had difficulty with the language were assisted by the researchers with translations into Xhosa and Afrikaans. The researchers were both trained in using the CANSAS and experienced in data gathering with an awareness of the ethics important to the research. In spite of the assistance received, patients and carers may still have had difficulty understanding the instrument, which may have resulted in participants under-reporting needs, although the reporting of relatively fewer numbers of needs by the staff in this study in comparison to the literature reviewed makes under-reporting less likely.

The researchers in this study were the Valkenberg hospital ACT team clinicians, which could have resulted in a response bias with patients and carers feeling coerced to participate. Patients and carers may also have felt a pressure to under-report needs so as not to disappoint the ACT clinicians.

5.5 Contributions of study

This study demonstrates that the needs of people with severe mental illness taken from multiple perspectives is an under researched area and that few studies look at needs from three perspectives, those of the patient, the carer and the professional staff.

The study is the first in this area to be conducted in an African setting. It highlights the need for additional studies to be conducted in middle- and low-income countries as well in ACT service settings focused on individual needs.

It adds weight to the literature finding that needs in those with severe mental illness are protean and that it is best to clarify needs and their associations within each individual context.

The study adds to growing body of literature advocating the adoption of the recovery model in assertive community treatment services and in the broader mental health services in South Africa.

5.6 Recommendations for future research

Future research in the area of individual needs assessment will greatly enhance clinical practice in South Africa. The findings of this study both support the notion that even when unwell, people with severe mental illness are able to assess their needs using the CANSAS and the calls for the CANSAS to be used as one the routine outcome measures in the clinical management of people with severe mental illness in differing cultural settings (Buhler et al., 2001; Salvi et al., 2005; Wiersma, 2009; Ponizovsky et al., 2014). Translation and validation of the CANSAS into the common South African languages will enable the tool to be reliably used amongst different cultural groupings and its routine use in varied clinical settings will allow for comparison of needs among different patient populations. This may better inform service provision and resource allocation.

Services are planned for on a platform level, thus a study incorporating ACT teams from different hospitals and focused on the associations of needs would be valuable. It will assist in better mapping out the need profile of patients currently enrolled in this precious service as well as helping to ensure that appropriate supports are planned for at a strategic level within the health service.

The findings of the study allude to the importance of the service adopting a recovery orientation. A qualitative study focused on ACT patients' views and experiences of their accounts of recovery would be a useful starting point in this process. It would also be useful to conduct research monitoring the recovery orientation of the service and also recovery-orientated outcomes so as to support the introduction of strength-based assessments and person-centred treatment approaches.

5.7 Conclusions

This study has attempted to map out the individual needs of Valkenberg Hospital ACT team patients assessed from different perspectives. It has demonstrated that the perspectives on needs differ and that patients identify needs consistent with the recovery principle of 'personhood' (Anthony, 2004).

The study findings support the calls for adopting recovery-orientated practices within South African mental health services and provide a crucial first contribution to the evidence base needed to help the country shift to the recovery-oriented mental health services now embedded in South Africa's new national mental health plan (South African Department of Health, 2012). The new policy embraces participation of service users and their families in decision-making at all levels of service development and delivery, and this study's findings support the need for broadening decision-making beyond providers to a multi-perspective paradigm to inform services. It supports embracing person-centred care where needs and recovery priorities are defined by the individual patient, with family, clinicians and the wider community providing supports to the process (Farkas, 2007).

CHAPTER 6 REFERENCES

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CHAPTER 7 APPENDICES

7.1 Consent forms

7.1.1 Participant information leaflet and consent form

Participant Information Leaflet and Consent Form

Title of research project: The relationship between user, carer and staff perceptions of need in an assertive community treatment team in South Africa

Investigator: Dr QZ Cossie

Address: Valkenberg Hospital, APH building, Observatory

Contact number: 021 4403267

You are being invited to take part in a research project. Please take time to read this leaflet as it explains the research project. Please ask the study staff or doctor any questions about any part of this project that you do not fully understand. It is important that you are fully satisfied that you clearly understand what this research is about and how you could be involved.

Also, your participation is entirely voluntary and you are free to choose not to participate. If you do not participate, this will not affect your usual care in any way whatsoever. You are free to withdraw from the study at any point, even after you agree to take part.

This study has been approved by the Research Ethics Committee of the Faculty of Health Sciences of the University of Cape Town and will be conducted in accordance with the ethical guidelines and principles of the International Declaration of Helsinki (2000), South African Guidelines for Good Clinical Practice and the Medical Research Council (MRC) Ethical Guidelines for Research.

Purpose of study

The purpose of this study is three fold:

1. We would like to find out the needs of mental health users following up with the Valkenberg Hospital Assertive Community Treatment (ACT) team from the

perspective of the user themselves, their carer and that of the ACT team key worker.

2. We would like to find out the factors that are associated with the perceived needs.
3. We would like to measure the level of agreement of perceived needs between the user, carer and ACT team key worker.

What will happen if you decide to take part in the study?

If you consent to take part in this study, you will be helped to complete a standardised questionnaire asking you about your needs. You will also be assessed using two rating scales to determine the severity of your illness. You will then be asked to identify a close relative to complete the same standardised questionnaire asking your relative what they think your needs are. Should your relative consent to take part in the study, they will be helped in completing the questionnaire. An ACT team member will then complete the same questionnaire asking them what they think your needs are. The ACT team member will also document demographic and historical clinical information obtained from your hospital clinical folder.

The questionnaire and the rating scales should not take longer than 40 minutes to complete and the entire information gathering process will occur during your normal contacts with the ACT team.

If it is not possible to collect all the information needed at one visit, then at the next booked visit by the ACT team you may be asked for consent to continue with the questionnaire and the rating scales. Remember you are free to withdraw from the study at any point, even after you agree to take part.

What are the risks and discomforts of this study?

There are no identifiable risks should you choose to participate in the study. The study will not affect your current or future treatment. You and the ACT team will make decisions regarding treatment options independently from this study. You do not have to participate in this study to receive treatment.

Are there any benefits to you being in the study?

There may not be any direct benefits to you as a result of the study; however this study may contribute towards an improved in the service provided to ACT team clients in future. You may benefit by receiving a comprehensive assessment of your condition during the course of the study.

Will you receive any reward for taking part in this study?

You will not be paid to take part in this study.

Who will see the information which is collected about you during the study?

All personal information obtained during the study will be treated as strictly confidential. It will only be discussed by members of the study team and anyone directly involved in your treatment. Information collected from you will be stored in a secure computer and in hospital records. Information from the study could be published in professional literature but at no time will your identity be revealed in any way.

Who do I speak to if I have questions about the study?

You have the right to ask questions at any time about any aspect of the study. If you have questions which the study team cannot answer adequately, please phone Dr Q Cossie at (021) 4403267. We will inform you should any new information become available during the course of the study that may have a bearing on your safety.

Voluntary participation

Your participation in this study is **entirely voluntary**. You have the right to withdraw from the study at any time. If you decide to withdraw from the study, this will not have an influence on your present or future treatment at this or any other institution.

You are entitled to a signed copy of this document.

You can contact the Research Ethics Committee of the Faculty of Health Sciences of the University of Cape Town at 021 406 6492 if you have any concerns or complaints that have not been adequately addressed by the study team.

If you agree to take part, please complete the following section:

Declaration by participant

By signing below, I ………………………………………………………………….. agree to take part in a research study entitled: **The relationship between user, carer and staff perceptions of need in an assertive community treatment team in South Africa.**

I declare that:

- I have read or had read to me this information and consent form and it is written in a language in which I am fluent and comfortable.
- I have had a chance to ask questions and all my questions have been adequately answered.
- I understand that taking part in this study is **voluntary** and I have not been pressurised to take part.
- I may choose to leave the study at any time and will not be penalised or prejudiced in any way.

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

Signature of participant……………………. Signature of witness …………………….

Declaration by investigator

I ………………………………...……. 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 a translator. (*If a translator is used then the translator must sign the declaration below.)*

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

Signature of investigator……………………… Signature of witness ……………………

Declaration by translator

I ……………………………………………………………………………….. Declare that:

- I assisted the investigator…………………………………. to explain the information in this document to…………………….. using the language medium of Xhosa/ Afrikaans.
- We encouraged him/ her to ask questions and took adequate time to answer them.
- I conveyed a factually correct version of what was related to me.
- I am satisfied that the participant fully understands the content of this informed consent document and has had all his/ her questions satisfactorily answered.

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

Signature of translator ……………………….. Signature of witness …………………….

7.1.2 Carer information leaflet and consent form

Title of research project: The relationship between user, carer and staff perceptions of need in an assertive community treatment team in South Africa

Investigator: Dr QZ Cossie

Address: Valkenberg Hospital, APH building, Observatory

Contact number: 021 4403267

You are being invited to take part in a research project. Please take time to read this leaflet, which will explain the details of this project. Please ask the study staff or doctor any questions about any part of this project that you do not fully understand. It is important that you are fully satisfied that you clearly understand what this research is entails and how you could be involved. Also, your participation is **entirely voluntary** and you are free to decline to participate. If you do not participate, this will not affect you or your family member's usual care in any way whatsoever. You are free to withdraw from the study at any point, even after you agree to take part.

This study has been approved by the **Research Ethics Committee of the Faculty of Health Sciences of the University of Cape Town** and will be conducted in accordance with the ethical guidelines and principles of the International Declaration of Helsinki (2000), South African Guidelines for Good Clinical Practice and the Medical Research Council (MRC) Ethical Guidelines for Research.

Purpose of the study

The purpose of this study is three fold:

Firstly we would like to determine the needs of mental health users following up with the Valkenberg Hospital Assertive Community Treatment (ACT) team from the perspective of the user themselves, their carer and ACT team key worker. Secondly we would like to determine the factors that are associated with the perceived need and lastly we would like to measure the level of agreement of perceived need between the user, carer and key worker.

Study procedure

Your relative has identified you as someone who is close to them and has an understanding of their mental health needs. If you agree to take part in this study, you will be assisted to complete a standardised questionnaire that will assess your perception of your relative's mental health needs.

Your relative has been asked to complete a similar questionnaire assessing their perception of their own needs. They will also be assessed using two rating scales to determine the severity of their illness. An ACT team member will then be assigned to complete a similar questionnaire assessing your relative's needs from the ACT team perspective. The ACT team member will also document your relatives demographic and historical clinical obtained from the hospital clinical folder.

The questionnaire and the rating scales take no longer than 20 minutes to complete and the entire information gathering process will occur during your normal contacts with the ACT team.

Discomfort and risks associated with the study

Your participation is not coupled to any identifiable risks. The study will not affect you or your family member's current or future treatment. You, your family member and the ACT team will make decisions regarding treatment options independently from this study. You do not have to participate in this study to receive treatment.

Potential benefits of the study

There may not be any direct benefits to you as a result of the study; however this study may contribute towards an improvement in the service provided to ACT team clients in future. Your family member may benefit by receiving a comprehensive assessment of their condition during the course of the study.

Compensation for study participation

You will not be paid to take part in this study.

Confidentiality

All personal information obtained during the study will be treated as strictly confidential. It will only be discussed by members of the study team and anyone directly involved in your relative's treatment. Information collected from you will be stored in a secure computer and in hospital records. Information from the study could be published in professional literature but at no time will your identity be revealed in any way.

The right to ask questions / Voluntary participation

You have the right to ask questions at any time about any aspect of the study. If you have questions, please phone Dr Q Cossie at (021) 4403267. We will inform you should any new information become available during the course of the study that may have a bearing on you or your family member's safety.

Your participation in this study is **entirely voluntary**. You have the right to withdraw from the study at any time. If you decide to withdraw from the study, this will not have an influence on you or your family member's present or future treatment at this or any other institution.

You are entitled to a signed copy of this document.

You can contact the Research Ethics Committee of the Faculty of Health Sciences of the University of Cape Town at 021 406 6492 if you have any concerns or complaints that have not been adequately addressed by the study team.

If you agree to take part, please complete the following section:

Declaration by carer

By signing below, I ……………………………………………………………….. agree to take part in a research study entitled: **The relationship between user, carer and staff perceptions of need in an assertive community treatment team in South Africa.**

I declare that:

- I have read or had read to me this information and consent form and it is written in a language in which I am fluent and comfortable.
- I have had a chance to ask questions and all my questions have been adequately answered.
- I understand that taking part in this study is **voluntary** and I have not been pressurised to take part.
- I may choose to leave the study at any time and will not be penalised or prejudiced in any way.

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

Signature of carer………………………….. Signature of witness ……………………….

Declaration by investigator

I ……………………………….....……. 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 a translator. (*If a translator is used then the translator must sign the declaration below.)*

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

Signature of investigator ……………………… Signature of witness……………………

Declaration by translator

I ……………………………………………………………………….. declare that:

- I assisted the investigator…………………………………. to explain the information in this document to…………………….. using the language medium of Xhosa/ Afrikaans.
- We encouraged him/ her to ask questions and took adequate time to answer them.
- I conveyed a factually correct version of what was related to me.
- I am satisfied that the participant fully understands the content of this informed consent document and has had all his/ her questions satisfactorily answered.

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

Signature of translator ………………………… Signature of witness …………………...

7.2 Demographic and clinical questionnaire

The relationship between user, carer and staff perceptions of need in an assertive community treatment team in South Africa:

Demographic and Clinical Questionnaire

Identifying data

1 Interviewer: ________________________________

2 Date: ________________________________

3 Name: ________________________________

4 Address: ________________________________

5 Folder number: ________________________________

1. Gender: 1= female 2=male ☐

2. Age: ☐

3. Marital status: ☐
   1= single, never married
   2=married, divorced or separated
   3=married
   4=spouse died

4. Highest educational level ☐
   1= less than std 6
   2= std 6-8
   3= std 8-10
   4= tertiary education

5. Occupation: ☐
   1= professional/ technical/ artisan employed
   2= non-professional employed
   3= unemployed, receiving disability grant
   4= unemployed, not receiving disability grant

6. Accommodation type: ☐
   1= own house
   2= family house, lives inside
   3= other house, lives inside
   4= family house, lives outside
   5= other house, lives outside
   6= no fixed abode

7. Name of carer: ______________________________________

8. Age of carer: _____________________

9. Type of carer: ☐
   1= parent
   2= spouse
   3= other family
   4= other carer
   5= no carer identified

Clinical information

10. Age at onset illness: ☐

11. Duration following up with ACTT : ☐
    (in years and months)

12. Primary DSM IV diagnosis: ☐
    1 = schizophrenia
    2= schizoaffective
    3= Bipolar
    4= other

13. Substance diagnosis: ☐

1= cannabis abuse/ dependence
2= methamphetamine abuse/ dependence
3= alcohol abuse/dependence
4= combination of cannabis, methamphetamine, alcohol abuse/dependence
5= other
6= none

7.3 Camberwell Assessment of Need Short Appraisal Schedule (CANSAS)

CANSAS/5

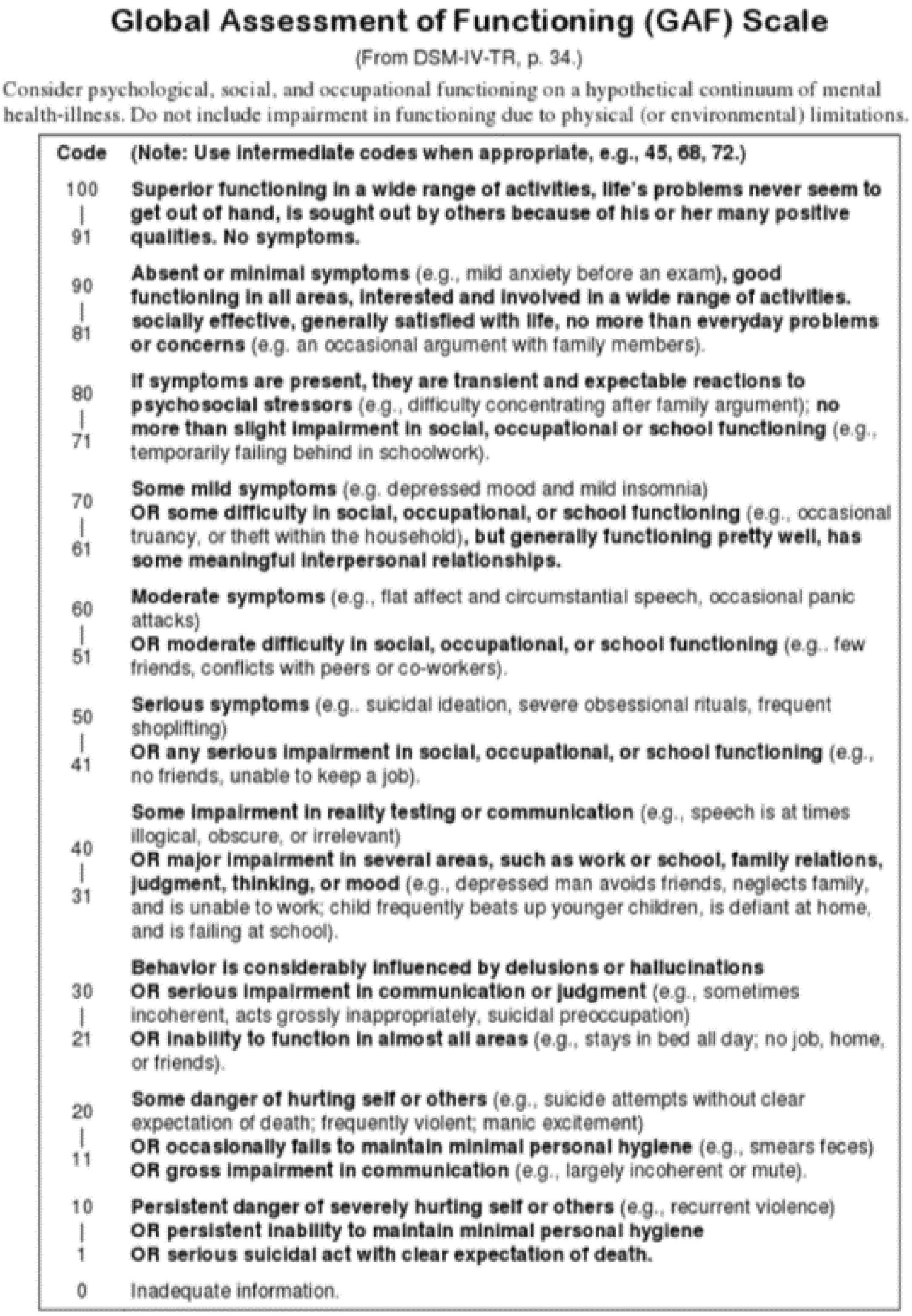
Camberwell Assessment of Need Short Appraisal Schedule

User/Client name

Need rating
0 = no problem 2 = unmet need
1 = met need 9 = not known

Assessment number	1	2	3	4
Circle who is interviewed (U=User, S=Staff, C=Carer)	U / S / C	U / S / C	U / S / C	U / S / C
Date of assessment				
Initials of assessor				
1 **Accommodation** *What kind of place do you live in?*				
2 **Food** *Do you get enough to eat?*				
3 **Looking after the home** *Are you able to look after your home?*				
4 **Self-care** *Do you have problems keeping clean and tidy?*				
5 **Daytime activities** *How do you spend your day?*				
6 **Physical health** *How well do you feel physically?*				
7 **Psychotic symptoms** *Do you ever hear voices or have problems with your thoughts?*				
8 **Information on condition and treatment** *Have you been given clear information about your medication?*				
9 **Psychological distress** *Have you recently felt very sad or low?*				
10 **Safety to self** *Do you ever have thoughts of harming yourself?*				
11 **Safety to others** *Do you think you could be a danger to other people's safety?*				
12 **Alcohol** *Does drinking cause you any problems?*				
13 **Drugs** *Do you take any drugs that aren't prescribed?*				
14 **Company** *Are you happy with your social life?*				
15 **Intimate relationships** *Do you have a partner?*				
16 **Sexual expression** *How is your sex life?*				
17 **Child care** *Do you have any children under 18?*				
18 **Basic education** *Any difficulty in reading, writing or understanding English?*				
19 **Telephone** *Do you know how to use a telephone?*				
20 **Transport** *How do you find using the bus, tube or train?*				
21 **Money** *How do you find budgeting your money?*				
22 **Benefits** *Are you getting all the money you are entitled to?*				
A **Met needs – count the number of 1s in the column**				
B **Unmet need – count the number of 2s in the column**				
C **Total number of needs – add together A + B**				

7.4 Global Assessment of Functioning (GAF) scale



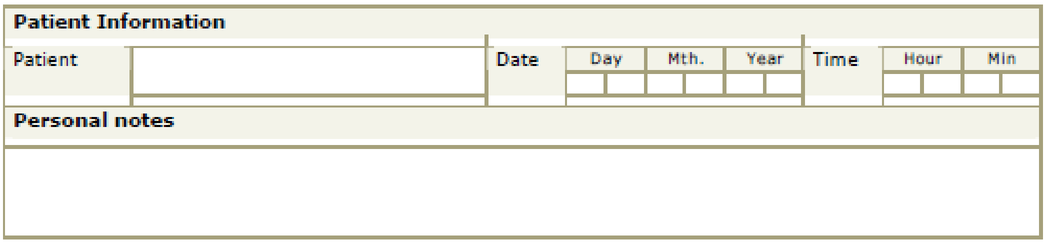
Global Assessment of Functioning (GAF) Scale

(From DSM-IV-TR, p. 34.)

Consider psychological, social, and occupational functioning on a hypothetical continuum of mental health-illness. Do not include impairment in functioning due to physical (or environmental) limitations.

Code	**(Note: Use intermediate codes when appropriate, e.g., 45, 68, 72.)**
100 | 91	**Superior functioning in a wide range of activities, life's problems never seem to get out of hand, is sought out by others because of his or her many positive qualities. No symptoms.**
90 | 81	**Absent or minimal symptoms** (e.g., mild anxiety before an exam), **good functioning in all areas, interested and involved in a wide range of activities. socially effective, generally satisfied with life, no more than everyday problems or concerns** (e.g. an occasional argument with family members).
80 | 71	**If symptoms are present, they are transient and expectable reactions to psychosocial stressors** (e.g., difficulty concentrating after family argument); **no more than slight impairment in social, occupational or school functioning** (e.g., temporarily falling behind in schoolwork).
70 | 61	**Some mild symptoms** (e.g. depressed mood and mild insomnia) **OR some difficulty in social, occupational, or school functioning** (e.g., occasional truancy, or theft within the household), **but generally functioning pretty well, has some meaningful interpersonal relationships.**
60 | 51	**Moderate symptoms** (e.g., flat affect and circumstantial speech, occasional panic attacks) **OR moderate difficulty in social, occupational, or school functioning** (e.g., few friends, conflicts with peers or co-workers).
50 | 41	**Serious symptoms** (e.g., suicidal ideation, severe obsessional rituals, frequent shoplifting) **OR any serious impairment in social, occupational, or school functioning** (e.g., no friends, unable to keep a job).
40 | 31	**Some impairment in reality testing or communication** (e.g., speech is at times illogical, obscure, or irrelevant) **OR major impairment in several areas, such as work or school, family relations, judgment, thinking, or mood** (e.g., depressed man avoids friends, neglects family, and is unable to work; child frequently beats up younger children, is defiant at home, and is failing at school).
30 | 21	**Behavior is considerably influenced by delusions or hallucinations OR serious impairment in communication or judgment** (e.g., sometimes incoherent, acts grossly inappropriately, suicidal preoccupation) **OR inability to function in almost all areas** (e.g., stays in bed all day; no job, home, or friends).
20 | 11	**Some danger of hurting self or others** (e.g., suicide attempts without clear expectation of death; frequently violent; manic excitement) **OR occasionally fails to maintain minimal personal hygiene** (e.g., smears feces) **OR gross impairment in communication** (e.g., largely incoherent or mute).
10 | 1	**Persistent danger of severely hurting self or others** (e.g., recurrent violence) **OR persistent inability to maintain minimal personal hygiene OR serious suicidal act with clear expectation of death.**
0	Inadequate information.

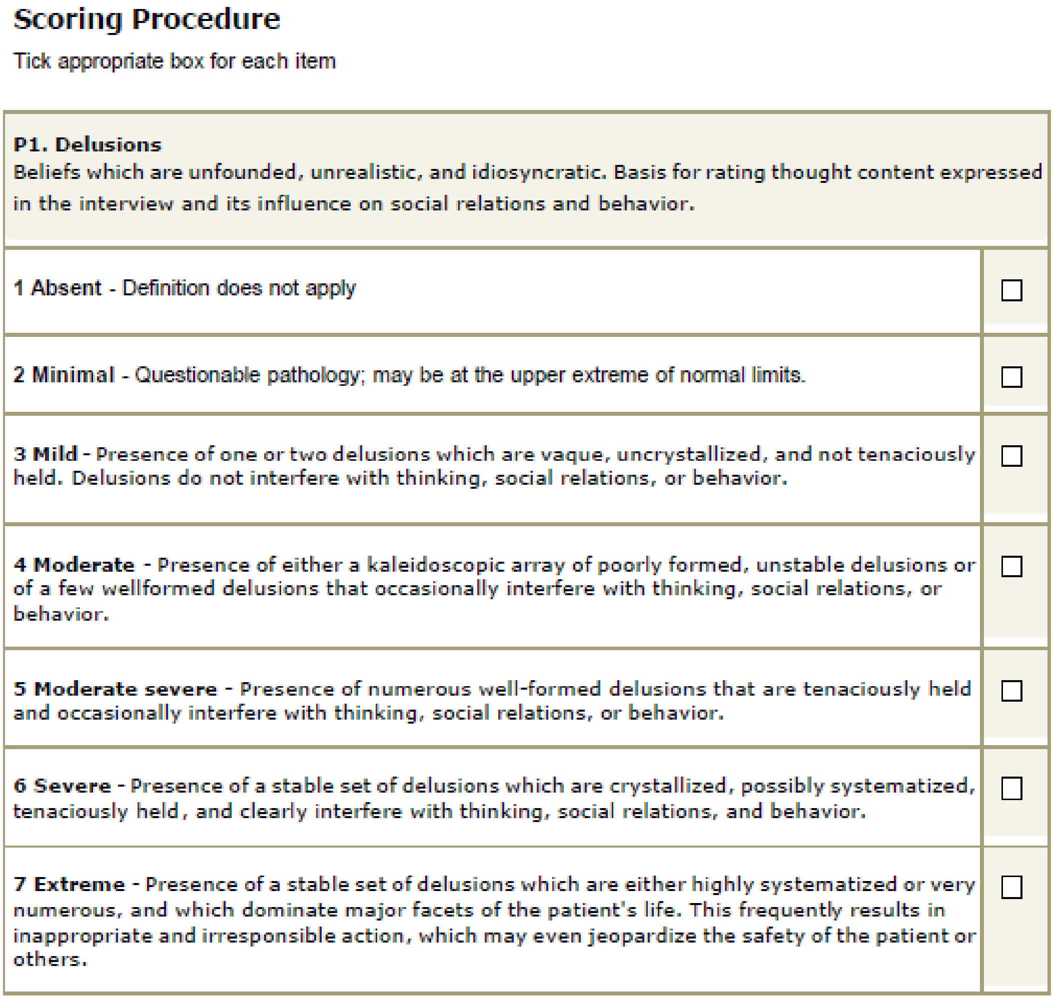
7.5 Positive and Negative Syndrome Scale (PANSS)



Patient Information

Patient		Date	Day	Mth.	Year	Time	Hour	Min

Personal notes



Scoring Procedure

Tick appropriate box for each item

P1. Delusions
Beliefs which are unfounded, unrealistic, and idiosyncratic. Basis for rating thought content expressed in the interview and its influence on social relations and behavior.

1 Absent - Definition does not apply	☐
2 Minimal - Questionable pathology; may be at the upper extreme of normal limits.	☐
3 Mild - Presence of one or two delusions which are vaque, uncrystallized, and not tenaciously held. Delusions do not interfere with thinking, social relations, or behavior.	☐
4 Moderate - Presence of either a kaleidoscopic array of poorly formed, unstable delusions or of a few wellformed delusions that occasionally interfere with thinking, social relations, or behavior.	☐
5 Moderate severe - Presence of numerous well-formed delusions that are tenaciously held and occasionally interfere with thinking, social relations, or behavior.	☐
6 Severe - Presence of a stable set of delusions which are crystallized, possibly systematized, tenaciously held, and clearly interfere with thinking, social relations, and behavior.	☐
7 Extreme - Presence of a stable set of delusions which are either highly systematized or very numerous, and which dominate major facets of the patient's life. This frequently results in inappropriate and irresponsible action, which may even jeopardize the safety of the patient or others.	☐

P2. Conceptual disorganization

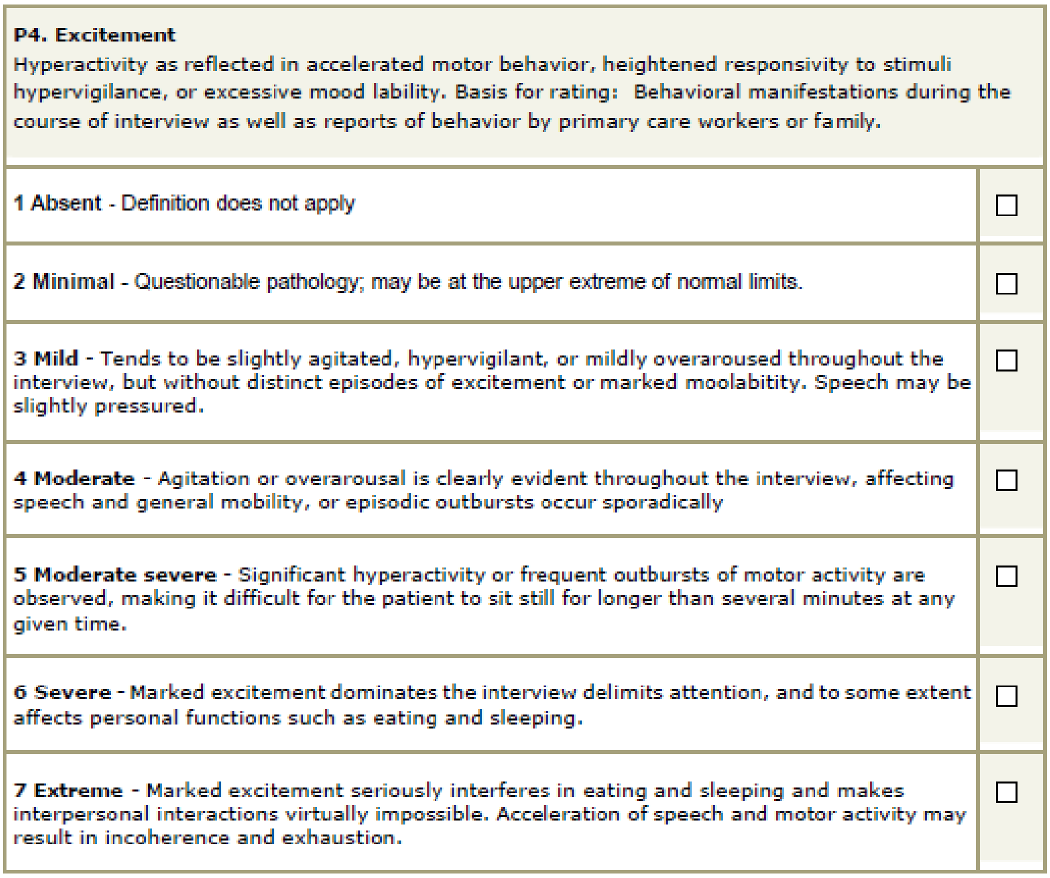
Disorganized process of thinking characterized by disruption of goal-directed sequencing, e.g., circumstantiality, tangentiality, loose associations non sequiturs, gross illogicality, or thought block. Basis for rating: cognitive-verbal processes observed during the course of interview.

1 Absent - Definition does not apply	☐
2 Minimal - Questionable pathology; may be at the upper extreme of normal limits.	☐
3 Mild - Thinking is circumstantial, tangential, or paralogical. There is some difficulty in directina thoughts toward a goal and some loosening o7 associations may be evidenced under pressure.	☐
4 Moderate - Able to focus thoughts when communications are brief and structured, but becomes loose or irrelevant when dealing with more complex communications or when under minimal pressure.	☐
5 Moderate severe - Generally has difficulty in organizing thoughts, as evidenced by frequent irrelevances, disconnectedness. or loosening of associations even when not under pressure.	☐
6 Severe - Thinking is seriously derailed and internally inconsistent, resulting in gross irrelevancies and disruption of thought processes, which occur almost constantly.	☐
7 Extreme - Thoughts are disrupted to the point where the patient is incoherent. There is marked loosening of associations, which results in total failure of communication, e.g., "word salad. or mutism.	☐

P3. Hallucinatory behavior

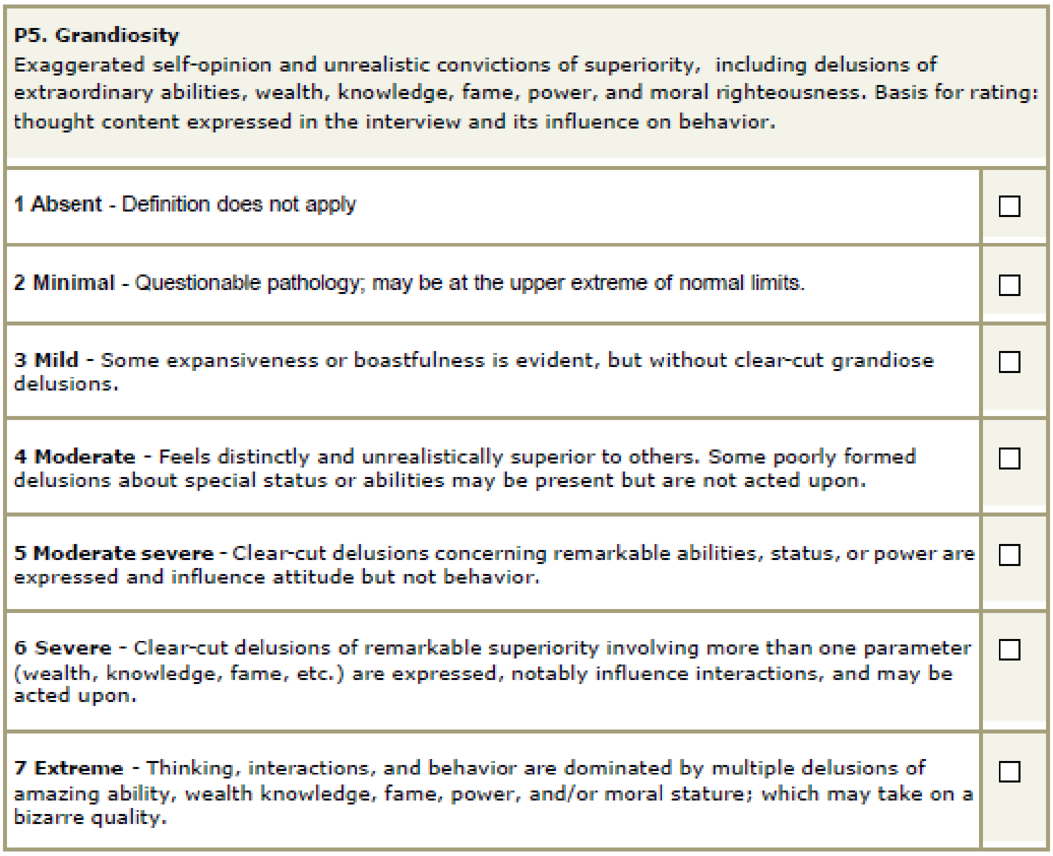
Verbal report or behavior indicating perceptions which are not generated by external stimuli. These may occur in the auditory visual, olfactory, or somatic realms. Basis for rating: Verbal report and physical manifestations during the course of interview as well as reports of behavior by primary care workers or family.

1 Absent - Definition does not apply	☐
2 Minimal - Questionable pathology; may be at the upper extreme of normal limits.	☐
3 Mild - One or two clearly formed but infrequent hallucinations, or else a number of vaque abnormal perceptions which do not result in distortions of thinking or behavior.	☐
4 Moderate - Hallucinations occur frequently but not continuously, and the patient's thinking and behavior are affected only to a minor extent.	☐
5 Moderate severe - Hallucinations are frequent, may involve more than one sensory modality, and tend to distort thinking and/or disrupt behavior. Patient may have a delusional interpretation of these experiences and respond to them emotionally and, on occasion, verbally as well.	☐
6 Severe - Hallucinations are present almost continuously, causing major disruption of thinking and behavior. Patient treats these as real perceptions, and functioning is impeded by frequent emotional and verbal responses to them.	☐
7 Extreme - Patient is almost totally preoccupied with hallucinations, which virtually dominate thinking and behavior. Hallucinations are provided a rigid delusional interpretation and provoke verbal and behavioral responses, including obedience to command hallucinations.	☐



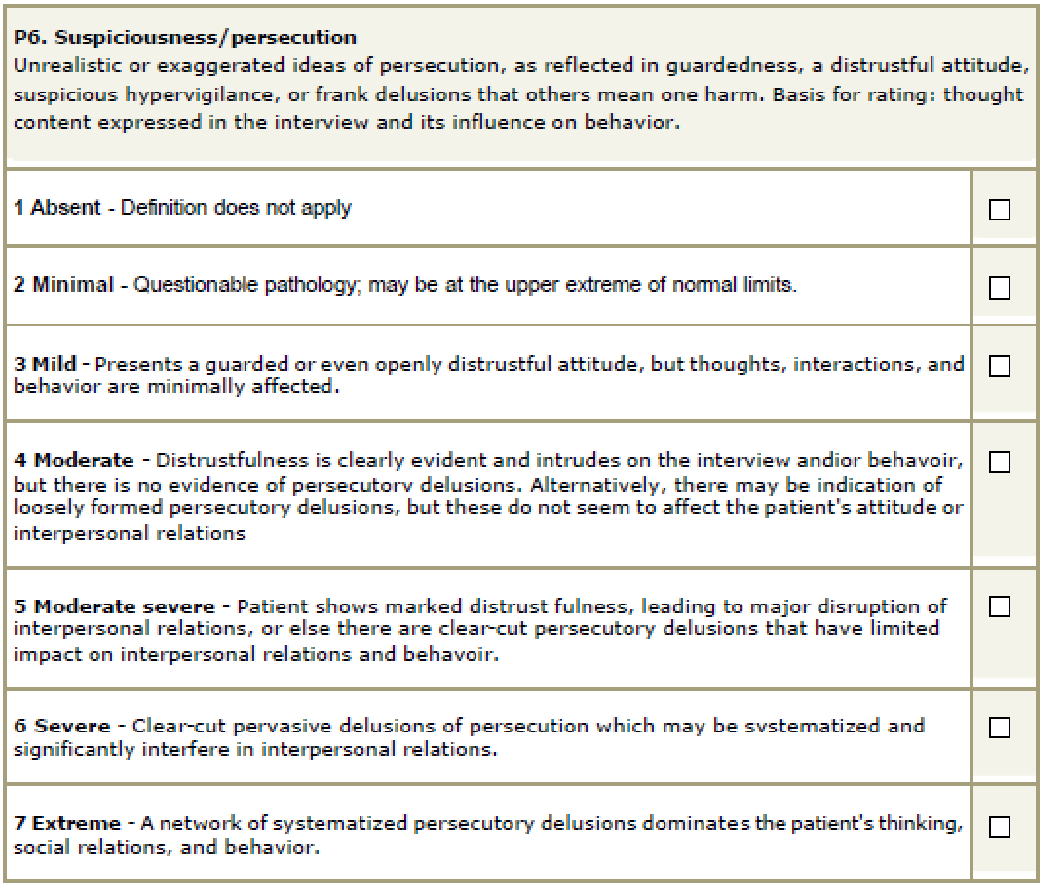
P4. Excitement
Hyperactivity as reflected in accelerated motor behavior, heightened responsivity to stimuli hypervigilance, or excessive mood lability. Basis for rating: Behavioral manifestations during the course of interview as well as reports of behavior by primary care workers or family.

1 Absent - Definition does not apply	☐
2 Minimal - Questionable pathology; may be at the upper extreme of normal limits.	☐
3 Mild - Tends to be slightly agitated, hypervigilant, or mildly overaroused throughout the interview, but without distinct episodes of excitement or marked moolabitity. Speech may be slightly pressured.	☐
4 Moderate - Agitation or overarousal is clearly evident throughout the interview, affecting speech and general mobility, or episodic outbursts occur sporadically	☐
5 Moderate severe - Significant hyperactivity or frequent outbursts of motor activity are observed, making it difficult for the patient to sit still for longer than several minutes at any given time.	☐
6 Severe - Marked excitement dominates the interview delimits attention, and to some extent affects personal functions such as eating and sleeping.	☐
7 Extreme - Marked excitement seriously interferes in eating and sleeping and makes interpersonal interactions virtually impossible. Acceleration of speech and motor activity may result in incoherence and exhaustion.	☐



P5. Grandiosity
Exaggerated self-opinion and unrealistic convictions of superiority, including delusions of extraordinary abilities, wealth, knowledge, fame, power, and moral righteousness. Basis for rating: thought content expressed in the interview and its influence on behavior.

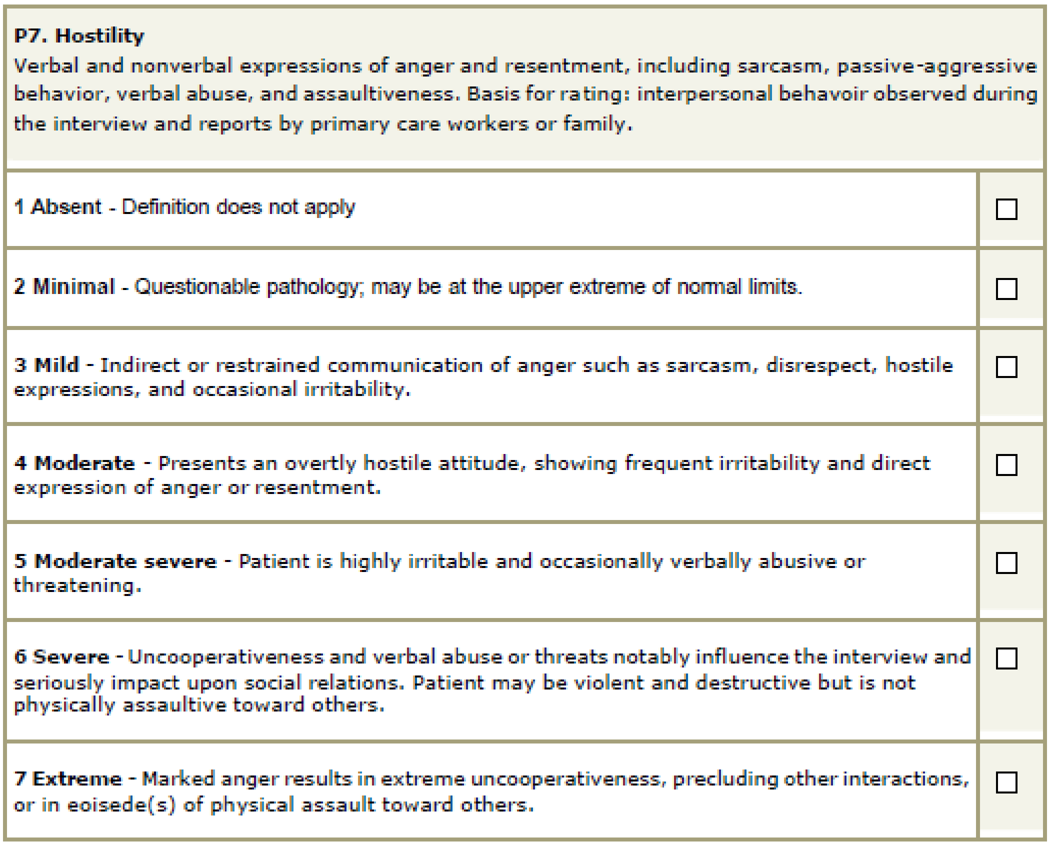
1 Absent - Definition does not apply	☐
2 Minimal - Questionable pathology; may be at the upper extreme of normal limits.	☐
3 Mild - Some expansiveness or boastfulness is evident, but without clear-cut grandiose delusions.	☐
4 Moderate - Feels distinctly and unrealistically superior to others. Some poorly formed delusions about special status or abilities may be present but are not acted upon.	☐
5 Moderate severe - Clear-cut delusions concerning remarkable abilities, status, or power are expressed and influence attitude but not behavior.	☐
6 Severe - Clear-cut delusions of remarkable superiority involving more than one parameter (wealth, knowledge, fame, etc.) are expressed, notably influence interactions, and may be acted upon.	☐
7 Extreme - Thinking, interactions, and behavior are dominated by multiple delusions of amazing ability, wealth knowledge, fame, power, and/or moral stature; which may take on a bizarre quality.	☐



P6. Suspiciousness/persecution

Unrealistic or exaggerated ideas of persecution, as reflected in guardedness, a distrustful attitude, suspicious hypervigilance, or frank delusions that others mean one harm. Basis for rating: thought content expressed in the interview and its influence on behavior.

1 Absent - Definition does not apply	☐
2 Minimal - Questionable pathology; may be at the upper extreme of normal limits.	☐
3 Mild - Presents a guarded or even openly distrustful attitude, but thoughts, interactions, and behavior are minimally affected.	☐
4 Moderate - Distrustfulness is clearly evident and intrudes on the interview andior behavoir, but there is no evidence of persecutorv delusions. Alternatively, there may be indication of loosely formed persecutory delusions, but these do not seem to affect the patient's attitude or interpersonal relations	☐
5 Moderate severe - Patient shows marked distrust fulness, leading to major disruption of interpersonal relations, or else there are clear-cut persecutory delusions that have limited impact on interpersonal relations and behavoir.	☐
6 Severe - Clear-cut pervasive delusions of persecution which may be svstematized and significantly interfere in interpersonal relations.	☐
7 Extreme - A network of systematized persecutory delusions dominates the patient's thinking, social relations, and behavior.	☐



P7. Hostility

Verbal and nonverbal expressions of anger and resentment, including sarcasm, passive-aggressive behavior, verbal abuse, and assaultiveness. Basis for rating: interpersonal behavoir observed during the interview and reports by primary care workers or family.

1 Absent - Definition does not apply	☐
2 Minimal - Questionable pathology; may be at the upper extreme of normal limits.	☐
3 Mild - Indirect or restrained communication of anger such as sarcasm, disrespect, hostile expressions, and occasional irritability.	☐
4 Moderate - Presents an overtly hostile attitude, showing frequent irritability and direct expression of anger or resentment.	☐
5 Moderate severe - Patient is highly irritable and occasionally verbally abusive or threatening.	☐
6 Severe - Uncooperativeness and verbal abuse or threats notably influence the interview and seriously impact upon social relations. Patient may be violent and destructive but is not physically assaultive toward others.	☐
7 Extreme - Marked anger results in extreme uncooperativeness, precluding other interactions, or in eoisede(s) of physical assault toward others.	☐

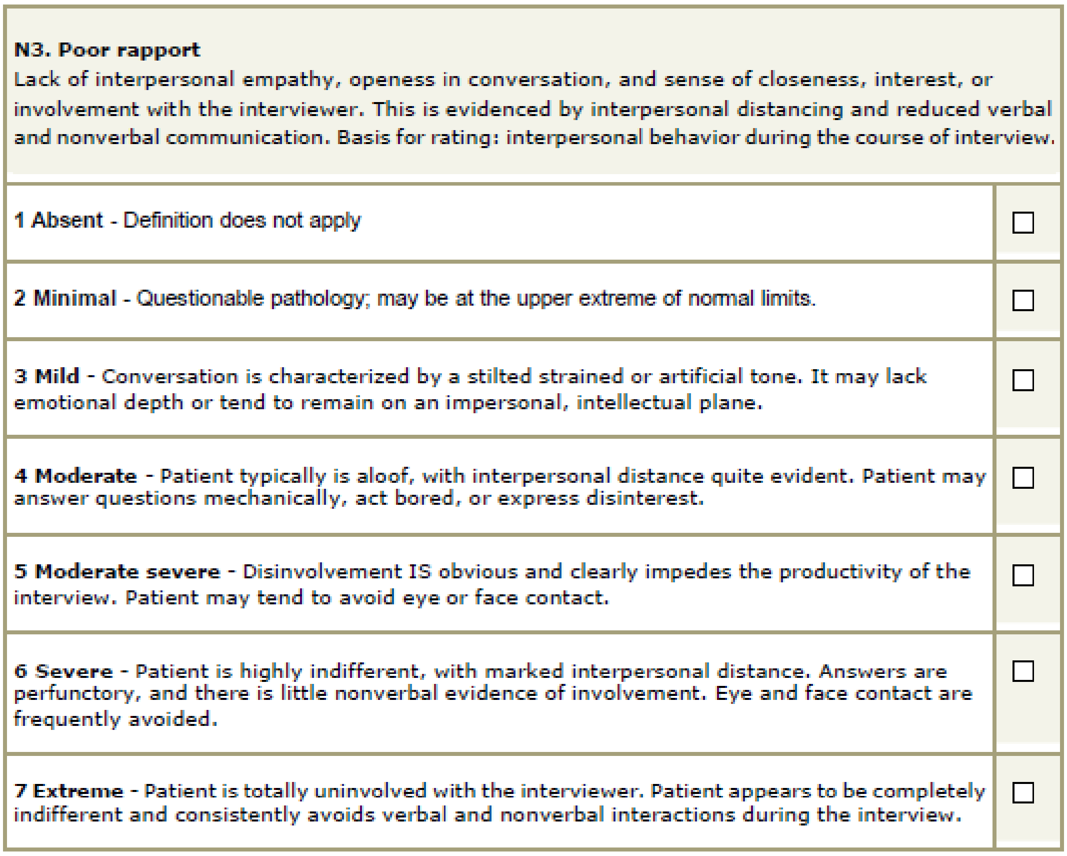
NEGATIVE SCALE (N)

N1. Blunted affect
Diminished emotional responsiveness as characterized by a reduction in facial expression, modulation of feelings, and communicative gestures. Basis for rating: observation of physical manifestations of affective tone and emotional responsiveness during the course of interview.

1 Absent - Definition does not apply	☐
2 Minimal - Questionable pathology; may be at the upper extreme of normal limits.	☐
3 Mild - Changes in facial expression and communicative gestures seem to be stilted, forced, artificial, or lacking in modulation.	☐
4 Moderate - Reduced range of facial expression and few expressive gestures result in a dull appearance.	☐
5 Moderate severe - Affect is generally ~flat-, with only occasional changes in facial expression and a paucity of communicative gestures.	☐
6 Severe - Marked flatness and deficiency of emotions exhibited most of the time. There may be unmodulated extreme affective discharges, such as excitement, rage, or inappropriate uncontrolled laughter.	☐
7 Extreme - Changes in facial expression and evidence of communicative gestures are virtually absent. Patient seems constantly to show a barren or "wooden" expression.	☐

N2. Emotional withdrawal
Lack of interest in, involvement with, and affective commitment to life's events. Basis for rating: reports of functioning from primary care workers or family and observation of interpersonal behavoir during the course of interview.

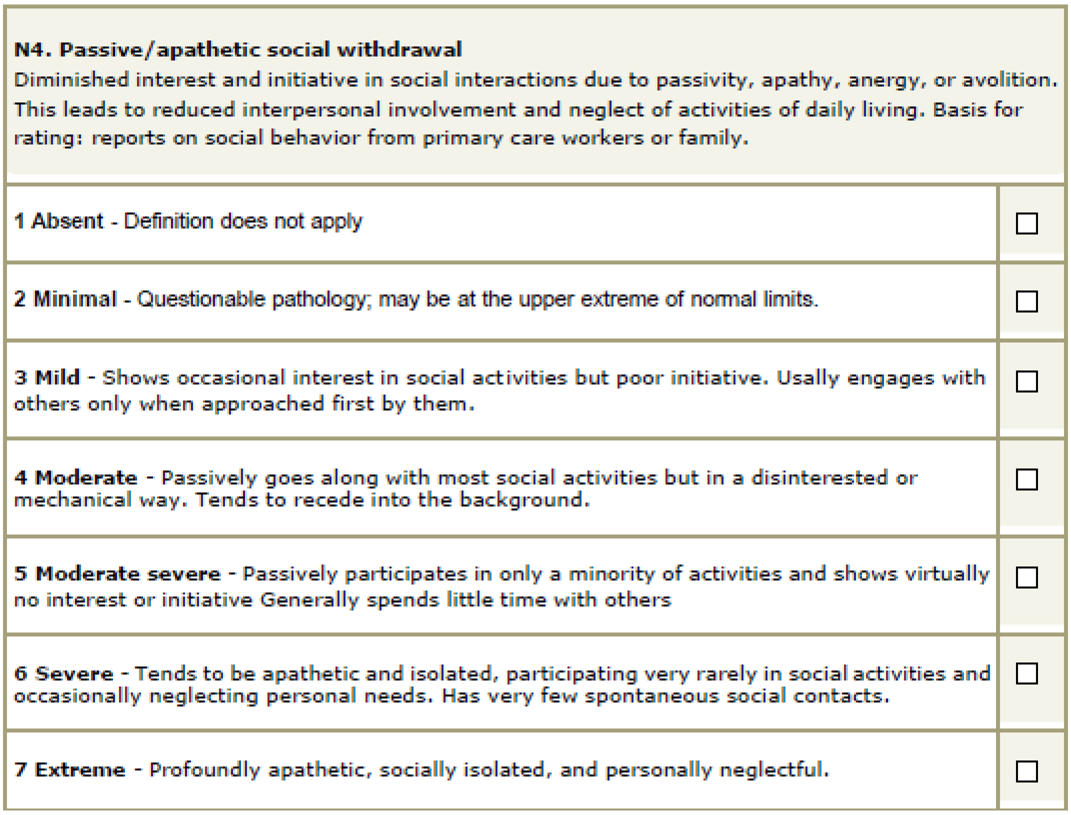
1 Absent - Definition does not apply	☐
2 Minimal - Questionable pathology; may be at the upper extreme of normal limits.	☐
3 Mild - Usually lacks initiative and occasionally may show deficient interest in surrounding events.	☐
4 Moderate - Patient is generally distanced emotionally from the milieu and its challenges but, with encouragement, can be engaged.	☐
5 Moderate severe - Patient is clearly detached emotionally from persons and events in the milieu, resisting all efforts at engagement. Patient appears distant, docile, and purposeless but can be involved m communication at least briefly and tends to personal needs, sometimes with assistance.	☐
6 Severe - Marked deficiency of interest and emotional commitment results in limited conversation with others and frequent neglect of personal functions, for which the patient requires supervision	☐
7 Extreme - Patient is almost totally withdrawn, uncommunicative, and neglectful of personal needs as a result of profound lack of interest and emotional commitment.	☐



N3. Poor rapport

Lack of interpersonal empathy, openess in conversation, and sense of closeness, interest, or involvement with the interviewer. This is evidenced by interpersonal distancing and reduced verbal and nonverbal communication. Basis for rating: interpersonal behavior during the course of interview.

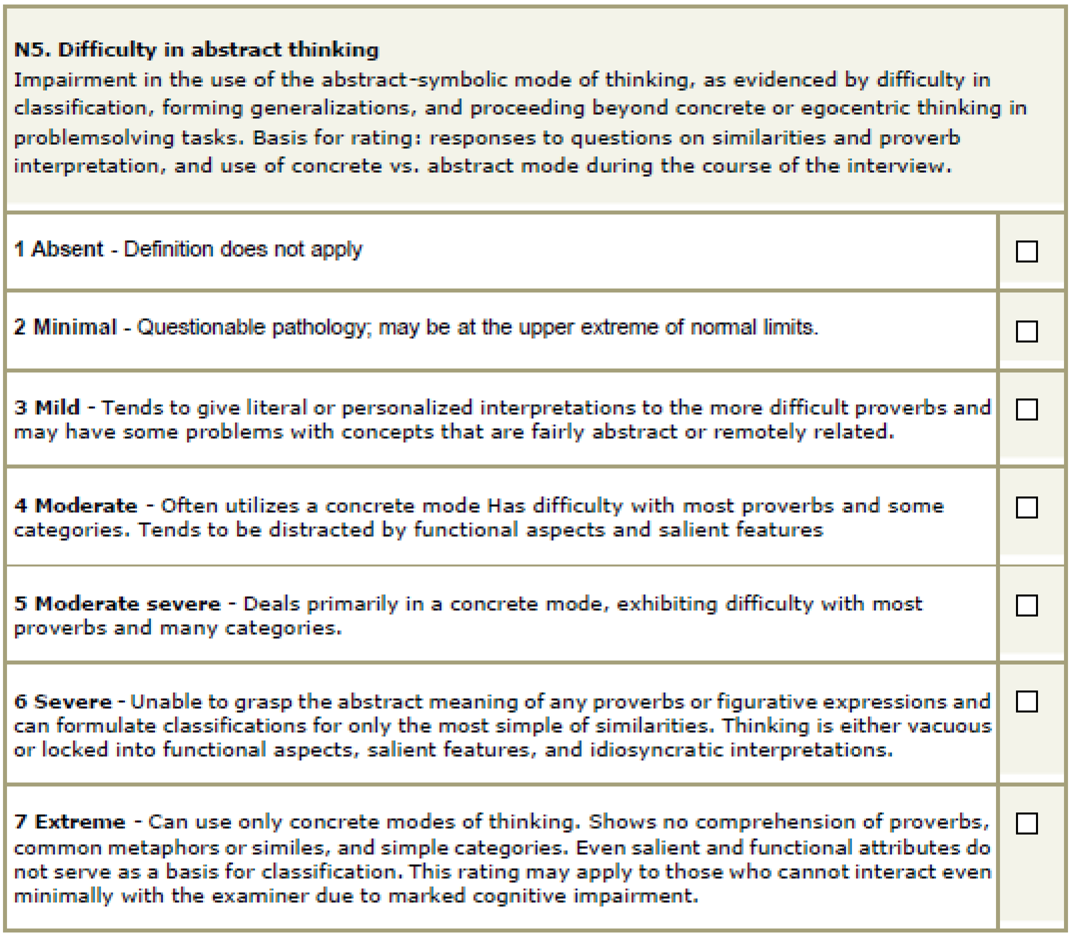
1 Absent - Definition does not apply	☐
2 Minimal - Questionable pathology; may be at the upper extreme of normal limits.	☐
3 Mild - Conversation is characterized by a stilted strained or artificial tone. It may lack emotional depth or tend to remain on an impersonal, intellectual plane.	☐
4 Moderate - Patient typically is aloof, with interpersonal distance quite evident. Patient may answer questions mechanically, act bored, or express disinterest.	☐
5 Moderate severe - Disinvolvement IS obvious and clearly impedes the productivity of the interview. Patient may tend to avoid eye or face contact.	☐
6 Severe - Patient is highly indifferent, with marked interpersonal distance. Answers are perfunctory, and there is little nonverbal evidence of involvement. Eye and face contact are frequently avoided.	☐
7 Extreme - Patient is totally uninvolved with the interviewer. Patient appears to be completely indifferent and consistently avoids verbal and nonverbal interactions during the interview.	☐



N4. Passive/apathetic social withdrawal

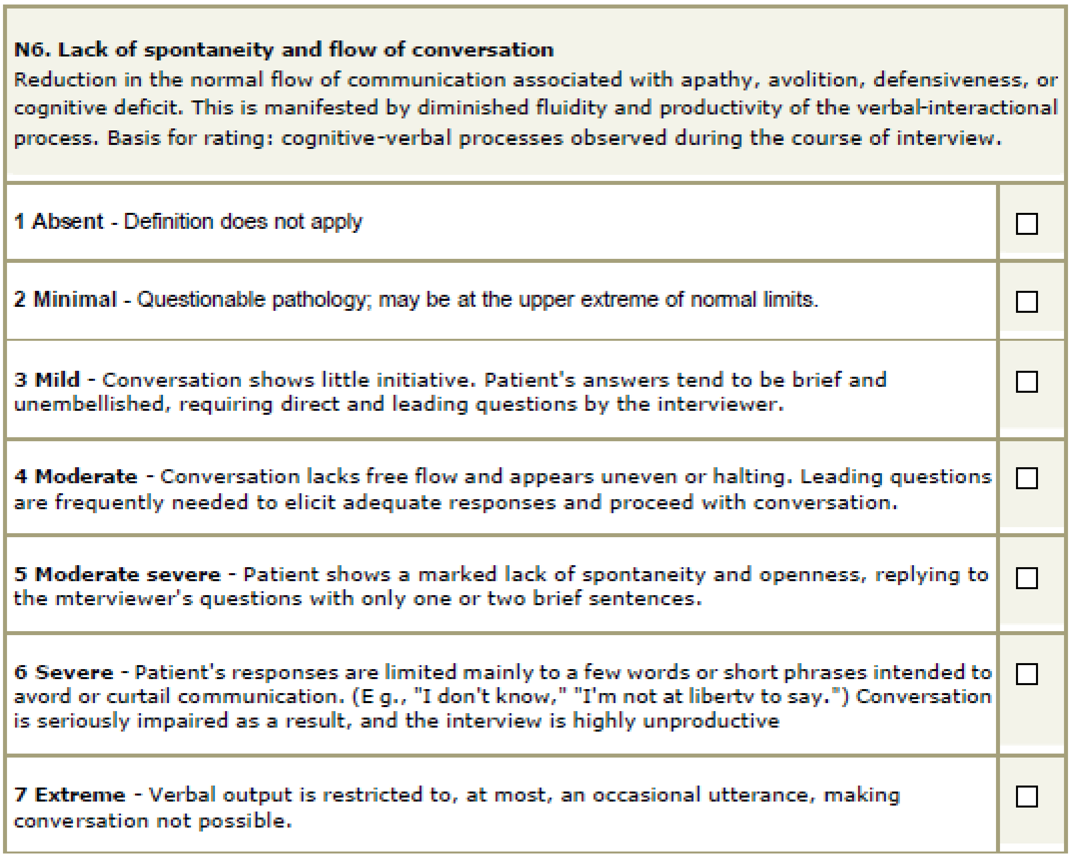
Diminished interest and initiative in social interactions due to passivity, apathy, anergy, or avolition. This leads to reduced interpersonal involvement and neglect of activities of daily living. Basis for rating: reports on social behavior from primary care workers or family.

1 Absent - Definition does not apply	☐
2 Minimal - Questionable pathology; may be at the upper extreme of normal limits.	☐
3 Mild - Shows occasional interest in social activities but poor initiative. Usally engages with others only when approached first by them.	☐
4 Moderate - Passively goes along with most social activities but in a disinterested or mechanical way. Tends to recede into the background.	☐
5 Moderate severe - Passively participates in only a minority of activities and shows virtually no interest or initiative Generally spends little time with others	☐
6 Severe - Tends to be apathetic and isolated, participating very rarely in social activities and occasionally neglecting personal needs. Has very few spontaneous social contacts.	☐
7 Extreme - Profoundly apathetic, socially isolated, and personally neglectful.	☐



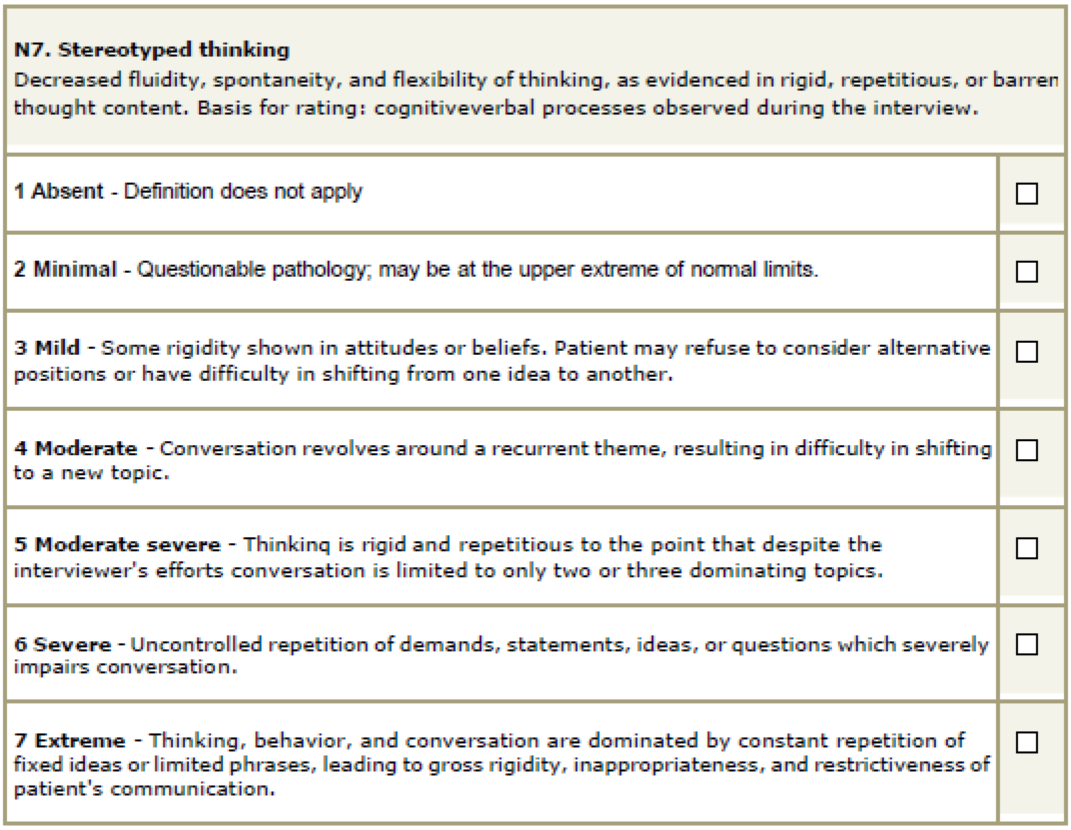
N5. Difficulty in abstract thinking
Impairment in the use of the abstract-symbolic mode of thinking, as evidenced by difficulty in classification, forming generalizations, and proceeding beyond concrete or egocentric thinking in problemsolving tasks. Basis for rating: responses to questions on similarities and proverb interpretation, and use of concrete vs. abstract mode during the course of the interview.

1 Absent - Definition does not apply	☐
2 Minimal - Questionable pathology; may be at the upper extreme of normal limits.	☐
3 Mild - Tends to give literal or personalized interpretations to the more difficult proverbs and may have some problems with concepts that are fairly abstract or remotely related.	☐
4 Moderate - Often utilizes a concrete mode Has difficulty with most proverbs and some categories. Tends to be distracted by functional aspects and salient features	☐
5 Moderate severe - Deals primarily in a concrete mode, exhibiting difficulty with most proverbs and many categories.	☐
6 Severe - Unable to grasp the abstract meaning of any proverbs or figurative expressions and can formulate classifications for only the most simple of similarities. Thinking is either vacuous or locked into functional aspects, salient features, and idiosyncratic interpretations.	☐
7 Extreme - Can use only concrete modes of thinking. Shows no comprehension of proverbs, common metaphors or similes, and simple categories. Even salient and functional attributes do not serve as a basis for classification. This rating may apply to those who cannot interact even minimally with the examiner due to marked cognitive impairment.	☐



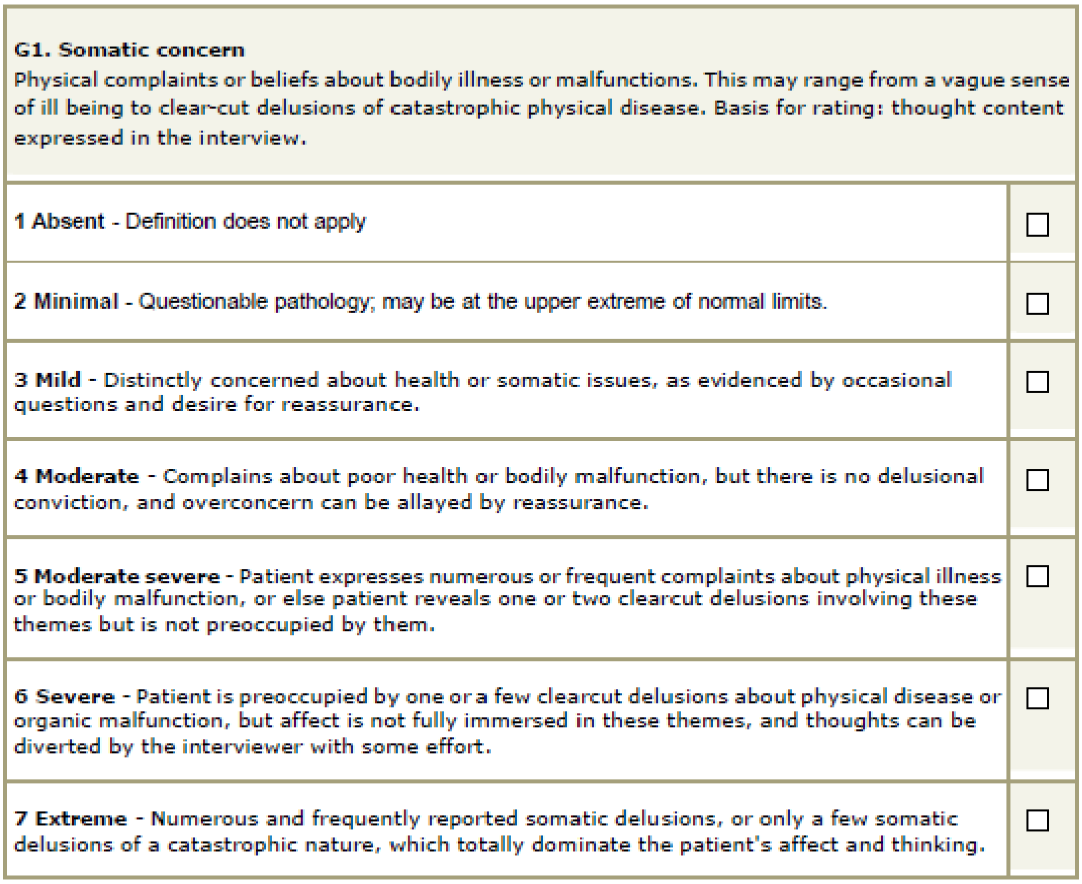
N6. Lack of spontaneity and flow of conversation
Reduction in the normal flow of communication associated with apathy, avolition, defensiveness, or cognitive deficit. This is manifested by diminished fluidity and productivity of the verbal-interactional process. Basis for rating: cognitive-verbal processes observed during the course of interview.

1 Absent - Definition does not apply	☐
2 Minimal - Questionable pathology; may be at the upper extreme of normal limits.	☐
3 Mild - Conversation shows little initiative. Patient's answers tend to be brief and unembellished, requiring direct and leading questions by the interviewer.	☐
4 Moderate - Conversation lacks free flow and appears uneven or halting. Leading questions are frequently needed to elicit adequate responses and proceed with conversation.	☐
5 Moderate severe - Patient shows a marked lack of spontaneity and openness, replying to the mterviewer's questions with only one or two brief sentences.	☐
6 Severe - Patient's responses are limited mainly to a few words or short phrases intended to avord or curtail communication. (E g., "I don't know," "I'm not at libertv to say.") Conversation is seriously impaired as a result, and the interview is highly unproductive	☐
7 Extreme - Verbal output is restricted to, at most, an occasional utterance, making conversation not possible.	☐

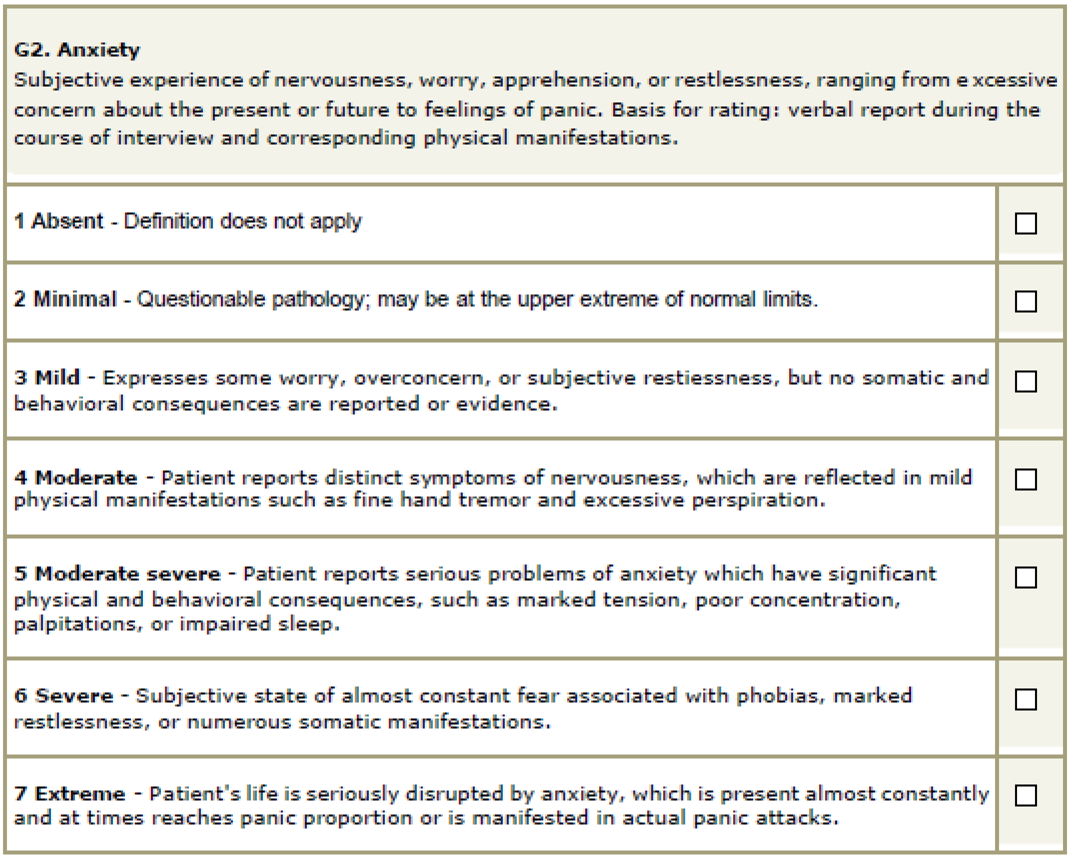


N7. Stereotyped thinking Decreased fluidity, spontaneity, and flexibility of thinking, as evidenced in rigid, repetitious, or barren thought content. Basis for rating: cognitiveverbal processes observed during the interview.	
1 Absent - Definition does not apply	☐
2 Minimal - Questionable pathology; may be at the upper extreme of normal limits.	☐
3 Mild - Some rigidity shown in attitudes or beliefs. Patient may refuse to consider alternative positions or have difficulty in shifting from one idea to another.	☐
4 Moderate - Conversation revolves around a recurrent theme, resulting in difficulty in shifting to a new topic.	☐
5 Moderate severe - Thinkinq is rigid and repetitious to the point that despite the interviewer's efforts conversation is limited to only two or three dominating topics.	☐
6 Severe - Uncontrolled repetition of demands, statements, ideas, or questions which severely impairs conversation.	☐
7 Extreme - Thinking, behavior, and conversation are dominated by constant repetition of fixed ideas or limited phrases, leading to gross rigidity, inappropriateness, and restrictiveness of patient's communication.	☐

GENERAL PSYCHOPATHOLOGY SCALE (G)

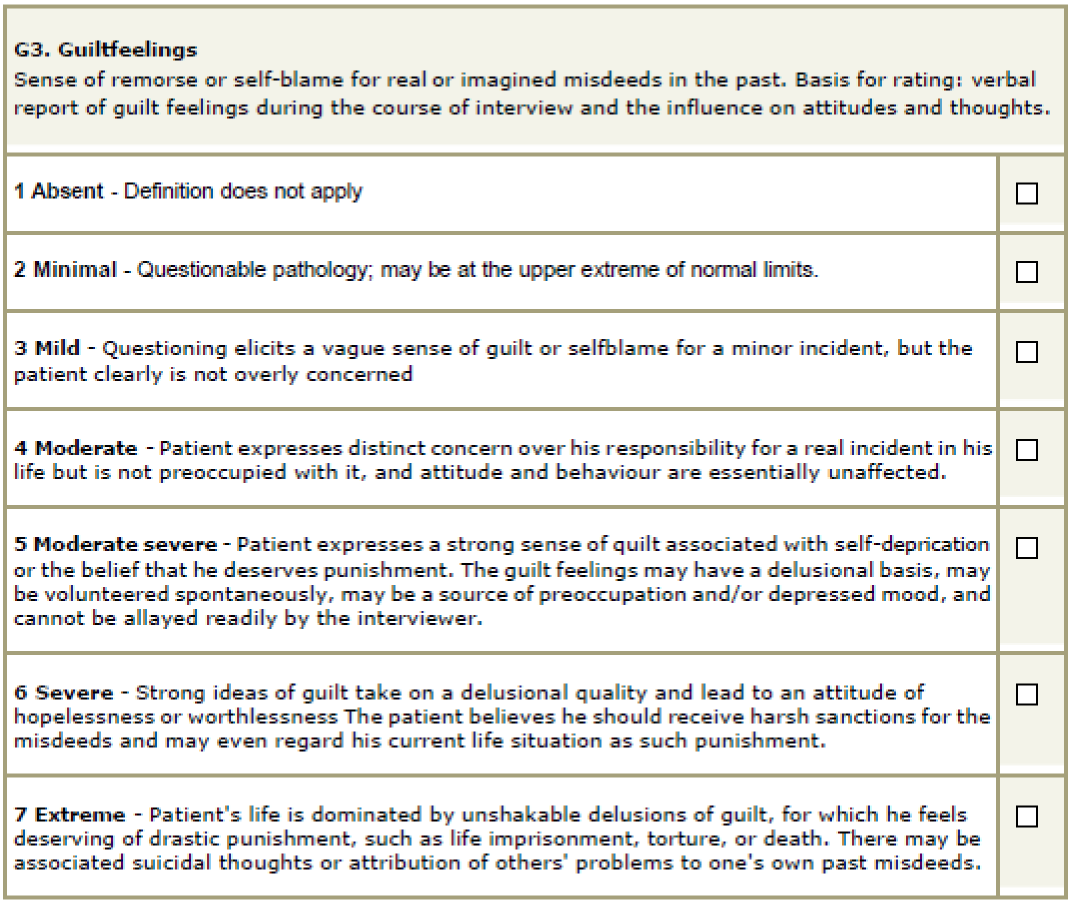


G1. Somatic concern Physical complaints or beliefs about bodily illness or malfunctions. This may range from a vague sense of ill being to clear-cut delusions of catastrophic physical disease. Basis for rating: thought content expressed in the interview.	
1 Absent - Definition does not apply	☐
2 Minimal - Questionable pathology; may be at the upper extreme of normal limits.	☐
3 Mild - Distinctly concerned about health or somatic issues, as evidenced by occasional questions and desire for reassurance.	☐
4 Moderate - Complains about poor health or bodily malfunction, but there is no delusional conviction, and overconcern can be allayed by reassurance.	☐
5 Moderate severe - Patient expresses numerous or frequent complaints about physical illness or bodily malfunction, or else patient reveals one or two clearcut delusions involving these themes but is not preoccupied by them.	☐
6 Severe - Patient is preoccupied by one or a few clearcut delusions about physical disease or organic malfunction, but affect is not fully immersed in these themes, and thoughts can be diverted by the interviewer with some effort.	☐
7 Extreme - Numerous and frequently reported somatic delusions, or only a few somatic delusions of a catastrophic nature, which totally dominate the patient's affect and thinking.	☐



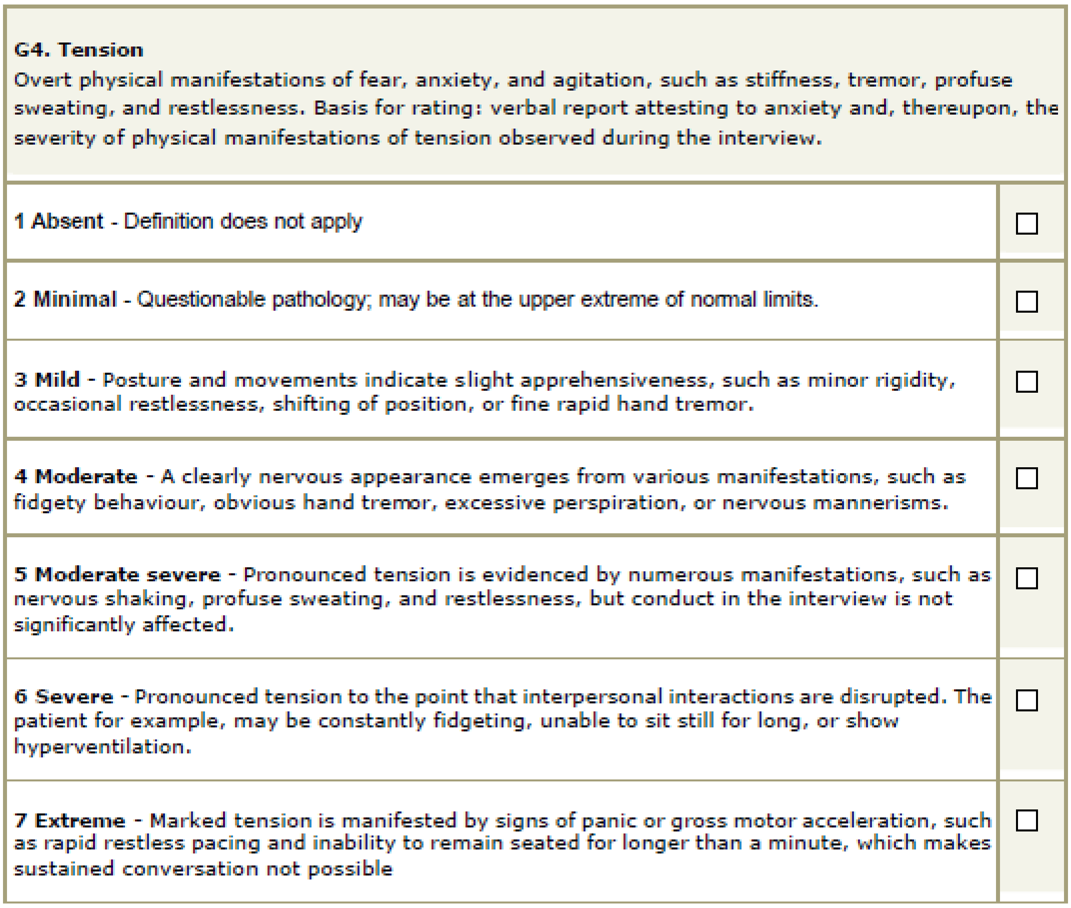
G2. Anxiety
Subjective experience of nervousness, worry, apprehension, or restlessness, ranging from e xcessive concern about the present or future to feelings of panic. Basis for rating: verbal report during the course of interview and corresponding physical manifestations.

1 Absent - Definition does not apply	☐
2 Minimal - Questionable pathology; may be at the upper extreme of normal limits.	☐
3 Mild - Expresses some worry, overconcern, or subjective restiessness, but no somatic and behavioral consequences are reported or evidence.	☐
4 Moderate - Patient reports distinct symptoms of nervousness, which are reflected in mild physical manifestations such as fine hand tremor and excessive perspiration.	☐
5 Moderate severe - Patient reports serious problems of anxiety which have significant physical and behavioral consequences, such as marked tension, poor concentration, palpitations, or impaired sleep.	☐
6 Severe - Subjective state of almost constant fear associated with phobias, marked restlessness, or numerous somatic manifestations.	☐
7 Extreme - Patient's life is seriously disrupted by anxiety, which is present almost constantly and at times reaches panic proportion or is manifested in actual panic attacks.	☐

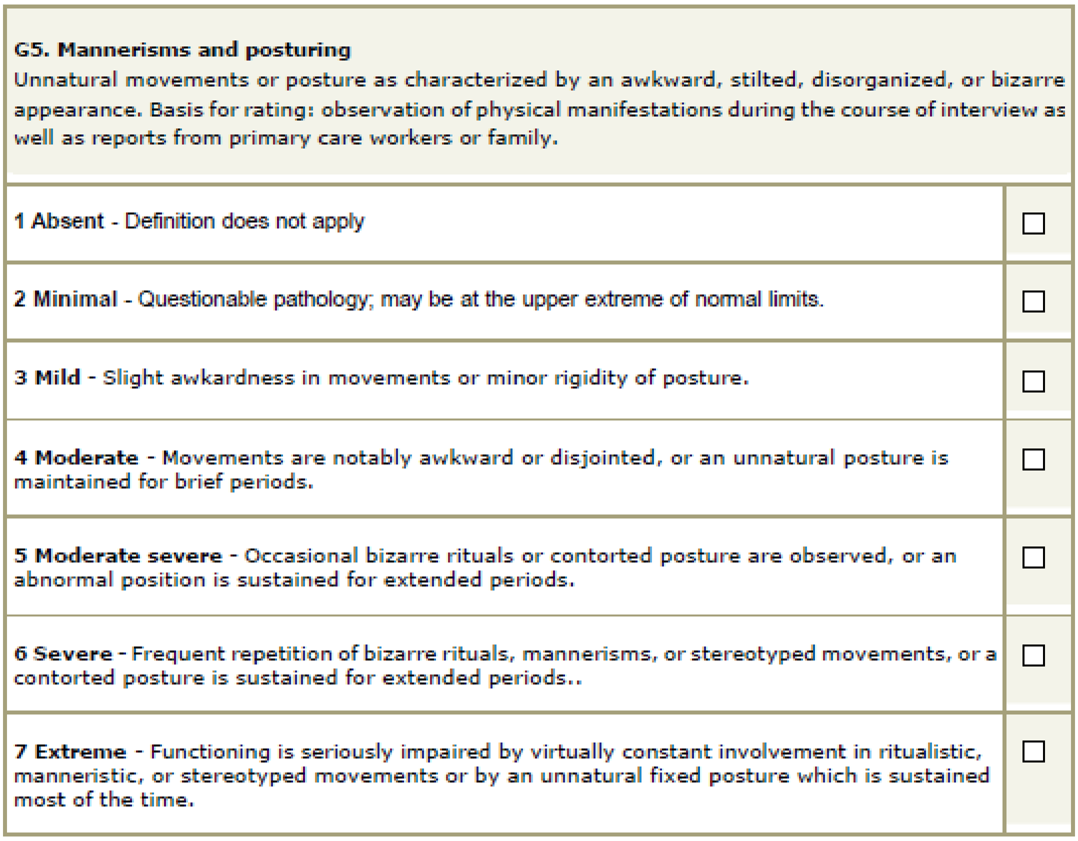


G3. Guiltfeelings
Sense of remorse or self-blame for real or imagined misdeeds in the past. Basis for rating: verbal report of guilt feelings during the course of interview and the influence on attitudes and thoughts.

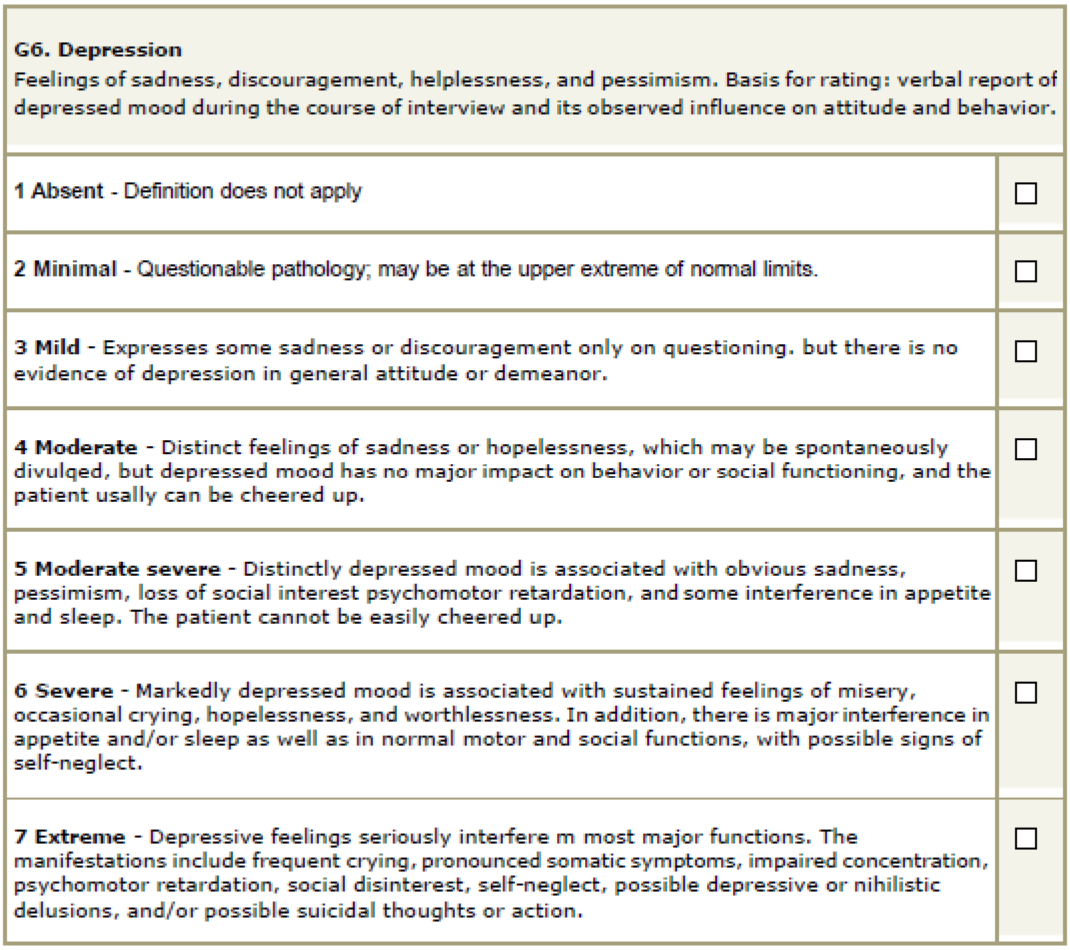
1 Absent - Definition does not apply	☐
2 Minimal - Questionable pathology; may be at the upper extreme of normal limits.	☐
3 Mild - Questioning elicits a vague sense of guilt or selfblame for a minor incident, but the patient clearly is not overly concerned	☐
4 Moderate - Patient expresses distinct concern over his responsibility for a real incident in his life but is not preoccupied with it, and attitude and behaviour are essentially unaffected.	☐
5 Moderate severe - Patient expresses a strong sense of guilt associated with self-deprication or the belief that he deserves punishment. The guilt feelings may have a delusional basis, may be volunteered spontaneously, may be a source of preoccupation and/or depressed mood, and cannot be allayed readily by the interviewer.	☐
6 Severe - Strong ideas of guilt take on a delusional quality and lead to an attitude of hopelessness or worthlessness The patient believes he should receive harsh sanctions for the misdeeds and may even regard his current life situation as such punishment.	☐
7 Extreme - Patient's life is dominated by unshakable delusions of guilt, for which he feels deserving of drastic punishment, such as life imprisonment, torture, or death. There may be associated suicidal thoughts or attribution of others' problems to one's own past misdeeds.	☐



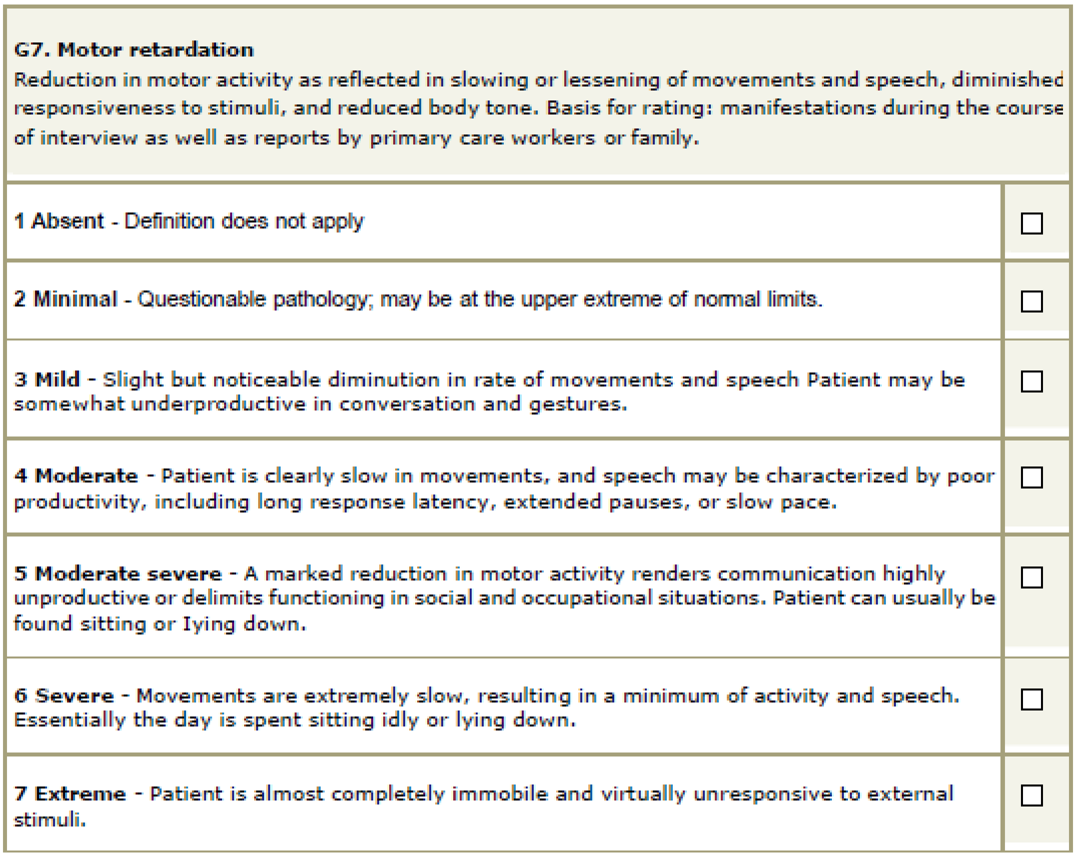
G4. Tension Overt physical manifestations of fear, anxiety, and agitation, such as stiffness, tremor, profuse sweating, and restlessness. Basis for rating: verbal report attesting to anxiety and, thereupon, the severity of physical manifestations of tension observed during the interview.	
1 Absent - Definition does not apply	☐
2 Minimal - Questionable pathology; may be at the upper extreme of normal limits.	☐
3 Mild - Posture and movements indicate slight apprehensiveness, such as minor rigidity, occasional restlessness, shifting of position, or fine rapid hand tremor.	☐
4 Moderate - A clearly nervous appearance emerges from various manifestations, such as fidgety behaviour, obvious hand tremor, excessive perspiration, or nervous mannerisms.	☐
5 Moderate severe - Pronounced tension is evidenced by numerous manifestations, such as nervous shaking, profuse sweating, and restlessness, but conduct in the interview is not significantly affected.	☐
6 Severe - Pronounced tension to the point that interpersonal interactions are disrupted. The patient for example, may be constantly fidgeting, unable to sit still for long, or show hyperventilation.	☐
7 Extreme - Marked tension is manifested by signs of panic or gross motor acceleration, such as rapid restless pacing and inability to remain seated for longer than a minute, which makes sustained conversation not possible	☐



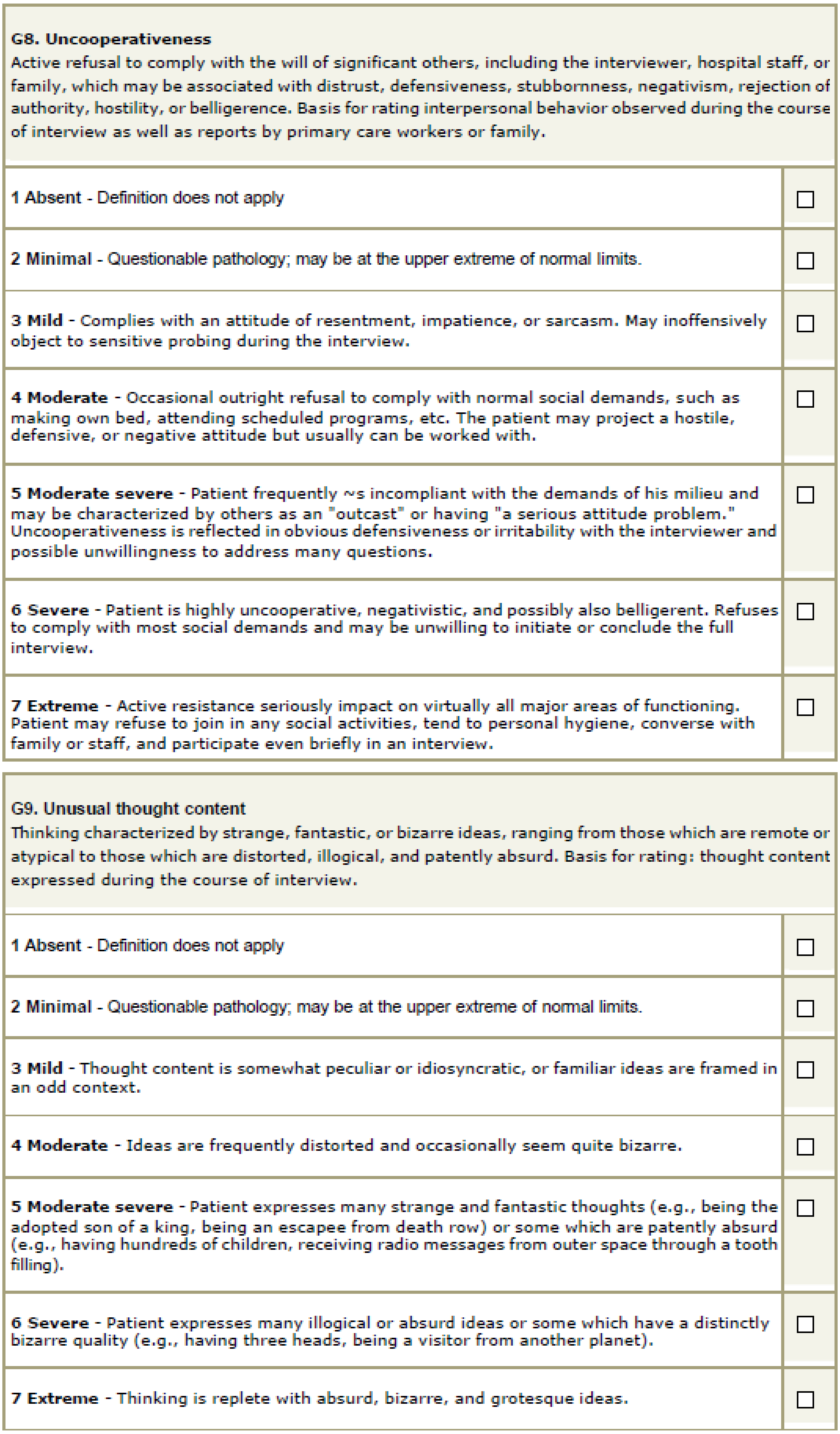
G5. Mannerisms and posturing Unnatural movements or posture as characterized by an awkward, stilted, disorganized, or bizarre appearance. Basis for rating: observation of physical manifestations during the course of interview as well as reports from primary care workers or family.	
1 Absent - Definition does not apply	☐
2 Minimal - Questionable pathology; may be at the upper extreme of normal limits.	☐
3 Mild - Slight awkardness in movements or minor rigidity of posture.	☐
4 Moderate - Movements are notably awkward or disjointed, or an unnatural posture is maintained for brief periods.	☐
5 Moderate severe - Occasional bizarre rituals or contorted posture are observed, or an abnormal position is sustained for extended periods.	☐
6 Severe - Frequent repetition of bizarre rituals, mannerisms, or stereotyped movements, or a contorted posture is sustained for extended periods..	☐
7 Extreme - Functioning is seriously impaired by virtually constant involvement in ritualistic, manneristic, or stereotyped movements or by an unnatural fixed posture which is sustained most of the time.	☐



G6. Depression Feelings of sadness, discouragement, helplessness, and pessimism. Basis for rating: verbal report of depressed mood during the course of interview and its observed influence on attitude and behavior.	
1 Absent - Definition does not apply	☐
2 Minimal - Questionable pathology; may be at the upper extreme of normal limits.	☐
3 Mild - Expresses some sadness or discouragement only on questioning. but there is no evidence of depression in general attitude or demeanor.	☐
4 Moderate - Distinct feelings of sadness or hopelessness, which may be spontaneously divulqed, but depressed mood has no major impact on behavior or social functioning, and the patient usally can be cheered up.	☐
5 Moderate severe - Distinctly depressed mood is associated with obvious sadness, pessimism, loss of social interest psychomotor retardation, and some interference in appetite and sleep. The patient cannot be easily cheered up.	☐
6 Severe - Markedly depressed mood is associated with sustained feelings of misery, occasional crying, hopelessness, and worthlessness. In addition, there is major interference in appetite and/or sleep as well as in normal motor and social functions, with possible signs of self-neglect.	☐
7 Extreme - Depressive feelings seriously interfere m most major functions. The manifestations include frequent crying, pronounced somatic symptoms, impaired concentration, psychomotor retardation, social disinterest, self-neglect, possible depressive or nihilistic delusions, and/or possible suicidal thoughts or action.	☐



G7. Motor retardation Reduction in motor activity as reflected in slowing or lessening of movements and speech, diminished responsiveness to stimuli, and reduced body tone. Basis for rating: manifestations during the course of interview as well as reports by primary care workers or family.	
1 Absent - Definition does not apply	☐
2 Minimal - Questionable pathology; may be at the upper extreme of normal limits.	☐
3 Mild - Slight but noticeable diminution in rate of movements and speech Patient may be somewhat underproductive in conversation and gestures.	☐
4 Moderate - Patient is clearly slow in movements, and speech may be characterized by poor productivity, including long response latency, extended pauses, or slow pace.	☐
5 Moderate severe - A marked reduction in motor activity renders communication highly unproductive or delimits functioning in social and occupational situations. Patient can usually be found sitting or Iying down.	☐
6 Severe - Movements are extremely slow, resulting in a minimum of activity and speech. Essentially the day is spent sitting idly or lying down.	☐
7 Extreme - Patient is almost completely immobile and virtually unresponsive to external stimuli.	☐

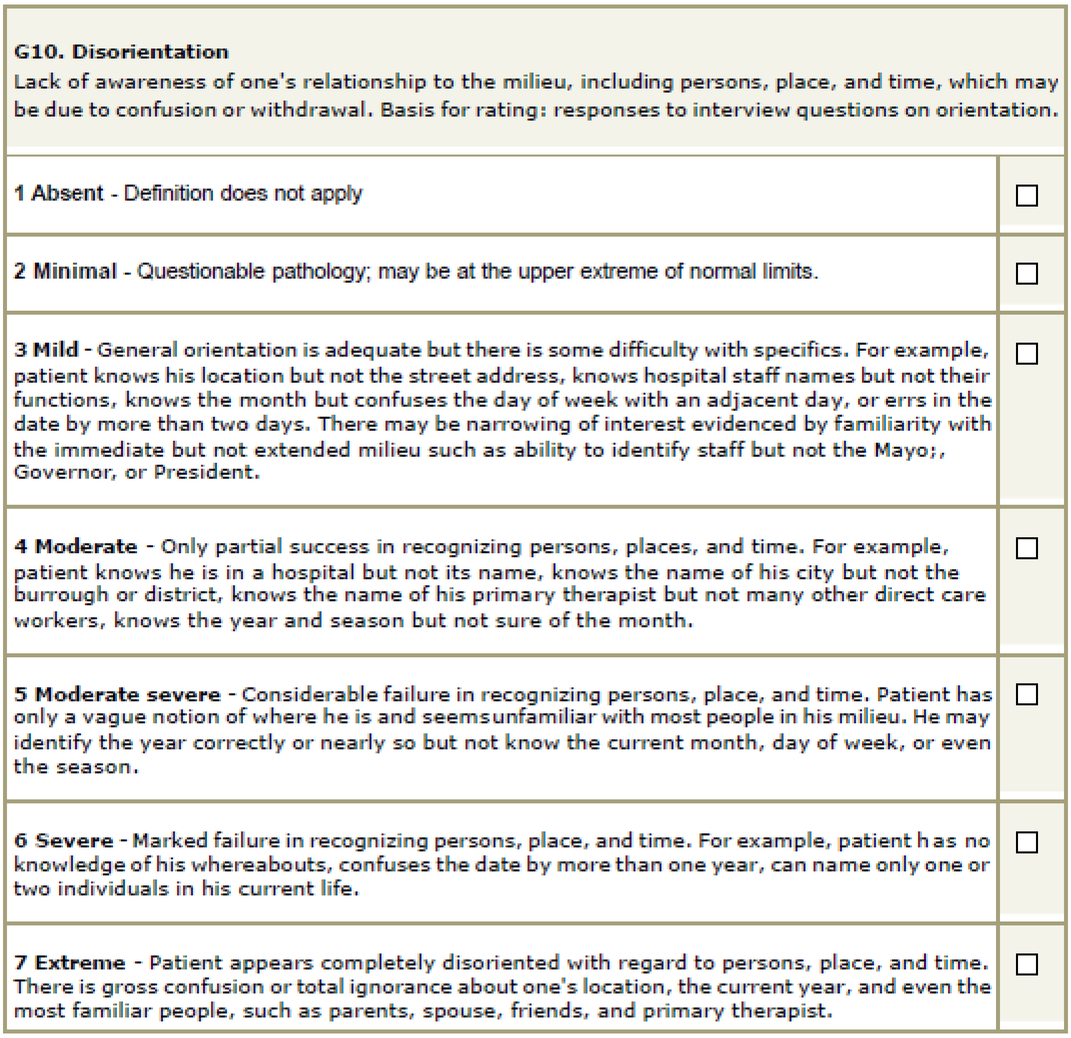


G8. Uncooperativeness
Active refusal to comply with the will of significant others, including the interviewer, hospital staff, or family, which may be associated with distrust, defensiveness, stubbornness, negativism, rejection of authority, hostility, or belligerence. Basis for rating interpersonal behavior observed during the course of interview as well as reports by primary care workers or family.

1 Absent - Definition does not apply	☐
2 Minimal - Questionable pathology; may be at the upper extreme of normal limits.	☐
3 Mild - Complies with an attitude of resentment, impatience, or sarcasm. May inoffensively object to sensitive probing during the interview.	☐
4 Moderate - Occasional outright refusal to comply with normal social demands, such as making own bed, attending scheduled programs, etc. The patient may project a hostile, defensive, or negative attitude but usually can be worked with.	☐
5 Moderate severe - Patient frequently ~s incompliant with the demands of his milieu and may be characterized by others as an "outcast" or having "a serious attitude problem." Uncooperativeness is reflected in obvious defensiveness or irritability with the interviewer and possible unwillingness to address many questions.	☐
6 Severe - Patient is highly uncooperative, negativistic, and possibly also belligerent. Refuses to comply with most social demands and may be unwilling to initiate or conclude the full interview.	☐
7 Extreme - Active resistance seriously impact on virtually all major areas of functioning. Patient may refuse to join in any social activities, tend to personal hygiene, converse with family or staff, and participate even briefly in an interview.	☐

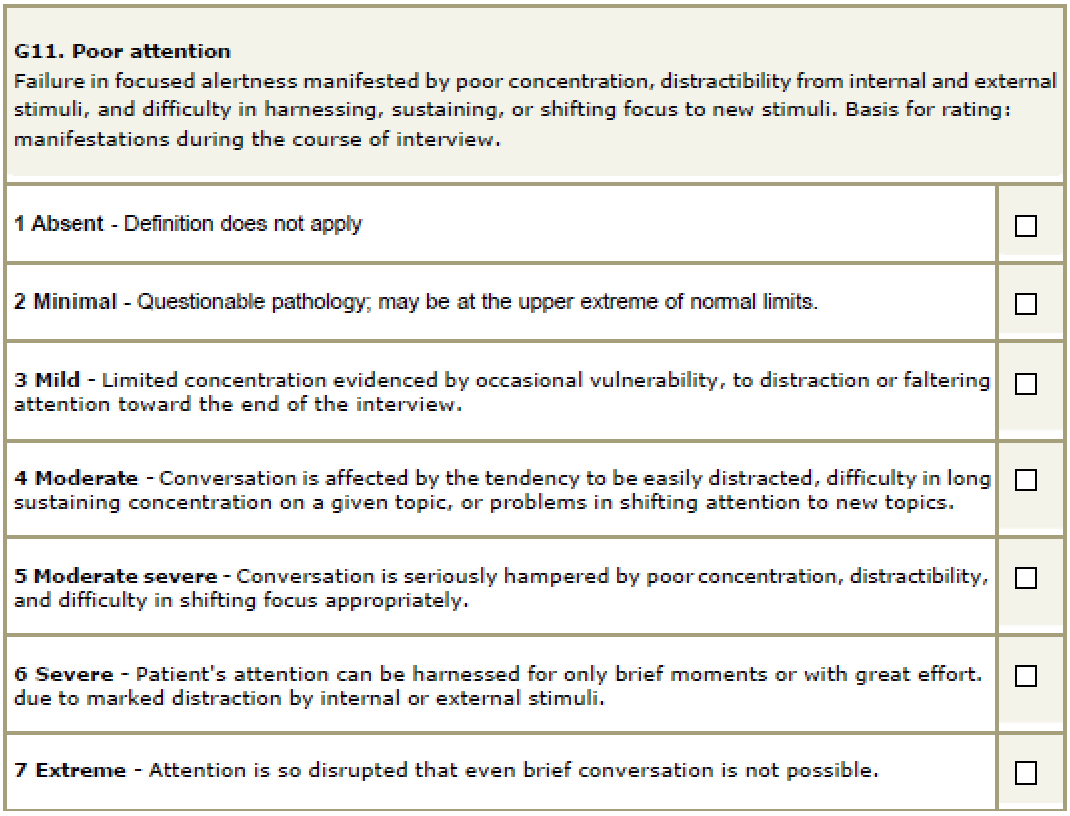
G9. Unusual thought content
Thinking characterized by strange, fantastic, or bizarre ideas, ranging from those which are remote or atypical to those which are distorted, illogical, and patently absurd. Basis for rating: thought content expressed during the course of interview.

1 Absent - Definition does not apply	☐
2 Minimal - Questionable pathology; may be at the upper extreme of normal limits.	☐
3 Mild - Thought content is somewhat peculiar or idiosyncratic, or familiar ideas are framed in an odd context.	☐
4 Moderate - Ideas are frequently distorted and occasionally seem quite bizarre.	☐
5 Moderate severe - Patient expresses many strange and fantastic thoughts (e.g., being the adopted son of a king, being an escapee from death row) or some which are patently absurd (e.g., having hundreds of children, receiving radio messages from outer space through a tooth filling).	☐
6 Severe - Patient expresses many illogical or absurd ideas or some which have a distinctly bizarre quality (e.g., having three heads, being a visitor from another planet).	☐
7 Extreme - Thinking is replete with absurd, bizarre, and grotesque ideas.	☐



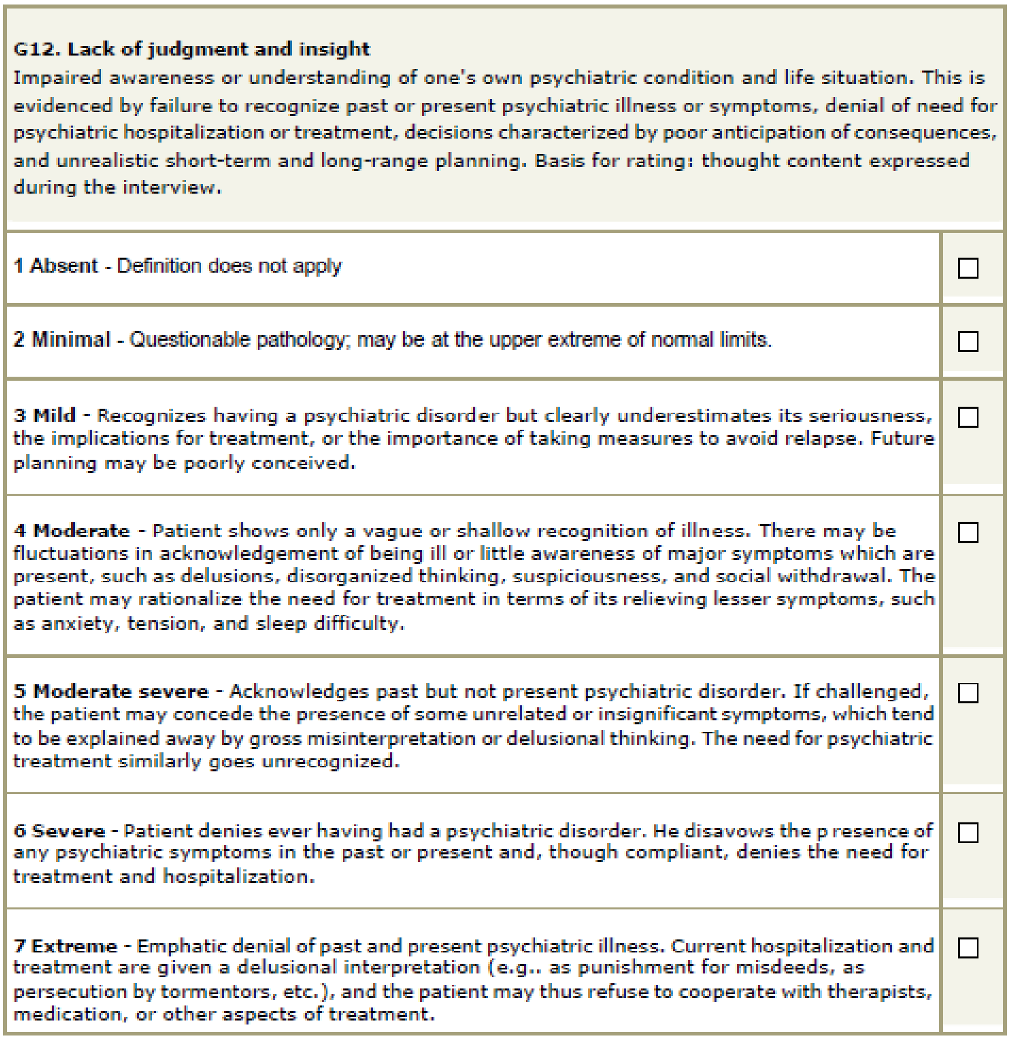
G10. Disorientation
Lack of awareness of one's relationship to the milieu, including persons, place, and time, which may be due to confusion or withdrawal. Basis for rating: responses to interview questions on orientation.

1 Absent - Definition does not apply	☐
2 Minimal - Questionable pathology; may be at the upper extreme of normal limits.	☐
3 Mild - General orientation is adequate but there is some difficulty with specifics. For example, patient knows his location but not the street address, knows hospital staff names but not their functions, knows the month but confuses the day of week with an adjacent day, or errs in the date by more than two days. There may be narrowing of interest evidenced by familiarity with the immediate but not extended milieu such as ability to identify staff but not the Mayo;, Governor, or President.	☐
4 Moderate - Only partial success in recognizing persons, places, and time. For example, patient knows he is in a hospital but not its name, knows the name of his city but not the burrough or district, knows the name of his primary therapist but not many other direct care workers, knows the year and season but not sure of the month.	☐
5 Moderate severe - Considerable failure in recognizing persons, place, and time. Patient has only a vague notion of where he is and seemsunfamiliar with most people in his milieu. He may identify the year correctly or nearly so but not know the current month, day of week, or even the season.	☐
6 Severe - Marked failure in recognizing persons, place, and time. For example, patient has no knowledge of his whereabouts, confuses the date by more than one year, can name only one or two individuals in his current life.	☐
7 Extreme - Patient appears completely disoriented with regard to persons, place, and time. There is gross confusion or total ignorance about one's location, the current year, and even the most familiar people, such as parents, spouse, friends, and primary therapist.	☐

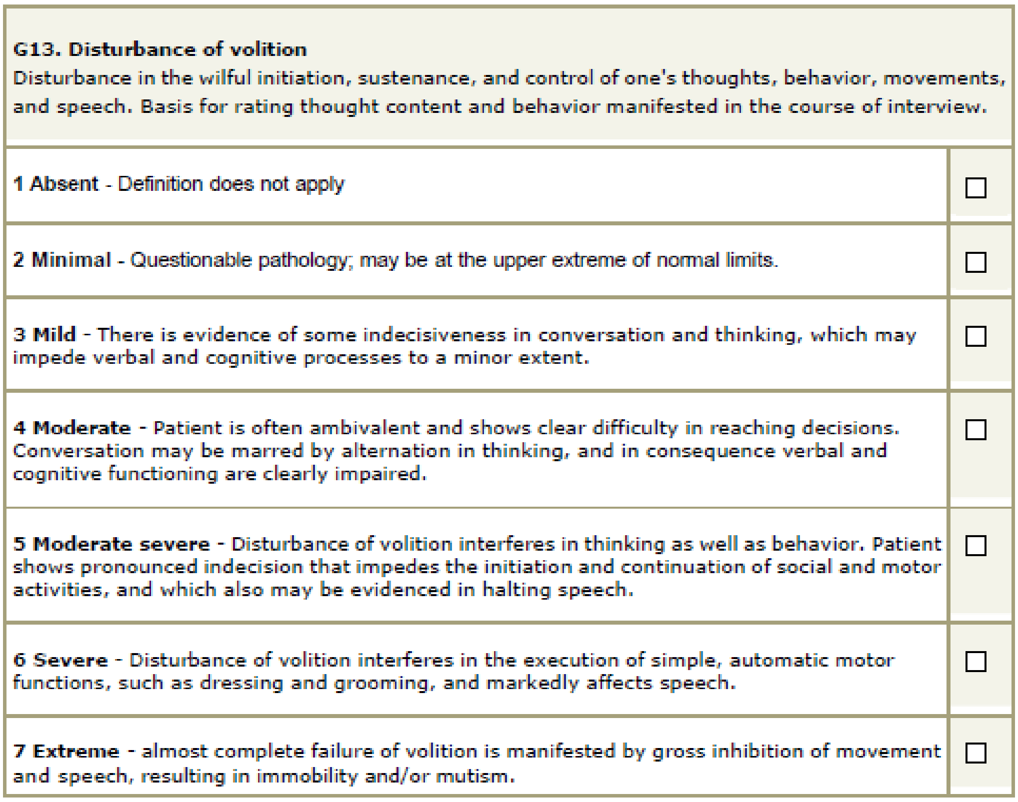


G11. Poor attention
Failure in focused alertness manifested by poor concentration, distractibility from internal and external stimuli, and difficulty in harnessing, sustaining, or shifting focus to new stimuli. Basis for rating: manifestations during the course of interview.

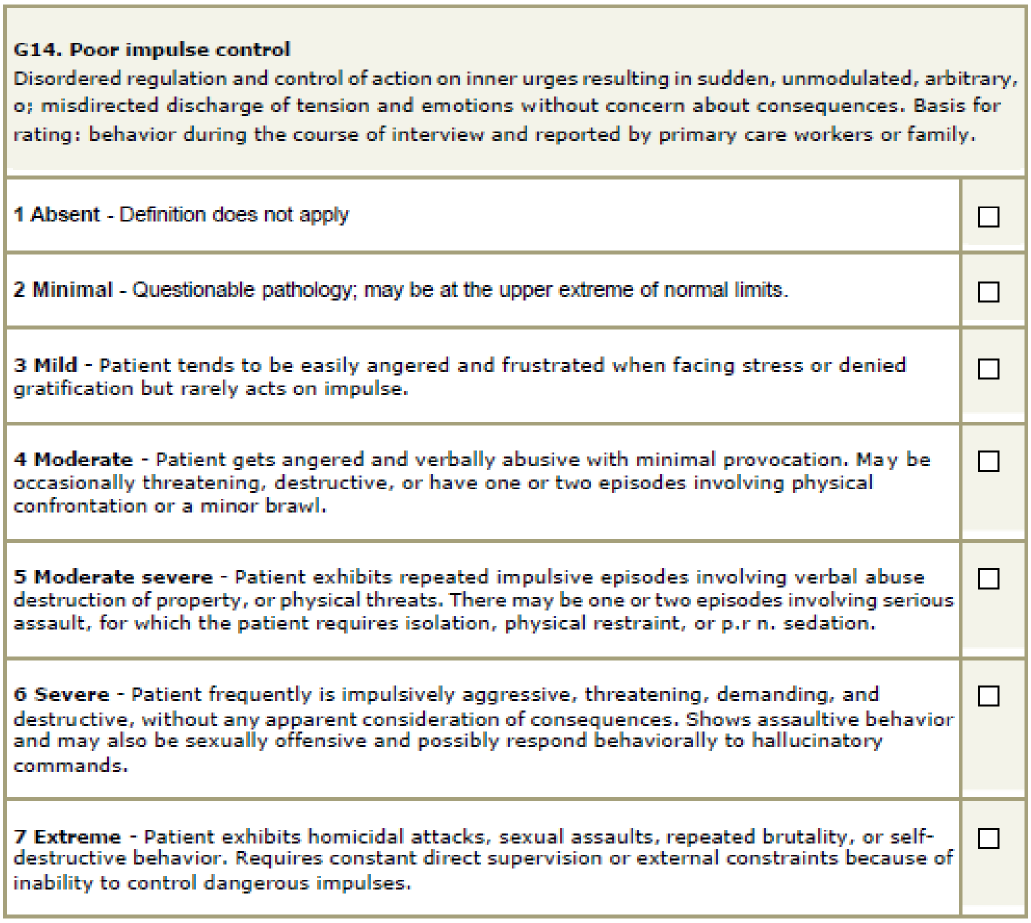
1 Absent - Definition does not apply	☐
2 Minimal - Questionable pathology; may be at the upper extreme of normal limits.	☐
3 Mild - Limited concentration evidenced by occasional vulnerability, to distraction or faltering attention toward the end of the interview.	☐
4 Moderate - Conversation is affected by the tendency to be easily distracted, difficulty in long sustaining concentration on a given topic, or problems in shifting attention to new topics.	☐
5 Moderate severe - Conversation is seriously hampered by poor concentration, distractibility, and difficulty in shifting focus appropriately.	☐
6 Severe - Patient's attention can be harnessed for only brief moments or with great effort. due to marked distraction by internal or external stimuli.	☐
7 Extreme - Attention is so disrupted that even brief conversation is not possible.	☐



G12. Lack of judgment and insight Impaired awareness or understanding of one's own psychiatric condition and life situation. This is evidenced by failure to recognize past or present psychiatric illness or symptoms, denial of need for psychiatric hospitalization or treatment, decisions characterized by poor anticipation of consequences, and unrealistic short-term and long-range planning. Basis for rating: thought content expressed during the interview.	
1 Absent - Definition does not apply	☐
2 Minimal - Questionable pathology; may be at the upper extreme of normal limits.	☐
3 Mild - Recognizes having a psychiatric disorder but clearly underestimates its seriousness, the implications for treatment, or the importance of taking measures to avoid relapse. Future planning may be poorly conceived.	☐
4 Moderate - Patient shows only a vague or shallow recognition of illness. There may be fluctuations in acknowledgement of being ill or little awareness of major symptoms which are present, such as delusions, disorganized thinking, suspiciousness, and social withdrawal. The patient may rationalize the need for treatment in terms of its relieving lesser symptoms, such as anxiety, tension, and sleep difficulty.	☐
5 Moderate severe - Acknowledges past but not present psychiatric disorder. If challenged, the patient may concede the presence of some unrelated or insignificant symptoms, which tend to be explained away by gross misinterpretation or delusional thinking. The need for psychiatric treatment similarly goes unrecognized.	☐
6 Severe - Patient denies ever having had a psychiatric disorder. He disavows the presence of any psychiatric symptoms in the past or present and, though compliant, denies the need for treatment and hospitalization.	☐
7 Extreme - Emphatic denial of past and present psychiatric illness. Current hospitalization and treatment are given a delusional interpretation (e.g.. as punishment for misdeeds, as persecution by tormentors, etc.), and the patient may thus refuse to cooperate with therapists, medication, or other aspects of treatment.	☐



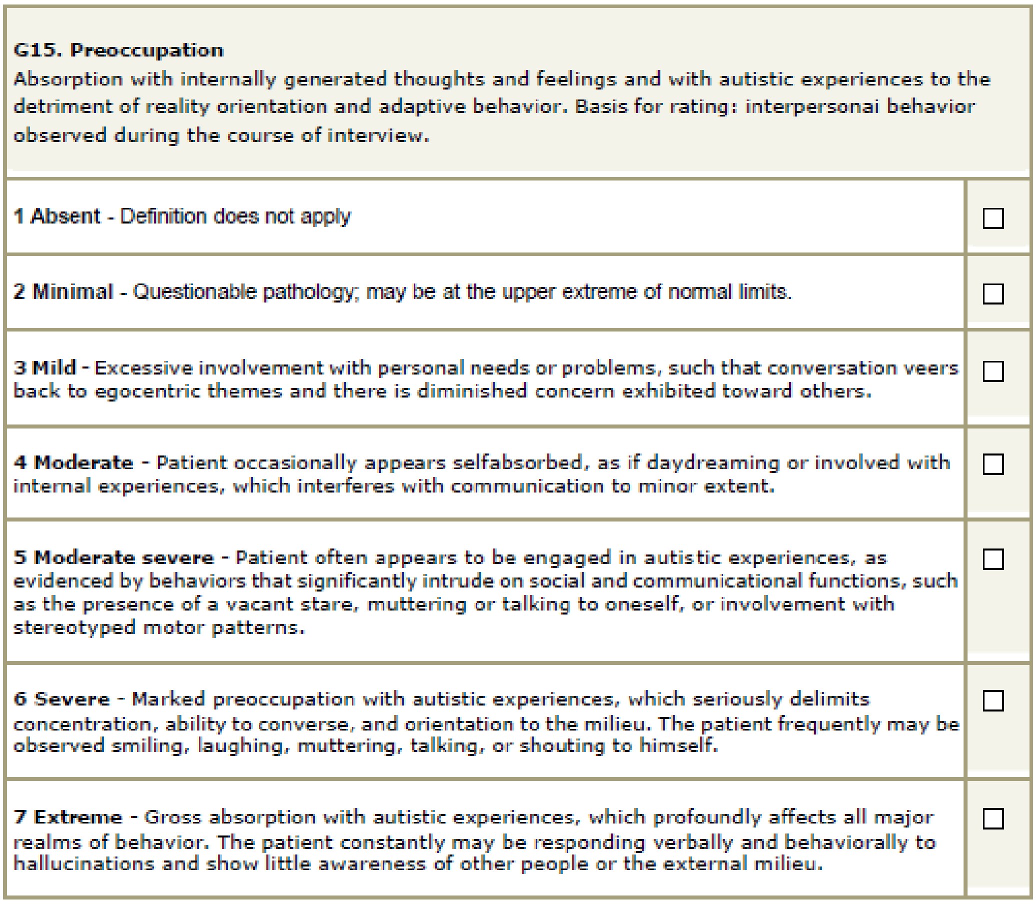
G13. Disturbance of volition Disturbance in the wilful initiation, sustenance, and control of one's thoughts, behavior, movements, and speech. Basis for rating thought content and behavior manifested in the course of interview.	
1 Absent - Definition does not apply	☐
2 Minimal - Questionable pathology; may be at the upper extreme of normal limits.	☐
3 Mild - There is evidence of some indecisiveness in conversation and thinking, which may impede verbal and cognitive processes to a minor extent.	☐
4 Moderate - Patient is often ambivalent and shows clear difficulty in reaching decisions. Conversation may be marred by alternation in thinking, and in consequence verbal and cognitive functioning are clearly impaired.	☐
5 Moderate severe - Disturbance of volition interferes in thinking as well as behavior. Patient shows pronounced indecision that impedes the initiation and continuation of social and motor activities, and which also may be evidenced in halting speech.	☐
6 Severe - Disturbance of volition interferes in the execution of simple, automatic motor functions, such as dressing and grooming, and markedly affects speech.	☐
7 Extreme - almost complete failure of volition is manifested by gross inhibition of movement and speech, resulting in immobility and/or mutism.	☐



G14. Poor impulse control

Disordered regulation and control of action on inner urges resulting in sudden, unmodulated, arbitrary, o; misdirected discharge of tension and emotions without concern about consequences. Basis for rating: behavior during the course of interview and reported by primary care workers or family.

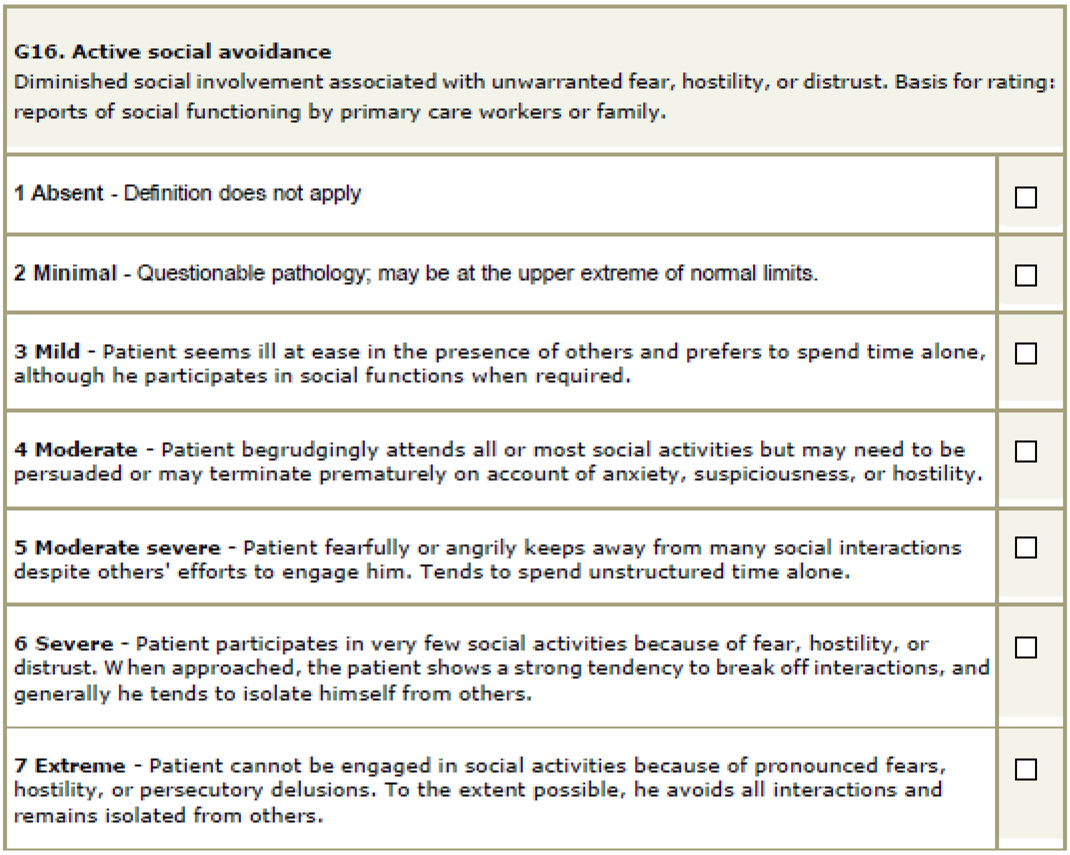
1 Absent - Definition does not apply	☐
2 Minimal - Questionable pathology; may be at the upper extreme of normal limits.	☐
3 Mild - Patient tends to be easily angered and frustrated when facing stress or denied gratification but rarely acts on impulse.	☐
4 Moderate - Patient gets angered and verbally abusive with minimal provocation. May be occasionally threatening, destructive, or have one or two episodes involving physical confrontation or a minor brawl.	☐
5 Moderate severe - Patient exhibits repeated impulsive episodes involving verbal abuse destruction of property, or physical threats. There may be one or two episodes involving serious assault, for which the patient requires isolation, physical restraint, or p.r n. sedation.	☐
6 Severe - Patient frequently is impulsively aggressive, threatening, demanding, and destructive, without any apparent consideration of consequences. Shows assaultive behavior and may also be sexually offensive and possibly respond behaviorally to hallucinatory commands.	☐
7 Extreme - Patient exhibits homicidal attacks, sexual assaults, repeated brutality, or self-destructive behavior. Requires constant direct supervision or external constraints because of inability to control dangerous impulses.	☐



G15. Preoccupation

Absorption with internally generated thoughts and feelings and with autistic experiences to the detriment of reality orientation and adaptive behavior. Basis for rating: interpersonal behavior observed during the course of interview.

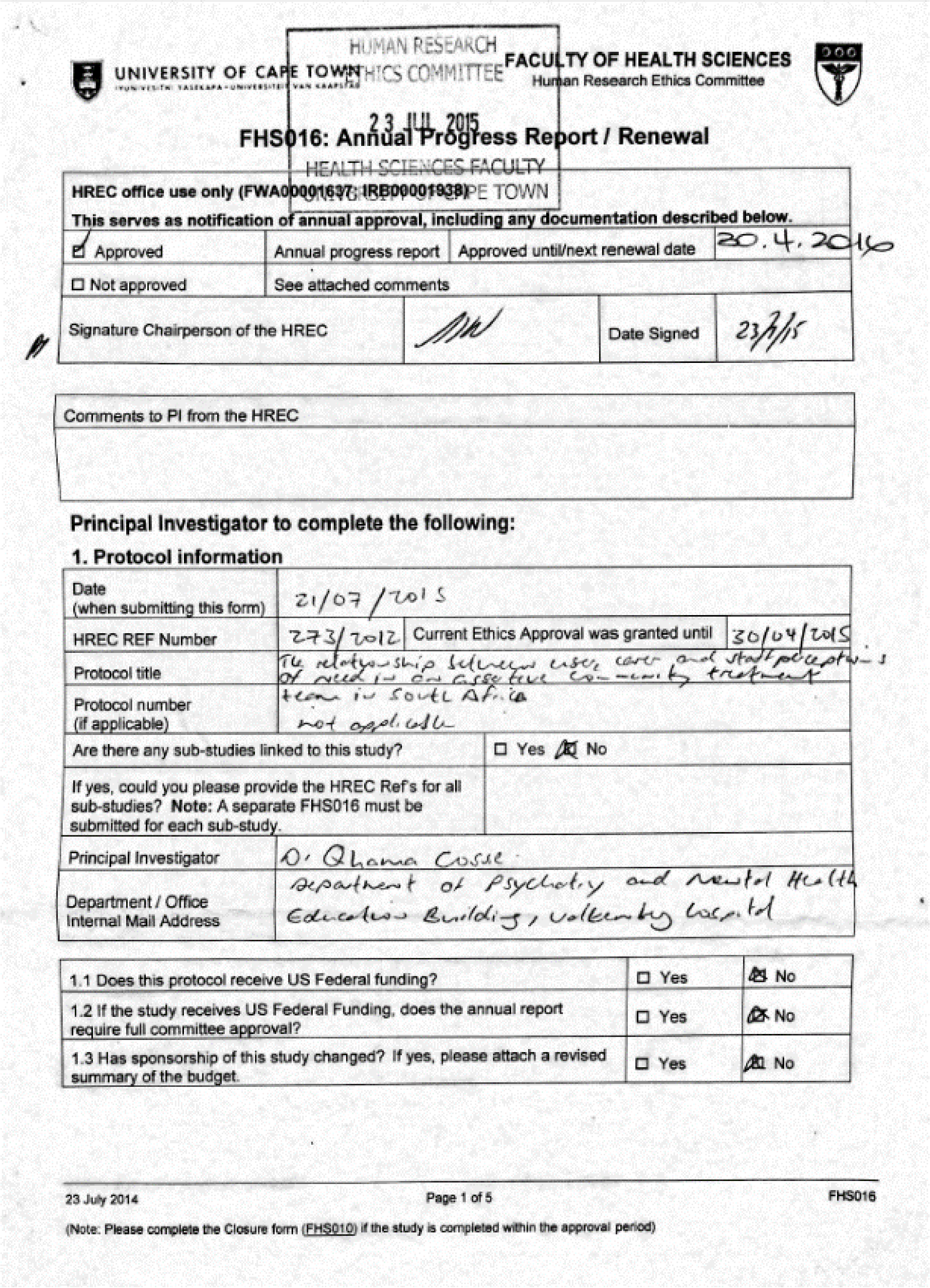
1 Absent - Definition does not apply	☐
2 Minimal - Questionable pathology; may be at the upper extreme of normal limits.	☐
3 Mild - Excessive involvement with personal needs or problems, such that conversation veers back to egocentric themes and there is diminished concern exhibited toward others.	☐
4 Moderate - Patient occasionally appears selfabsorbed, as if daydreaming or involved with internal experiences, which interferes with communication to minor extent.	☐
5 Moderate severe - Patient often appears to be engaged in autistic experiences, as evidenced by behaviors that significantly intrude on social and communicational functions, such as the presence of a vacant stare, muttering or talking to oneself, or involvement with stereotyped motor patterns.	☐
6 Severe - Marked preoccupation with autistic experiences, which seriously delimits concentration, ability to converse, and orientation to the milieu. The patient frequently may be observed smiling, laughing, muttering, talking, or shouting to himself.	☐
7 Extreme - Gross absorption with autistic experiences, which profoundly affects all major realms of behavior. The patient constantly may be responding verbally and behaviorally to hallucinations and show little awareness of other people or the external milieu.	☐



G16. Active social avoidance
Diminished social involvement associated with unwarranted fear, hostility, or distrust. Basis for rating: reports of social functioning by primary care workers or family.

1 Absent - Definition does not apply	☐
2 Minimal - Questionable pathology; may be at the upper extreme of normal limits.	☐
3 Mild - Patient seems ill at ease in the presence of others and prefers to spend time alone, although he participates in social functions when required.	☐
4 Moderate - Patient begrudgingly attends all or most social activities but may need to be persuaded or may terminate prematurely on account of anxiety, suspiciousness, or hostility.	☐
5 Moderate severe - Patient fearfully or angrily keeps away from many social interactions despite others' efforts to engage him. Tends to spend unstructured time alone.	☐
6 Severe - Patient participates in very few social activities because of fear, hostility, or distrust. When approached, the patient shows a strong tendency to break off interactions, and generally he tends to isolate himself from others.	☐
7 Extreme - Patient cannot be engaged in social activities because of pronounced fears, hostility, or persecutory delusions. To the extent possible, he avoids all interactions and remains isolated from others.	☐

7.6 Ethics approval



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FACULTY OF HEALTH SCIENCES
Human Research Ethics Committee

HUMAN RESEARCH ETHICS COMMITTEE
23 JUL 2015
HEALTH SCIENCES FACULTY
UNIVERSITY OF CAPE TOWN

FHS016: Annual Progress Report / Renewal

HREC office use only (FWA00001637; IRB00001938) **This serves as notification of annual approval, including any documentation described below.**			
☑ Approved	Annual progress report	Approved until/next renewal date	20.4.2016
☐ Not approved	See attached comments		
Signature Chairperson of the HREC		Date Signed	23/7/15

Comments to PI from the HREC

Principal Investigator to complete the following:

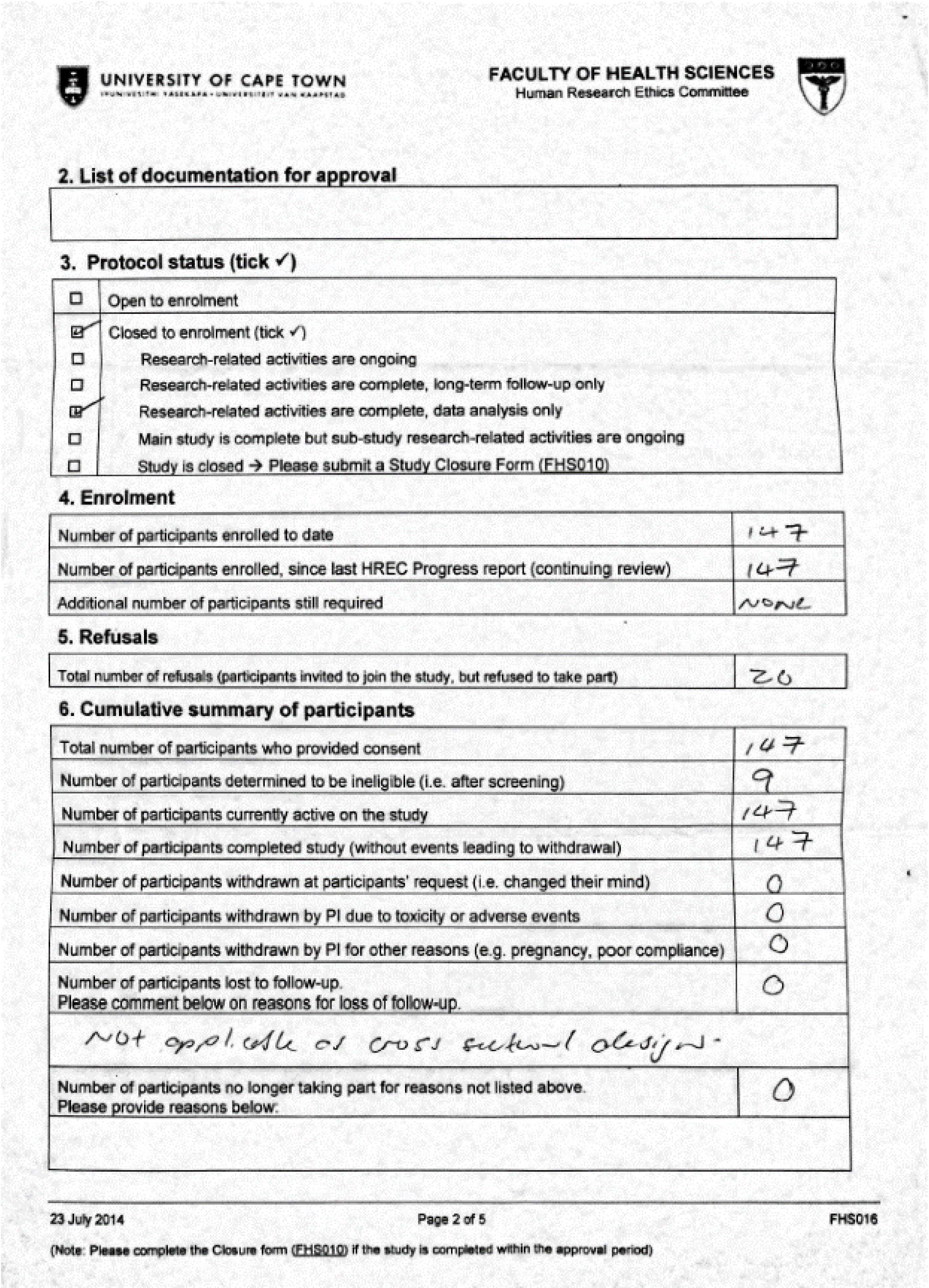
1. Protocol information

Date (when submitting this form)	21/07/2015		
HREC REF Number	273/2012	Current Ethics Approval was granted until	30/04/2015
Protocol title	The relationship between user, carer and staff perceptions of need in an assertive community treatment team in South Africa		
Protocol number (if applicable)	not applicable		
Are there any sub-studies linked to this study?	☐ Yes ☒ No		
If yes, could you please provide the HREC Ref's for all sub-studies? **Note:** A separate FHS016 must be submitted for each sub-study.			
Principal Investigator	Dr Qhama Cossie		
Department / Office Internal Mail Address	Department of Psychiatry and Mental Health Education Building, Valkenberg Hospital		

1.1 Does this protocol receive US Federal funding?	☐ Yes	☒ No
1.2 If the study receives US Federal Funding, does the annual report require full committee approval?	☐ Yes	☒ No
1.3 Has sponsorship of this study changed? If yes, please attach a revised summary of the budget.	☐ Yes	☒ No

23 July 2014 Page 1 of 5 FHS016

(Note: Please complete the Closure form (FHS010) if the study is completed within the approval period)



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FACULTY OF HEALTH SCIENCES

Human Research Ethics Committee

2. List of documentation for approval

3. Protocol status (tick ✓)

☐	Open to enrolment
☑	Closed to enrolment (tick ✓)
☐	Research-related activities are ongoing
☐	Research-related activities are complete, long-term follow-up only
☑	Research-related activities are complete, data analysis only
☐	Main study is complete but sub-study research-related activities are ongoing
☐	Study is closed → Please submit a Study Closure Form (FHS010)

4. Enrolment

Number of participants enrolled to date	147
Number of participants enrolled, since last HREC Progress report (continuing review)	147
Additional number of participants still required	None

5. Refusals

Total number of refusals (participants invited to join the study, but refused to take part)	20

6. Cumulative summary of participants

Total number of participants who provided consent	147
Number of participants determined to be ineligible (i.e. after screening)	9
Number of participants currently active on the study	147
Number of participants completed study (without events leading to withdrawal)	147
Number of participants withdrawn at participants' request (i.e. changed their mind)	0
Number of participants withdrawn by PI due to toxicity or adverse events	0
Number of participants withdrawn by PI for other reasons (e.g. pregnancy, poor compliance)	0
Number of participants lost to follow-up. Please comment below on reasons for loss of follow-up.	0
Not applicable as cross sectional design.	
Number of participants no longer taking part for reasons not listed above. Please provide reasons below:	0

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(Note: Please complete the Closure form (FHS010) if the study is completed within the approval period)