Guidelines for the psychological management of chronic kidney disease patients
(for the Psychologist)

Introduction

With increasing levels of sophistication in medical technology, chronically ill patients may be able to live longer lives and hence, the issue of quality of life (QOL). QOL encompasses 4 distinct areas, that cover the patient’s total experience of illness, namely physical health and symptomatology, functional status and activities of daily living, mental well-being and social role functioning and social support.

Guideline 1

Provide patients with an understanding of the medical assessment procedures

Prior to diagnosis of the patient’s medical condition, the medical team recommends that the patient undergo a battery of tests. Information should be provided to the patients about the reason for the tests and the procedures involved in testing.

Rationale

Medical procedures can cause fear, anxiety, confusion, irritation and a host of other negative feelings. Information about such procedures can help a) reduce confusion and anxiety on the part of the patient b) get the patient more involved in the treatment process, right from the very beginning.

Guideline 2

Help patients handle the diagnosis

Rationale

Diagnosis of a chronic kidney disease may elicit a number of emotional reactions which are manifested in many ways and which can have adverse effects (See Table 1).

It is important to note that these reactions, especially anxiety and depression, are often underdiagnosed, confused with symptoms of the disease or treatment or presumed to be normal and therefore not worthy of investigation. Assessing anxiety and depression and monitoring the same throughout the disease are thus important.

Guideline 3

Enhance patient adherence to treatment recommendations

Mental health professionals should:

1. Provide knowledge to the patients about the disease and the treatment

<table>
<thead>
<tr>
<th>Emotional Reaction</th>
<th>Manifestation</th>
<th>Adverse Effects</th>
</tr>
</thead>
<tbody>
<tr>
<td>Denial</td>
<td>Avoids the implication of the illness. Acts as if the illness is not severe or will go away. May deny even having the illness.</td>
<td>Interferes with the ability to monitor the condition, take initiative in seeking treatment or maintain a follow-up.</td>
</tr>
<tr>
<td>Anxiety</td>
<td>Is vigilant about every minor ache or pain. Feels anxious about the implication of the disease for the future and impact (work and leisure activities).</td>
<td>Intrinsically distressing. Can interfere with good functioning. Not so receptive to therapy. Shows increased symptomatology</td>
</tr>
<tr>
<td>Depression</td>
<td>Catastrophizes about the situation and generalizes negatively from the situation. Manifests weight loss, fatigue, sleeplessness, crying spells, pessimism and suicidal attempts.</td>
<td>Intrinsically distressing. Has a negative impact on long term hospitalization, rehabilitation and recovery.</td>
</tr>
</tbody>
</table>

Table 1 - Emotional Reactions: Their Manifestations and Adverse Effects
2. Facilitate the movement of patients in the direction of functional beliefs
3. Encourage social support, particularly from family members and friends
4. Enhance the patients self-management behaviours, namely self-regulation, self-monitoring, and self-reinforcement
5. Break down the barriers to adherence

Illustrations of the same are presented in Table 2.

### Rationale

Treatment recommendations for the patient include medication and diet. Getting the patient to adhere to the same is thus an important goal. Research has indicated that certain factors affect adherence adversely: a) lack of knowledge or understanding about the disease/treatment, b) dysfunctional health beliefs, c) lack of social support and isolation, d) poor self-management techniques, e) practical barriers to adherence.

There is evidence that knowledge about the disease and treatment can reduce anxiety, help the patient feel in control of the situation and show greater involvement in the treatment process. Getting patients to move in the direction of healthy beliefs is also relevant, such as, that one is vulnerable to a host of infections, that the treatment will result in benefits. Social support helps patients feel reassured that there are resources beyond their own. Self-management approaches have been found to improve clinical outcomes and to reduce costs. Finally getting patients to address barriers, rather than being defeated by the same, is very pertinent.

### Guideline 4

Facilitate patient/family adjustment to the impact of the disease.

Patients can be helped to adjust to the impact of the disease in the following areas (see Table 3):  

1. Coming to terms with their appearance  
2. Reaching higher levels of independence  
3. Assessing and addressing job difficulties  
4. Building up self-esteem

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### Table 2

<table>
<thead>
<tr>
<th>Principles</th>
<th>Techniques</th>
<th>Implementation examples</th>
</tr>
</thead>
<tbody>
<tr>
<td>Knowledge</td>
<td>Information</td>
<td>Provide comprehensive education about disease management, consequences of adherence, non- adherence. Use scenarios that threaten adherence, followed by a discussion of how such situations can be addressed (e.g. attending a party where prohibited food items are served)</td>
</tr>
<tr>
<td>Belief system</td>
<td>Self-Control</td>
<td>Help patients believe that the illness is under their control</td>
</tr>
<tr>
<td>Social support</td>
<td>Initiative</td>
<td>Get patients to understand that the treatment benefits far outweigh its barriers</td>
</tr>
<tr>
<td></td>
<td>Assistance</td>
<td>Have family members prepare appropriate diet</td>
</tr>
<tr>
<td></td>
<td>Companionship</td>
<td>Encourage friends to exercise along with the patient</td>
</tr>
<tr>
<td>Self-management</td>
<td>Self-awareness</td>
<td>Assist patients in developing self-awareness of their behaviour (use of diet logs)</td>
</tr>
<tr>
<td></td>
<td>Self-monitoring</td>
<td>Have patients track the intake of nutrients</td>
</tr>
<tr>
<td></td>
<td>Self-reinforcement</td>
<td>Encourage patients to reward self for improvement</td>
</tr>
<tr>
<td>Addressing barriers</td>
<td>Goal-setting</td>
<td>Get patients to break down bigger goals into smaller achievable ones; suggest pill reminders for those who forget to take their medication</td>
</tr>
<tr>
<td></td>
<td>AIDS in adherence</td>
<td>Help patients avoid cues that result in unhealthy eating patterns (e.g. avoid buying salty items when shopping)</td>
</tr>
</tbody>
</table>
5. Reestablishing normal social relationships

6. Coping with financial expenses

7. Dealing with pain

Family members can also be helped via counselling or family therapy to address the following issues:

1. Increasing resources to deal with additional responsibility.

2. Helping the patient to increase adherence.

3. Coping with the patient’s negative moods and behaviour. 4. Finding alternative ways to achieve intimacy (for spouses).

Rationale

This disease has an impact on all areas of life—physical, social, marital, emotional, occupational, financial, etc.

Physically, the patients may experience pain and manifest a change in skin colour, reduction in strength and weight fluctuations and decreased activity levels and physical independence. Patients may have trouble reestablishing normal social relationships. If chronic illness interferes with hobbies, leisure and work activities, then the self-concept may be damaged. The increase in expenditure, because of prolonged intake of medication, special diet, transportation and hospitalization, may cause a financial crunch.

Patients are not the only ones affected. As the saying goes ‘Individuals don’t develop illnesses, families do.’ Disruption in the life of one family member places increased responsibility on the family and the spouse, if the patient is married. Moreover, patients go through alterations in mood and increases in anxiety and dependency, which in turn may affect other family members adversely. Non-adherence on the part of the patient is not uncommon. Decrease in sexual activity between the couple may occur.

Guideline 5

Assist patients in dealing with the progression of the disease

When progression of the disease takes place, the role of the mental health professional is to help the patient a) make a decision about the treatment procedure, b) adjust to the process, c) Integrate the disease into one’s lifestyle.

Table 4 - Aspects and Manner of Help to be Provided Regarding Progression of the Disease

<table>
<thead>
<tr>
<th>Aspect</th>
<th>Manner of help provided</th>
</tr>
</thead>
<tbody>
<tr>
<td>Making a decision about the procedure</td>
<td>Information should be provided to the patient such as the need to create an access, the duration of each dialysis session, the likely experience during the session, the dietary and medical prescriptions and lifestyle changes</td>
</tr>
<tr>
<td>Adjusting to the treatment process</td>
<td>Patients can be helped to a) understand the benefits of treatment b) identify problems in following the treatment and make attempts to solve them and c) talk to those who have successfully adjusted to the treatment process</td>
</tr>
</tbody>
</table>
Rationale

When progression of the disease takes place, the patient has to decide about treatment options, namely dialysis (hemodialysis or peritoneal dialysis) or transplantation. Whatever be the option decided upon, the patient is likely to face a host of problems and hence has to be prepared for the same in advance. This preparation should take the form of information as well as support and reassurance. Since the disease is a life long process, patients should be helped to cope effectively with the illness and treatment. The signs of effective coping are: a) Dealing effectively with uncomfortable feelings, b) Generating hope, c) Enhancing one’s self-esteem, d) Maintaining relationships with others, e) Maintaining a sense of well-being.

Guideline 6

Psychological Assessment of the patients should be conducted periodically

Psychologists should assess the functional status and well-being as soon as possible, after referral, in order to obtain baseline data and to allow early intervention to improve functioning and well-being. Psychologists should regularly reassess functioning and well-being to ascertain the patient’s current status and the effectiveness of interventions to improve functioning and well-being. Reassessment is needed when a patient reports increased frequency or severity of symptoms, has a new complication of kidney disease, has an access for dialysis placed, starts dialysis, changes modality, or participates in a clinical or rehabilitation intervention (e.g. counseling, peer support, education, physical therapy) Standardized survey instruments that are valid, reliable, responsive to changes, easily interpretable and easy to use should be employed. A list of tests is presented in Table 5.

Rationale

Impairment in indices of functioning and well-being are associated with

1. worse outcome in chronic kidney disease,
2. low income and low education,
3. conditions that cause chronic disease (diabetes or hypertension) or complications of decreased GFR (anemia, malnutrition, bone disease, neuropathy),
4. level of GFR that is below a GFR of approximately 60 ml/min/1.73 m².

Reduced kidney functioning is associated with increasing symptoms, such as tiring easily, weakness, low energy,

<table>
<thead>
<tr>
<th>Instrument</th>
<th>Symptoms</th>
<th>Physical function</th>
<th>Mental function</th>
<th>Employment</th>
<th>Social function</th>
</tr>
</thead>
<tbody>
<tr>
<td>Beck Depression Inventory (BDI)</td>
<td>Depressive</td>
<td>No</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
</tr>
<tr>
<td>Cognitive Depression Index (CDI)</td>
<td>No</td>
<td>No</td>
<td>Yes</td>
<td>No</td>
<td>No</td>
</tr>
<tr>
<td>FSAD Severity Coefficient</td>
<td>Yes</td>
<td>No</td>
<td>No</td>
<td>No</td>
<td>No</td>
</tr>
<tr>
<td>Euro QOL</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
</tr>
<tr>
<td>Health Index (HI)</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
<td>No</td>
</tr>
<tr>
<td>Illness effects Questionnaire (IEQ)</td>
<td>Yes</td>
<td>No</td>
<td>Yes</td>
<td>No</td>
<td>Yes</td>
</tr>
<tr>
<td>Karnofsky Performance Scale (KPS)</td>
<td>Yes</td>
<td>Yes</td>
<td>No</td>
<td>Yes</td>
<td>Yes</td>
</tr>
<tr>
<td>MOS Short Form 36(SF-36)</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
</tr>
<tr>
<td>Multidimensional Scale of Perceived Social Support</td>
<td>Yes</td>
<td>No</td>
<td>No</td>
<td>No</td>
<td>Yes</td>
</tr>
<tr>
<td>NIANES Adult Questionnaire (NIANES)</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
</tr>
<tr>
<td>Quality of Well being Scale (QWB)</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
</tr>
<tr>
<td>Rand Health Insurance Experiment Instrument (RHIIE)</td>
<td>No</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
</tr>
<tr>
<td>Sickness Impact Profile (SIP)</td>
<td>No</td>
<td>No</td>
<td>Yes</td>
<td>No</td>
<td>No</td>
</tr>
<tr>
<td>Social Adjustment Scale Self Report (SAS-SR)</td>
<td>No</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
</tr>
<tr>
<td>State Trail Anxiety Inventory (STAI)</td>
<td>Anxiety</td>
<td>No</td>
<td>Yes</td>
<td>No</td>
<td>No</td>
</tr>
<tr>
<td>Symptom Checklist—90R (SCL-90R)</td>
<td>Yes</td>
<td>No</td>
<td>Yes</td>
<td>No</td>
<td>No</td>
</tr>
</tbody>
</table>

Table 5 - Domains of Functioning and Well-being Measured by Specific Instruments
cramps, bruising, bad tasting mouth, hiccoughs and poor odor perspiration and poorer physical function scores. Decreased GFR is also associated with poorer psychosocial functioning (higher anxiety, higher distress, decreased sense of well-being, higher depression and negative health perception), with lower employment and with reduced social functioning and social interaction.

**Guideline 7**

Organise and implement patient education programs

What is most required for all patients with a chronic kidney disease is a patient education program. The goals of such a patient education program are as follows:

1. To provide patients with comprehensive information about the disease process, and treatment (medical and dietary).
2. To provide education about ESRD treatment options.
3. To help patients cope with daily problems (nutrition and medication).
4. To help patients express feelings and communicate problems effectively.
5. To explore with patients effective coping strategies to deal with problems.
6. To help build up the self-esteem of the patients.
7. To serve as an informal support group for family members and patients.

The content of such a program should include information on the following:

1. Structure and functions of the kidney.
2. Signs and symptoms of CKD.
3. Causes and assessment of CKD.
4. Course and prognosis of CKD.
5. Treatment (medication, diet).
6. Importance of adherence and strategies for increasing adherence.
7. Treatment options for ESRD: Dialysis and transplantation.
8. Impact of CKD including ESRD (physical, socio emotional, financial, occupational)
9. Coping strategies to deal with stress in different areas.
10. Relevance of functional health beliefs.
11. Relevance of social support.
12. Clearing up myths and misconceptions.

**Rationale**

Patient education pertaining to kidney disease produces positive outcomes. It results in fewer treatment complications, leads to improved emotionality and positive behaviour change, helps ESRD personnel spend less time addressing non adherence and behavioural problems, increases knowledge about kidney disease and treatment options and heightens a persons sense of responsibility, independence and involvement.

**Guideline 8**

If the patient is a child help him/ her and family members understand the illness, adhere to the treatment recommendations and adjust to the illness and treatment

1. Give information to the child and family about the illness and the treatment.
2. Build up the resources of the child (increase frustration tolerance, self-esteem, independence, communication skills, appropriate health beliefs).
3. Get family members, peers and health care providers to provide support to the sick child.
4. Help family members to adjust to their new roles, responsibilities and relationships.

**Rationale**

Pediatric nephrology patients experience anxiety, anger and withdrawal because of diet and other restrictions imposed on their daily living. Hospital admissions can be a source of anxiety for the child. The short stature and abnormal gait can be especially stressful for the child. Poor academic achievement, increased irritability, anxiety depression and dependency is often evident. Interference with the mastery of age-related tasks and consequent lowered self-esteem has also been noted. There is evidence that adherence and coping is facilitated by social support and the development of personal characteristics such as high frustration tolerance, independence, self-control, positive self-esteem, etc. Also, information about the illness and the treatment should be provided to children because a) they have a right to have this information b) they already sense that they have a problem and may experience high levels of anxiety, if information is withheld c) with knowledge, they can get better involved in the treatment process.

Management of an illness poses challenges to the family members. Concerns of control and possible non-compliance with the diet regimen can become the source of parent-child conflict. At times, it is socially isolating to have a child with a chronic medical problem. Management of a chronic illness can be financially draining and can compound strains in a marital relationship. Family members have to play new roles and take on added responsibilities (double jobs, household chores and child psycho. management of CKD patients (for the Psychologist)
care) as well as enter into new relationships, to accommodate the needs of the child. Helping families to make these transitions is therefore imperative. End-note:

A multidisciplinary team is required to look after the welfare of the patients, namely the nephrologist, nurse, dialysis technician, dietician, medical social worker, health psychologist/human development specialist. Any or all of these personnel can function as patient educators depending on their knowledge in the field and their communication skills. However, psychological counselling can be undertaken only by those trained in the field.

References


