Chapter 3: PDCDB and PDPHDB:

Clinical and physiotherapeutic databases for medical practitioners for Parkinson's Disease

3.1 Introduction

In order to alleviate the absence of clinical databases for PD, researchers of the h-Techsight project in collaboration with the Guildford Parkinson's Disease Research Group (GPDRG) initiated a project to construct databases that will (a) help both researchers and clinicians involved with PWPD to give them critical insights of the drug concordance, the essence of this database and (b) help the physiotherapist to look for meaningful information by annotating the database. Besides, the data accumulated in both the databases will serve as the future legacy databases that can be mined for knowledge, the key facets of our research [95]. This chapter describes the databases for **P**arkinson's **D**isease **C**linical **D**ata**b**ase (PDCDB) and **P**arkinson's **D**isease **Ph**ysiotherapy **D**ata**b**ase (PDPHDB). Tables are described within single inverted commas while columns are described in italics.

3.2 Database Access for PDCDB

The database is currently implemented at the URL http://pdmp.cpe.surrey.ac.uk/index.jsp. It is a semantically enabled web site so that users looking for meaningful information regarding researchers involved in PD will be able to extract the RDF enabled FOAF (**F**riend **O**f **A** **F**riend). RDF is a machine enabled language that allows machines to interact with each other.

Users are required to register for free and input their data, which is solely for research purposes and no data is given to any 3rd party. Personal information like first and family names or their postal address are not required to fill in the form.

3.2.1 Implementation

The usage of the PDCDB and the implementation of the system have been presented elsewhere [96]. The system has 4 layers where the user can only see the presentation layer while communicating with the underlying layers of database, application and transport layer. For brevity, the following is summarised below:

Database Layer: The system is currently using MS SQL Server 2000 as a database back-end within an Intel based platform. The E-R diagram is shown in Figure 3.1.

Application Layer: This layer makes SQL queries through HTTP input and formats the result set in HTML

Transport Layer: Using the Jakarta Tomcat[♣] 4.1.24, which also acts as the web server, handles any requests from the user, processes it, checks for any security like user and password authentication, then returns the result set.

Presentation Layer: This layer is the layer that the user can see and this is provided by the web browser.

[♣] Jakarta.apache.org

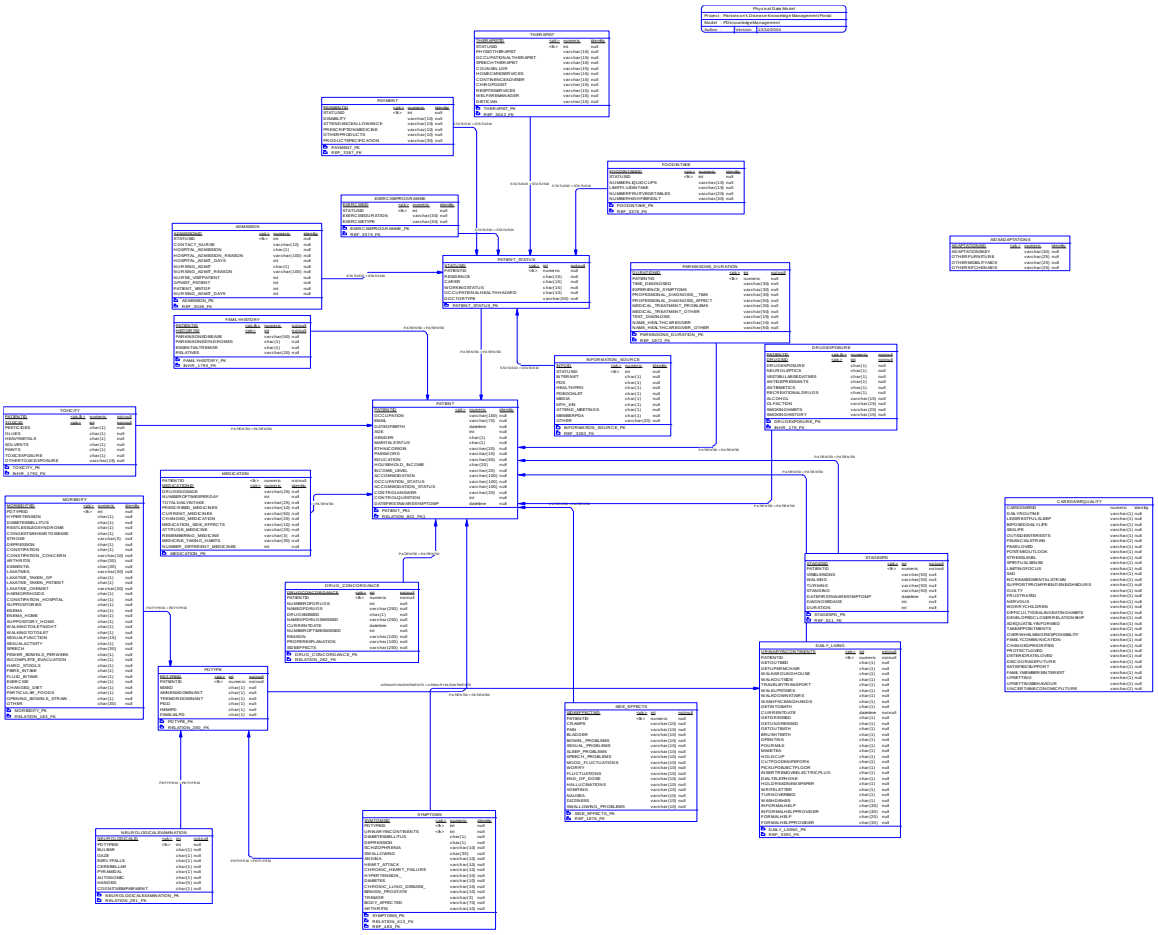

Figure 3.1 The E-R diagram for the database PDCDB (enlarged copy is shown in Appendix A)

3.2.2 Database Organisation

The primary objective of this database is to store anonymous, non-intrusive, confidential data from patients either through the World Wide Web or by mail, which will then be analysed by the domain experts. The findings will be used to improve understanding of the different facets of PD, which will ultimately help improve the quality of life. The information will cover history, diagnosis and symptoms experienced by people with PD. The information sought from PWPD will be to ask them about problems they have in everyday life, services and support they may receive and the medications that they take.

Currently, the database contains 6 main categories that help both the scientists and the health care givers to make clinical assessments of PD. These are Activities of Daily

Living, Drug Concordance, Stages of Parkinson's Disease, Parkinson's Disease Symptoms, Side Effects and Services and Support.

Activities of Daily Living

In PWPD no two individuals have the same symptoms or the same rate of PD [4]. As such, it is necessary to study the adjustments that PWPD make in their life style for successful living with the disease. A prolonged and a concerted approach is required to meet the challenges of the disease. A positive mental attitude is therefore necessary to overcome the challenges in independence that they encounter in their daily life. The scope of this research is to find out the daily activities that constitute successful living and identify those activities to help improve the quality of life. For example, whether adequate resources and time are allocated to get dressed, make a cup of tea or conduct exercise [17].

This category monitors the activities for patients and their impact on daily life. It is designed to identify the list of 25 daily activities that are affected by PD. The table 'Daily_Living' stores the information about getting out of bed (*GetOutbed*), from an armchair (*GetUpArmChair*), get into (*GetIntobath*) and out of a bath (*GetOutbath*), get dressed (*GetDressed*), whether the patient can walk around the house (*WalkAroundHouse*)or outside (*WalkOutside*), walk up (*WalkUpstairs*) or down the staircase(*WalkDownstairs*), wash and dry dishes (*WashDishes*). It is linked to the 'Patient_Profile' table that stores information about their *Email* by the foreign key relationship of *PatientID.*

Drug Concordance

The treatment of PD can either be conducted with the usage of pharmaceutical, non-pharmaceutical, surgical or a combination of one or all of these techniques. The management of pharmaceutical treatment is aimed at the symptomatic control by a combination of ***levodopa*** drugs with ***dopamine agonists*** [11]. The wearing-off effect of ***levodopa*** drugs can lead to the recurrence of Parkinsonian symptoms [4]. Yet, the goal of administrating ***dopaminergic*** drugs in conjunction with ***levodopa*** without any

adverse affect remains the corner stone of pharmaceutical treatment of PD [11]. Side effects, like ***dyskinesia,*** are not a result of PD but due to excess of levodopa. In our research, domain experts, neurologists and specialist nurses, found from experience that patients routinely missed the key drugs. In the effective management of PD it is essential to strictly follow the timetable of the prescribed medicines [120]. As such, the scope of the category was to determine factors and seek possible reasons for the number and name of drugs missed by PWPD and find out, if any, the socio-economic factors for missing the drugs.

This category deals with the table 'Drug_Concordance' that is structured to contain the *NameOfDrugs,* like **Sinement** and **Mirapex,** that the patient is currently taking along with the *NumberOfDrugs,* if any, they missed and the *NameOfDrugsMissed*. It also asks for the *Reason* for missing the drugs, whether any *ProperExplanation* was given to the patient by the physician and if there are any *SideEffects* as a consequence for taking the drugs. It is connected to the 'Patient_Profile' by the foreign key relationship of *PatientID*.

Stages of Parkinson Disease

Early diagnosis is crucial to the effective management of PD. However, the slow onset of the disease can be compounded by the absence of any visible signs that might help both the patient and the relatives to notice any changes in appearance [17]. Even experienced neurologists have failed to identify the disease due to the difficulty in distinguishing PD from problems arising from the nervous system like benign essential tremor, head trauma, stroke, degenerative diseases of the central nervous system and drug induced Parkinsonism [120]. As such, the scope and the function of this category was to aid the domain experts in identifying the tell-tale signs of the onset of the disease.

The information that is sought is stored in the table 'StagesPD'. It asks for the *Duration* and the approximate *DiagnosedAge,* the age at which PD was diagnosed. It also asks for the effect of the rate of *Walking, Turning* and postural stability characterized by *Standing* for PD. Finally, the *Visible* signs, like symptoms affecting both sides of the body while being unable to walk, are also catalogued. Finally, through the foreign key relationship of *PatientID*, it connects to the 'Patient_Profile'.

Parkinson's Disease Symptoms

The absence of any biochemical tests in the diagnosis of PD [4] can cause problems in the early diagnosis of the disease. Added to this, is the absence of any known cause that can lead to the disease. The prognosis therefore lies in the history, physical examination [121] and experience of geriatricians, consultants and neurologists. The scope of the research of this category lies in the possible identifications of sources, such as family history. The genetic predisposition of the disease has been outlined elsewhere [121] while the effect of toxicity like pesticides, solvents and glues [4] is being investigated to aid in the research for the domain experts. Urinary incontinents, constipation, swallowing are some complaints [120] made by PWPD. As such, the possible linkage between such complaints and effects of other diseases like depression and schizophrenia are also modeled for the investigation by domain experts. Drug induced Parkinsonism has been described earlier in section 2.1.1 and the function of this model is to explore whether drugs like neuroleptics and anti-depressants have any effect on PD.

This category holds information relating to the symptoms that cause PD. Information is sought from patients whether any *Relatives* had Parkinsonian like symptoms in their 'FamilyHistory'. Any *RecreationalDrugs*, *Smokinghabits*, and drugs taken for *Antidepressants, Neuroleptics* and *VestibularSedatives* are stored in the table 'HistoryDrugExposure'. The environmental affects of toxins on PD have been mentioned earlier [12] and hence the 'ToxicityExposure' of *Pesticides, Glues, Solvents, HeavyMetals* and *Paints* are elicited from patients. The diagnosis (*Time_diagnosed)* of PD is evaluated in conjunction with the time from which they encountered the first symptoms, *Experience_Symptoms*, to the time when they had the first professional diagnosis of PD (*Professional_Diagnosis_time*) is stored in 'Parkinsons_Duration'. Information relating to any other medical treatment like **Arthritis, Urinary or bladder problems, Balance problems,** other **muscular problems** that can be co-related with PD is also sought (*Medical_Treatment_Problems*) along with the kind of health care giver, like General Practitioner, Neurologist or a Geriatrician (*Name_healthcaregiver*), who first evaluated PD and whether any tests like **MRI, DatScan or Drug Trial** (*Test_Diagnosis*) were carried out in the evaluation process. The medication that the

patient is taking is stored in 'PDMedication' which contains the prescribed medicines that are currently taken, *Current_medicines,* any change of medication during the course of treatment, *Changed_medication*, the attitude towards taking the medicines, *Attitude_medicine*, any deterioration of memory with the advancement of PD, *Remembering_medicine.* The side effects of taking medication are also noted (*Medication_side_effects*). They are related to 'Patient_Profile' by the *PatientID* foreign key relationship.

Side Effects

While a combination of ***levodopa*** and ***dopaminergic*** drugs remains the standard by which PD is treated, they are frequently associated with long term motor complications such as ***dyskinesias*** [11]. Other side-effects of ***levodopa*** include nausea, vomiting, loss of appetite, heartburn and peripheral effects on heart and blood-pressure [17]. Dietary factors like reducing the daily protein intake while increasing the carbohydrate intake can affect the clinical response to ***levodopa*** [122]. Education, physiotherapy and regular exercise can counter the side-effects of ***levodopa***. The purpose of this category is to provide the storage facility that will help the domain experts to investigate the side-effects of the medications taken by PWPD like hallucinations, dizziness and nausea and any other concomitant manifestation of symptoms like heart attack, depression and schizophrenia. The dietary intake and exercise that affects the morbidity of the patient and hence the quality of life is also modeled.

The different side effects of *Cramps, Bladder, Bowel problems, Sexual problems, Speech problems, Nausea, Dizziness, On-off fluctuations, Vomitting, Hallucinations* from taking different medications for PD are housed in 'Side_Effects'. This is related by the foreign key relationship of *PatientID* with 'Patient_Profile'. The 'Morbidity' (red colour) of the disease is also catalogued by asking patients whether they are suffering from *Angina, Arthritis, Stroke, Depression, DiabetesMellitus, Hypertension* and *Schizophrenia*. Since *Constipation* and *Haemorrhoids* are major side effects of medication, whether *Suppositories, Laxatives or Enema* have been given to the patients by their GP (*Laxative_taken_GP*) or by their Chemist (*Laxative_chemist*) can be

recorded. The 'Morbidity' table is related to the table containing the different types of PD ('PDtype') through the foreign key relationship of *PDTypeID*.

Services and support

Since PD affects mostly the mobility of the person, PWPD needs to avail themselves of the services provided by physiotherapists, speech therapists and occupational therapists [120]. Physiotherapists help to loosen the muscle movements and the joints while speech therapists help in overcoming the difficulty in communication. The following section (Section 3.3) describes the data model for physiotherapy. Family and friends are also involved in caring for PWPD. As such, the purpose of this section resides on developing a sub-model that will tell the investigators the access to therapists and any financial constraints PWPD have and the kind of care givers they seek.

This module houses information relating to the support services that are needed by a patient with PD. Information regarding the kind of 'Therapist', e.g. *Physiotherapist, OccupationalTherapist, SpeechTherapist, Counsellor, ContinenceAdviser* and *HomecareServices* the patient is receiving is stored. In order to enhance the integrity of the columns, check constraints like whether they are currently using or had in the past, made use of the services are built in the system. It is linked to 'Patient_Status' by the foreign key relationship of *StatusID* which in turn is related to 'Patient_Profile' by the foreign key relationship of *PatientID*. The same referential integrity constraint is implemented in 'Patient_Status' regarding the kind of physicians (*DoctorType*) that the patient is using to manage PD. 'Admissions' receives information on the patient's admission to the hospital(*Hospital_admit*), time spent in the hospital(*Hospital_admit_days*),number of times they have visited the GP (*GPVisit_Patient*), the district nurse(*Nurse_visitpatient*) and whether GP has visited them at home(*Patient_VisitGP*).

The kind and sources of information, like the *Internet, PDSbooklet* that the patient is receiving are catalogued in 'Information_Source'. This is related to 'Patient_Status' by the *StatusID* foreign key relationship. The different types (*ExerciseType*) and the duration (*ExerciseDuration*) of exercise regimen ('ExerciseProgramme') carried out by the patient is also stored. This along with the 'FoodIntake' and 'Payment' is associated

with the 'Patient_Status' by the *StatusID*. 'FoodIntake' monitors the number of fruit and vegetables (*NumberFruitVegetables*), the number of cups of liquid intake except soup (*LimitFluidIntake*). It was also necessary to know whether the patients can afford the services that are required for PD. As such, 'Payment' asks whether they are paying for their *PrescriptionMedicine*, receiving any benefits for their *Disability* or for any *AttendanceAllowance*.

3.3 Database Creation for PDPHDB

Data on physiotherapy with its implications and therapeutic possibilities on PWPD for health care providers is currently not available. As mentioned in the previous section, physiotherapy constitutes one of the ingredients in the effective management of the disease. Physiotherapy involves the use of treatment by physical means [120] and as mentioned by Sagar [120] can be useful to: (i) improve coordination and dexterity of hands, (ii) improve posture and increase awareness of body position, (iii) improve control of breathing, (iv) teach techniques to improve walking, (v) more efficient ways of coping with activities of daily life and (vi) offer general advice and support. Since specially taught exercises should form a regimen in the daily routine for PWPD, it was thought necessary to provide a repository that domain experts can use to get a better insight into the different techniques and the services that are offered and used. The aim of the database is to encompass all fields of physiotherapy that will enable both physiotherapists and primary health care givers to make a critical assessment in the future.

The PDPHDB, based on the core competencies, is classified into 5 categories: (a) Techniques, (b) Services, (c) Assessment and Carer Needs, (d) Communication and (e) Carer and Physiotherapists Information. The E-R diagram is shown in Figure 3.2. Database annotation is useful for declarative purposes. This was done to allow for interpretation of duplicate data that can be identified separately. The major disadvantage of annotation is that it requires the presence of curators who must have the experience and the knowledge for the domain [97].

Techniques

Physiotherapy should be used in conjunction with medication for the effective treatment. Strategies like exercise [32], should be strictly followed according to the specifications of physiotherapists. An exercise regimen can include relaxation techniques and strengthening exercise for the trunk and lower limbs. Other techniques can include hydrotherapy, acupuncture, visual cues and breathing exercises. The purpose of this category is to provide information for researchers and health care givers of the different techniques available that are also used by health care providers and to provide a co-relation between them.

This category lists the *benefits* and the *manualhandling* of 'Techniques' which interacts with 'OtherTechniques' by the foreign key relationship of *techniquesid*. 'OtherTechniques' describes the different kinds of techniques employed by physiotherapists. These techniques can be anything from *mechanical_treatment, pulmonary_rehabilitation, electricity, kinesitherapy, relaxation, alternative_medicine, cognitivestrategies* and *water_treatment*. Since many of these techniques can be used simultaneously, a reflexive relationship was established on this entity. 'Carers' is linked to the 'Techniques' table by the foreign key relationship of *carersid*. It outlines the *advice*, the *barriers*, the *activities_supported* by those who care for PWPD.

Services

The physiotherapy rendered to patients can depend on the range of services available at different locations. These services can vary from an external setting where there is a link between a hospital setting and the individual to an individual setting where there is an agreement between the care givers, the therapist and the patient about the aim of the therapy. As such, it was necessary to collate all the information that can be housed in the repository so that care givers can link the different techniques available to the services offered. This will improve the decision making of the care givers so that a real time solution can be provided to PWPD.

This category contains the 'Services' that provides the *focus*, the kind of p*hysiotherapy_support*, the *exercise_opportunities* available and the

assessment_coordination. It interacts with both the 'ExternalService' and the 'InternalService' by the foreign key relationship of *servicesid*. The annotation of the tables was described by the *servicedefinition*.

Assessment and Carer Needs

The services offered by the therapists depend on making an assessment for every individual case. It is essential that physiotherapists involve both the care givers and PWPD to arrive at a joint decision that would meet the requirements of the patient. In order to make an assessment it is essential to know the background like patient history, carer issues and social network. Physiotherapists make functional specifications like climbing up the stairs, turning in bed or walking [124] before they can measure the corresponding outcomes like gait assessment and balance assessment. The needs of the carers also need to be assessed since their participation depends on the education of the

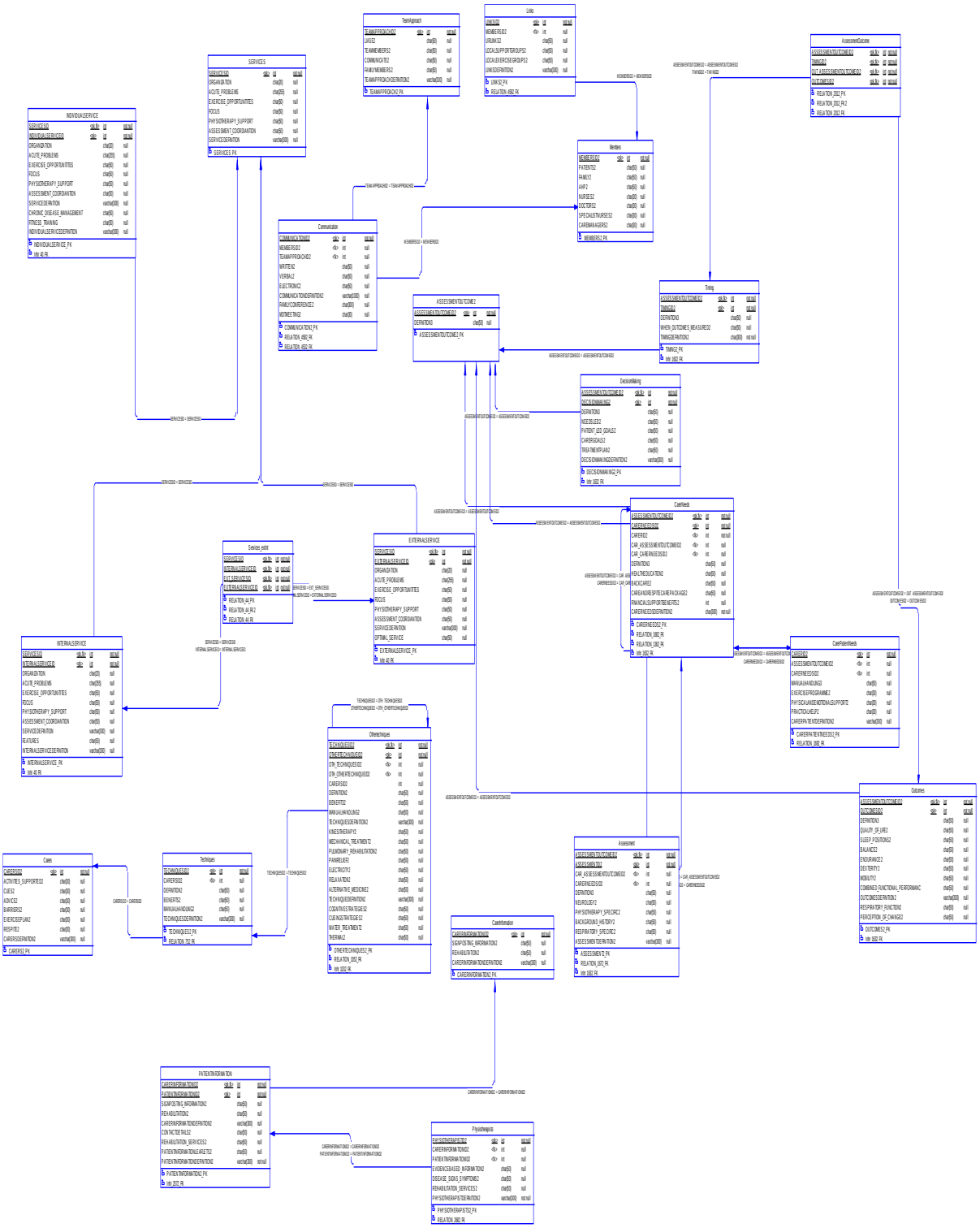

Figure 3.2 E-R diagram for PDPHDB (enlarged copy is shown in Appendix A)

disease and also on the financial well being of both the patient and the care giver. As such, in order to make a co-relation between the assessments made by the physiotherapists and the care givers and what causes a better outcome for the services offered, this category was designed to store the information.

Hence, it helps in the 'DecisionMaking' of the *treatmentplan*, the *carergoals* and the *patient_led_goals* for the 'CarerNeeds' which deals reflexively with the *healtheducation, backcare, careandrespitecarepackage* and *financialsupportbenefits* of the care givers. The 'CarerNeeds' interacts compulsorily with the 'CarerPatientNeeds' that contain information on the *exerciseprogramme, manualhandling, practicalhelp* and the *physicalandemotionalsupport* for care givers who deal with PWPD. The 'CareNeeds' entity also interacts with their 'Assessment' that stores the *background_history*, any *physiotherapy_specific* and *respiratory_specific* problems that they encounter and the kind of *neurology* that they have to deal with. 'Timing' engages the *timing* and *when_outcomes_measured* by a many-to-many relationship with 'Outcomes' that measures the *quality_of_life, sleep_positions, balance, endurance, dexterity, mobility, perception_of_change* and *respiratory_function*.

Communication

An effective communication between the primary, secondary and associated health care teams is necessary in providing a service that is beneficial to PWPD. As such, a team approach that constitutes physiotherapists, consultants, specialist nurses and general practitioners that liaises and inter-relates with each other is crucial in the understanding of how to provide a comprehensive service. It is in this context that information is sought to provide a better understanding of the team approach.

In this category, 'TeamApproach' includes *teammembers* and *familymembers* who *liase* and *communicate* with many *written, verbal, electronic, familyconference* forms of 'Communication'. The 'Members' of this category includes *patients, family, nurses, doctors, ahp* (allied health professionals), *specialistnurses* and *caremanagers* also communicates with 'Communication' by the foreign key relationship of *membersid* besides maintaining 'Links' that contains the names of *localsupportgroups, localexercisegroups* and any *URLinks*.

Carer and Physiotherapists Information

Individuals suffering from PD require information regarding the services offered by physiotherapists. In order to make an informed decision, details regarding the kind of information like social services, literature on health promotion and the addresses of both carers and physiotherapists need to be listed. This category was designed to list the interlinking between carers and physiotherapists to give health care providers a better insight into the working relationship between the two and their effect on the PWPD.

This category contains information regarding any *rehabilitation* and *signposting_information* for 'CarerInformation' which interacts by the foreign key relationship of *carerinformationid* with 'PatientInformation' that contains information regarding *contactdetails, rehabilitation_services* and *patientinformationleaflets.* It then interacts with 'Physiotherapists' by the patientinformationid foreign key relationship to provide *evidencebased_information* on *disease_signs_symptoms* for *physiotherapists*.

3.4 Summary And Future Development

The purpose of PDCDB is to help facilitate the co-ordination between the research fraternities associated with PD and the user community, to access the data and draw inferences accordingly. The outcome of the research would provide insights into the drug concordance, the activities of daily living, the care givers quality, the services offered, symptoms and the side effects of the drugs on the patients. Since a lot depends on the altruism of the user to provide the data, we strongly encourage users to avail themselves of this opportunity. Any new outcome of the research would be shared with the community and will be posted on the semantically enabled web site. The ontologies developed with the help of domain experts would then be integrated into the database. The PDPHDB is an annotated database that houses information relating to the Techniques, Services, Assessment and Carer Needs, Communication and Carer and Physiotherapists Information. PDPHDB and PDCDB could be combined to form a federated database. The accumulated data in the future would then be mined for inferred knowledge.

The following chapter shows how ontologies can be extracted from heterogeneous databases and how they are integrated into the database. The ontologies extracted are then aligned with a foundational ontology.