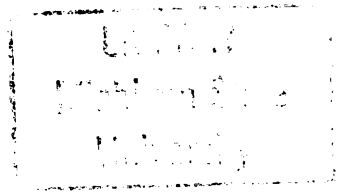

DESIGN AND EVALUATION OF A HEALTH CARE NEEDS ASSESSMENT TOOL FOR ADULTS WITH CEREBRAL PALSY AND MENTAL RETARDATION

By

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Abstract

The purpose of this project was to design and evaluate an instrument to assess the health care needs of adult mentally retarded persons who have cerebral palsy in the areas of: oxygenation, nutrition, elimination, activity/rest, protection, neurological function, endocrine function, and fluids and electrolytes. Nine nurses from a community mental health center in Lansing, Michigan participated in the instrument evaluation.

The results of the evaluation indicated that the tool was appropriate for use with the target population and could be useful for assessment of other populations with neuromuscular defects. The overall format of the tool was seen as usable with some recommendations for change. The final tool consists of 76 items within the nine categories noted above. The potential uses of the tool in primary care practice together with the role of the clinical nurse specialist in utilizing the tool in the primary care setting are discussed.

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Chapter I

The Problem

Introduction

The health care needs of developmentally disabled persons are the responsibility of the provider in the primary health care setting. A lack of education for primary care providers coupled with a reliance on Medicaid as a funding source has created barriers both in terms of delivery of health care and interest in the various health care needs of this population (Crocker & Rubin, 1989). For adults with developmental disabilities, the generic health care system lags behind the science that has extended their lives (Thomas, 1986).

Nurses in advanced practice who are part of the primary health care system are challenged to utilize past experience and current knowledge to develop comprehensive and focused assessment aids to meet the demand of the complex health conditions of these persons (McCarthy, 1987). The purpose of this project is to develop an assessment tool which will guide diagnosis and treatment by providers of primary health care. This health needs assessment tool will bring into focus the diverse needs of this population of developmentally disabled persons in the areas of oxygenation, nutrition, elimination, activity/rest, protection, neurological function, endocrine function, and fluids and electrolytes. By the development of this tool, the writer supports the right of the

developmentally disabled to treatment in the full sense, so that individuals can reach their optimum personal outcome (Rubin, 1989).

Background

Institutions for the housing of children and adults with cognitive or other handicapping disorders began in the United States and Europe in the late 19th century. Prior to this time agrarian communities absorbed large numbers of mildly retarded persons. When, due to urbanization, families and society could no longer maintain a supportive environment, alternative residential placement was sought (Nelson & Crocker, 1978).

Initially, institutions attempted to rehabilitate residents with the intent of returning persons to their homes. Institutions began to proliferate during the early part of the 20th century until, in 1970, there were 202 public institutions with 186,000 residents (Nelson & Crocker, 1978). Due to inadequate public funds, custodial care became the norm.

The Mental Retardation Facilities and Community Health Centers Construction Act of 1963 paved the way for the sweeping changes that have occurred in the past 20 years (Evans, 1968). Under this legislation, custodial mental institutions were replaced by therapeutic centers under the management of community mental health boards. To this end, a concerted nationwide effort has

been made possible through federal, state, and local interaction to return the mentally ill and mentally retarded to their local communities where it was felt they would benefit from a more normal social and physical environment (Evans, 1968).

The process of returning persons from state institutions to their communities of origin has been termed "deinstitutionalization". A latter development in the interpretation and definition of deinstitutionalization has been the concept of "normalization" (Wolfensberger, 1970). "Normalization" calls for the utilization of means that are as culturally normative as possible in order to establish and/or maintain personal behaviors and characteristics which are culturally normative (Martin & Laidlaw, 1984). The concept of normalization is easily translated into an "equality of opportunity" principle.

Normalization views disabled persons as developing individuals, not incurable invalids, and allows for integration of activities and services. Normalization also provides for continuity of services so that individuals can move along a continuum from supervision to independence (Heal, 1984). The underlying philosophy of "normalization" calls for full and complete utilization of generic services by disabled individuals and their families. Generic services are defined as any service

that attends to the health, education, welfare, rehabilitation, or employment needs of a broad spectrum of persons in the community. This does not include special programs for disabled persons (Savage, Norvak, & Heal, 1984).

Generic services of a community may be inadequate to deal with the special, sometimes complex health care needs of the developmentally disabled population. Sterling Garrard, a physician and champion of quality health care for the developmentally disabled, proposed that the "accountable agency is considered obligated to obtain an acceptable level of health care by all means necessary" (Yankauer, 1986).

Practitioners in the traditional health care system have had some exposure to the needs of the developmentally disabled population over the past 15-20 years. However, as a general rule no formal educational/clinical exposure has been contained in the curriculum of medical/nursing schools (Rubin, 1989). Consequently, when confronted with developmentally disabled persons in the primary care setting, the practitioner may experience confusion and lack of understanding related to the integration of the disability with the presenting problem. Health care providers obtaining a health history may be unaccustomed to getting information from a third party and these informants may

have little knowledge of the person's past health history (Crocker, 1989).

From personal experience and literature review, the author's conclusions are: 1) Current health care services are often inadequate/unwilling to provide comprehensive care to persons with developmental disabilities (Garrard, 1982); 2) Persons with developmental disabilities often have complex health care needs (McDonald, 1986); 3) Most developmentally disabled persons are unable to advocate for themselves (Garrard, 1982); 4) Reimbursement to providers is a disincentive to a broader and enlightened health care practice to persons with developmental disabilities (Ziring, 1987); and 5) Primary care as the comprehensive collaborative, integrated, accessible, accountable delivery system should be adequate to provide for the health care needs of the developmentally disabled, but primary practitioners have been found in many instances to be poorly prepared for the needs of this population (Crocker, 1987).

Persons with cerebral palsy have complex and long-term management problems. Since cerebral palsy is permanent and non-progressive, the goal of care is not to cure the disorder but rather to diagnose and treat symptoms early to prevent complications and restore/maintain functioning. No single treatment modality for cerebral palsy exists and so a

collaborative multidisciplinary team effort is essential to provide optimal care.

Specialized tools for assessment have been developed by other disciplines. For instance, occupational therapists have extensive assessment aids and equipment for evaluation and adaptation in areas of daily living activities. These aids have greatly increased the cerebral palsied persons independence at home and work. To date, nursing has not developed or adapted any tool to comprehensively assess the present and potential health needs of persons with cerebral palsy.

The tool to be developed by this writer for the purpose of this project will be limited to assessment in the physiological mode. Nursing, however, seeks to be ever aware of the complexity and holism of the person and collaborates with other professional and non-professional team members to provide for comprehensive care.

Statement of the Problem

Why is a specialized tool necessary for assessment of developmentally disabled persons with cerebral palsy? To date, very little has been done in the area of health care assessment tool development for developmentally disabled persons. Many providers are unfamiliar with this population and there is often confusion between disease and disability (Thomas, 1986). A

comprehensive work by Crocker & Rubin (1989) traced the involvement of the medical provider with the developmentally disabled population and provided valuable guidance for primary care of the developmentally disabled. An earlier article by Crocker, Yankauer & the Conference Steering Committee (1987) emphasized the importance of the provision of health care in a durable setting where the developmentally disabled person's health status is well known, an understanding relationship is developed with the client, care providers and/or family members' and finally, a comprehensive up-to-date record is available (Crocker & Yankauer, 1987).

In general, it seems that the direct specialty and illness care available to this population is compensated for by Medicaid. However, indirect services such as prevention, education, maintenance, coordination, and training, which require unusual amounts of time are not considered by the Medicaid system (Crocker et al., 1987). The results of this system are that provider participation in the Medicaid program has fallen far short of what was originally anticipated and has become a separate system of care rather than as was originally intended an entitlement program (Master, 1987). A study by Janicki, Jacobsen, & Ackerman (1985) found that older persons were less likely to have a family

physician treating them and were more likely to get Medicaid services through a clinic.

The "specialness" of developmentally disabled persons has been emphasized by medical care personnel. This "specialness" has been used as an excuse to not provide the appropriate care due to unfamiliarity with the complexity of the problems encountered. Crocker & Yankauer (1987) emphasized the importance of accurate evaluation of the diverse health care needs of this population.

Persons with cerebral palsy are living longer and in order to comprehensively evaluate their needs, the health care provider must be acquainted with the special health care needs of this population. Professionals in other areas of service have specialized tools to assess needs related to their particular area of expertise. However, to date, no such tool is available for assessment of the health status and potential risks in the physiologic mode of persons with cerebral palsy. To this end, the availability of a special tool which would address the multiple possible health risks of adult persons with cerebral palsy is an essential component of the overall health assessment.

The purpose of this project was to develop and evaluate an assessment tool for use with adult persons who have cerebral palsy and are mentally retarded. This assessment tool was based on the assessment in the physiologic mode as proposed by Sister Callista

Roy (Andrews & Roy, 1986). The tool will be used to determine the current health status. Additionally, it is proposed that the tool will highlight potential health risks specific to this population and will be helpful to health care providers in planning long-term care and developing strategies for prevention of further disabilities. The tool will be used by the Clinical Nurse Specialist and primary care providers to: 1) address the special needs of persons with cerebral palsy; 2) provide a forum for utilization of information by care providers; 3) provide a basis for nursing diagnosis and intervention and education specific to this population; and 4) prevent disease development as a legacy of the disability by early assessment, education, and intervention. The tool utilized an organized question format developed from Roy's adaptational two-level assessment in the physiological mode. The adaptational method is seen by this writer as most appropriate to assess this population whose disabilities have necessitated multiple personal and environmental adaptations over time.

The following steps were used to develop the instrument: 1) literature was reviewed; 2) items in the instrument were correlated within Roy's physiological model based on the literature and clinical practice; 3) a questionnaire was distributed to a group of nurses to review and provide comments related to clarity, inclusiveness, exclusiveness, appropriateness,

and usefulness; 4) all comments were summarized; and 5) these summarized comments were used to develop the final instrument.

The Clinical Nurse Specialist in the role of primary care provider to the individual with cerebral palsy seeks to assess health status, illness conditions, response to illness and health risks utilizing advanced skills of history taking, physical examination, and analysis of objective findings (ANA, 1980). The services of nurses at the advanced practice level to coordinate, facilitate, and provide for the multiple health needs of the developmentally disabled client is seen as a key element in the future planning for health care delivery (Crocker, 1989). The nurse's function with individuals who have cerebral palsy is to combine clinical expertise in health needs of such individuals with the role of organizing and managing health care interventions with this client population (Cole, 1987).

Definition of Concepts

Three concepts will be defined in order to clarify the background which prompts this tool development and the context in which the tool will be utilized. The concepts which will be defined are: 1) Primary Care; 2) Cerebral Palsy; and 3) Mental Retardation/Developmental Disability.

Primary Care: Primary care is a concept of health care delivery distinguished from other levels of personal health

services by the scope, character, and integration of the services provided (Manpower Policy for Primary Health Care, 1978). Primary health care includes the initial contact of the person with the health care system and includes a full range of services (Silver, 1977). The attributes of accessibility, comprehensiveness, coordination, continuity, and accountability describe primary care as it should be practiced. Responsibility for primary care is exercised by physicians, clinical nurse specialists, nurse practitioners, and physician assistants and is provided in a variety of locations (Manpower Policy for Primary Health Care, 1978).

For the general population, primary care--as a generic health care system--provides health maintenance, illness treatment, illness prevention, and disease treatment and prevention. The provision of all of the above services requires a competent provider who understands care management and who has access to a comprehensive clinical file and accessible specialty services (Crocker et al., 1987). The population of persons who have cerebral palsy and are mentally retarded require all of the services noted above with primary emphasis on health maintenance/illness prevention and coordination of specialty services. In general, illness and disease treatment are readily provided but prevention and maintenance services, which consume

much provider time and are not compensated for by Medicaid, are not currently available (Crocker, 1989). An attempt to provide primary care services may be done by some specialty care providers who are not familiar with the extent of care management involved (Thomas, 1986).

The availability of a specialized nursing assessment tool in the primary care setting is seen as a highly desirable option for primary care providers. The tool based on Roy's adaptation model would be valuable not only in making nursing diagnoses but would also guide appropriate interventions. Many practitioners are unfamiliar with the population of persons who have cerebral palsy. The availability of antibiotics and improved techniques of feeling and positioning have increased the life span of persons who in years past would have died from respiratory and cardiac conditions (McDonald & Tyson, 1988). The presence of the disability's late manifestation may not be familiar to many providers (Thomas, 1986).

The assessment tool developed as a result of this project will be a beginning attempt to utilize and adapt an already existing nursing tool to maximize health and wellness and prevent the late complications of cerebral palsy. It will fill an educational gap in many primary care providers' knowledge of and approach to assessment of this population.

Cerebral Palsy: The term cerebral palsy is applied to a cluster of symptoms resulting from a disorder of movement and posture due to a non-progressive lesion of the immature brain (Davis & Hill, 1980). The diagnosis of cerebral palsy is a matter of clinical judgement and involves an evolution of motor problems and associated dysfunctions with increasing difficulties experienced in middle to late childhood (Crocker, 1989). Although cerebral palsy is characterized primarily by disorders of motor function, sensory deficits and intellectual impairments varying in type and degree may result in minimal to severe dysfunction.

The etiologic factors of cerebral palsy may be classified according to the time of occurrence: prenatal, perinatal, or postnatal. Approximately 10 percent of all cases of cerebral palsy occur prenatally. In 75 percent of individuals with cerebral palsy damage occurs perinatally, that is, between the onset of labor through the first 28 days of extrauterine life. Postnatal factors account for about 15 percent of cases (Davis & Hill, 1980).

The most predominant clinical manifestation are resultant from the neuromuscular disabilities and are classified as spastic, athetoid, ataxic, and mixed palsies. Many health care problems encountered by adults with cerebral palsy are a result of deterioration of muscle function, primarily secondary to poor

management of the original disability (Crocker, 1989). The table which follows describes the percentage of individuals with cerebral palsy, the specific manifestations of each type of cerebral palsy, and the body parts involved (see Table 1).

Mental Retardation/Developmental Disability: Mental retardation is described as a developmental disorder characterized by subnormal functioning, learning, social adjustment, and maturation (Lego, 1984). There are two broad categories of mental retardation:

1. Cultural Familial Retardation is produced by normal genetic processes, environmental factors, or both. The cultural familial retarded person is generally at the low end of the normal distribution of intelligence given that the normal range lies between 50-150. Usually these persons have normal health, appearance, and physical abilities (Sue, Sue, & Sue, 1981).
2. Organic Retardation is the result of physiological and/or anatomical defects (Sue, Sue, & Sue, 1981). Persons with organic retardation appear to be outside of the normal curve disproportionately. Based on a normal curve of a population of 211 million, only 57 individuals should have an IQ below 20. However, the figure is estimated to be 104,935 (Sue, Sue, & Sue, 1981).

Table 1.

Manifestations of Cerebral Palsy

Type of Cerebral Palsy	Manifestation	Percent of each type	Pathophysiology	Body Parts Involved
Spastic	Muscle spacity Muscle Hypertonicity Primitive reflexes	50%	Lesion of upper motor neurons	One to all four extremities
Athetoid	Purposeless writhing movements Facial grimacing Chewing/swallowing problems Drooling	25%	Damage to extra-pyramidal system	Tongue, facial pharyngeal, and laryngeal muscles
Ataxic	Loss of posture and balance Unsteady wide based gait Clumsy, uncoordinated voluntary movements	<10%	Defects of cerebellum and cerebellar pathways	Upper and lower extremeties
Mixed	Any combination of the above	20%-40%	Combination of the above	Any or all of above

The concept of developmental disabilities is a clustering of early onset disorders of development. The meaning extends beyond conditions that originate in childhood and are characterized by mental retardation and includes any circumstances that in its effect significantly impinges on development (Crocker, 1989).

A functional definition of developmental disability was sought through the Rehabilitation, Comprehensive Services and Developmental Disabilities Amendments of 1978. This functional definition of developmental disabilities is:

> a severe chronic disability of a person which (A) is attributable to a mental or physical impairment or combination of mental and physical impairments, (B) is manifested before the person attains the age of twenty-two, (C) is likely to continue indefinitely, (D) results in substantial functional limitations in three or more of the following areas of major life activity, (I) self-care, (II) receptive and expressive language, (III) learning, (IV) mobility, (V) self-direction, (VI) capacity for independent living, (VII) economic sufficiency, and (E) reflects the person's need for a combination and sequence of special interdisciplinary or generic care, treatment, or other services which are of life-long or extended duration and are individually planned and coordinated (Crocker, 1989).

Conceptual Framework

Having reviewed the practicality of a behavioral adaptational assessment tool, it now becomes important to place the use of the tool within a theoretical structure of nursing. The context within which the tool will be implemented will enhance and complement the usefulness of the tool. In order to provide for

structure and consistency of practice, it is necessary to apply the use of the assessment tool within a nursing theory.

The adaptation theory as proposed by Sister Callista Roy (1984) seems well suited for use with persons who have cerebral palsy. The many and often complex health care needs of these persons are secondary to adaptations over time to the original disability. Many of these adaptations are ineffective and result in a negative health status. Adaptive behavior, according to Roy, is evidenced by effective responses to stimuli while health problems are the result of ineffective behavior/adaptation. The complex health needs of the developmentally disabled persons with cerebral palsy are the result of ineffective behavior secondary to the original condition of neurological, muscular, or mental deficits.

The assessment tool is based on Roy's assessment in the physiological mode and therefore, effective or ineffective behavior/responses in the areas of oxygenation, nutrition, elimination, activity/rest, protection, senses, fluid/electrolytes, and endocrine function will be examined.

Summary

In this first chapter, the writer has provided an introduction to the environment in which the person with cerebral palsy is treated/rehabilitated. The need for a specialized assessment tool

was discussed and the primary care setting where the tool will be utilized was described. The role of the Clinical Nurse Specialist as provider of primary care and the importance of the primary care system for this population was emphasized.

In chapter two, the literature relative to the health care needs of persons with developmental disabilities and specifically cerebral palsy will be reviewed. In chapter three, Sister Callista Roy's conceptual framework of adaptation will be further explored as the basis for the assessment tool development.

Chapter II

Literature Review

Introduction

In this chapter, the writer will review and critique the literature associated with primary health care of the developmentally disabled and, in particular, the health care needs of persons with cerebral palsy. The review will include the general medical needs of deinstitutionalized persons and the special needs of persons with cerebral palsy. Additionally, the current primary care services will be examined and alternative programs for delivery of services to developmentally disabled persons will be highlighted.

As the literature was received, it was noticed that the bulk of writings relative to this subject were in the form of position papers citing particular experiences and facts about the numbers and types of health care needs of the developmentally disabled population. Two descriptive research articles by Minihan (1986) and McDonald (1985) are cited in this review. Minihan considered the developmentally disabled persons health needs as community placement was being sought. The second article by McDonald used small group residential homes where clients were served by a local, highly motivated, and easily accessible system.

The position papers published in Mental Retardation (August 1987), provide valuable retrospective experiential information as

to the needs and services available at the time of a special symposium on health care of developmentally disabled persons in Auburn, Massachusetts, November 1986. Proposals for change both from educational and service delivery perspectives were reviewed in these papers. As a major attempt to operationalize some of the symposium's recommendations and to provide a specific manual for providers of care to persons who are developmentally disabled, Leslie Rubin, M.D. and Allen C. Crocker, M.D. co-authored a book in 1989 entitled Developmental Disabilities: Delivery of Medical Care for Children and Adults. The information gleaned from these sources is critiqued and reviewed in this paper and provides the basis of a need for a specialized assessment tool for persons who have cerebral palsy and are mentally retarded.

Medical Needs

Because of the prevalence of medical problems such as epilepsy and motor handicaps in the mentally retarded population, the influence of the medical approach was quite prevalent in the institution. Until the Joint Commission on Accreditation of Hospitals and the United States Department of Health, Education and Welfare through title XIX of the Social Security Act in the mid 1970's promulgated standards for medical care in residential settings, there had not been any sustained effort in the

institution, to assess the adequacy of medical care (Nelson & Crocker, 1978).

Figure 1 represents the medical problems reported in one institution of mentally retarded persons. An examination of these health issues demonstrates the high vulnerability of mentally retarded persons in the area of medical needs.

A review of 50 records of clients in a local community setting who receive nursing services indicated that each had an average of 4.64 health issues as shown in Figure 2.

The health care needs identified by Nelson & Crocker (1978) in an institutionalized setting were very similar to those found nine years later in the community by a group of nurses at a community mental health center. This leads the writer to conclude that the health care needs of deinstitutionalized persons living in community settings are constant. This conclusion is supported in a study done by a network of University Affiliated Facilities on 610 clients in a large midwestern program from July 1979 to June 1983. The authors concluded that given the range and type of health issues identified--similar to the studies previously cited--health care is a medical problem rather than an institutional one. One other conclusion of this study was that physicians do not feel adequately prepared to meet these complex health care

Figure 1.

Chronic or Reoccurring Conditions in Institutionalized Population

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Seizure----------34%

Physical handicaps----------33%

Deafness or severe hearing loss----------24%

Obesity----------19%

Respiratory disease----------13%

Ocular problems----------13%

Severe dental/periodontal disease----------11%

Blindness or severe visual deficits----------10%

Acute conditions (over a 3 month period)

Fever of undetermined origin----------30%

Respiratory infection----------17%

Nelson, R.P., & Crocker, A.C. (1978). The medical care of mentally retarded persons in public residential facilities. New England Journal of Medicine, 229(19), 1039-1044.

Figure 2.

Chronic or Reoccurring Conditions in Community Population.

Mobility deficits	60%
Dental deficits (edentulous, gingival hyperplasia, etc.)	54%
Hearing deficits and/or cerumen impaction	46%
Blind or vision impaired	38%
Taking neuroleptics/lithium	36%
Seizure disorder/taking anticonvulsants	34%
Hepatitis B markers	34%
Gastrointestinal deficits (constipation, hernias, etc.)	32%
Elevated blood pressure	14%
Genitourinary deficits	10%
Respiratory deficits	10%
Hypothyroidism	8%

(1988) Unpublished report of CSDD Nursing Staff.

needs in the community population (Buehler, Smith, & Fifield, 1985).

Specific Health Care Needs of Persons with Cerebral Palsy

Cerebral palsy is a nonprogressive disorder of the central nervous system and is characterized by disorders of motor function, sensory deficits, and intellectual impairments (Davis & Hill, 1980). The underlying pathophysiologic processes of cerebral dysfunction for adults with cerebral palsy cited by Rubin (1989) are outlined in Figure 3.

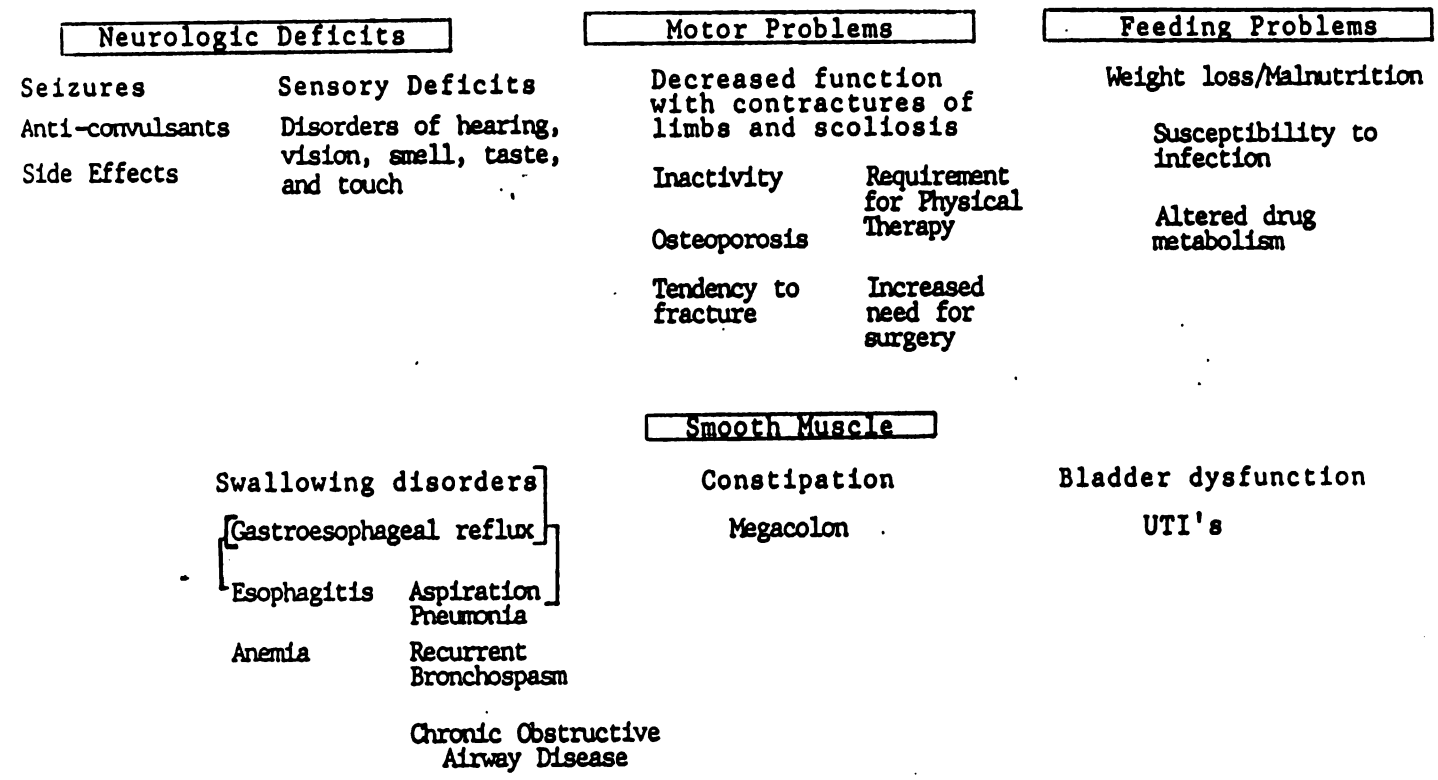
Because of the diverse manifestations of disease among the population of developmentally disabled who have cerebral palsy, an awareness of potential health care needs is essential for the provider. The assessment tool to be developed will highlight certain key considerations which will assist in comprehensive assessment and total management of care.

Generic Health Care Services

As developmentally disabled persons were placed in community settings, the local generic health care system was seen as ideal to provide both primary and specialty health care (Crocker, et al., 1987). However, there was no prior evidence to support the idea that the existing health care system was equipped or willing to provide services to this population, or that access to this system could be easily achieved (Yankauer, 1986).

Figure 3.

Cerebral Dysfuncion



Rubin, L. (1989). Management of children and adults with severe and profound central nervous system dysfunction. In L. Rubin & A.C. Crocker (Eds.), Developmental Disabilities: Delivery of Medical Care for Children and Adults. Philadelphia, London: Lea & Febiger, (pp. 390-397).

A study by Minihan (1986) in southeastern Massachusetts assessed the need for physician services among a group of institutionalized mentally retarded persons in anticipation of their transfer to community residencies. The study population consisted of 229 persons with a total of 782 medical conditions. These medical conditions were categorized into three levels. Level I conditions included those managed almost exclusively by a primary care provider. Level II were those conditions requiring specialty back up and Level III were those conditions managed solely by specialists. The determination of categories of care was done by an advisory committee consisting of a physician, a nurse, and a community services director. The identified medical conditions were obtained from a questionnaire completed by the institutional primary care physician and a nurse practitioner.

The availability of services for these persons was based on previous experiences of senior staff members in community residences who had sought physician services for developmentally disabled persons in their care. Available services were counted if these staff members were able to readily access the system and if the service was in fairly close proximity to the residence (Minihan, 1986).

The conclusion of this study posits that pockets of need were identified in certain communities especially for the specialty

services of neurology, behavioral neurology, psychiatry, and orthopedic services. It was determined that primary care services were adequate and available in this region (Minihan, 1986). However, this adequacy was not based on a direct investigation for the population being studied, only for a population with similar health needs. The question also arises as to whether the physicians who were willing to provide services to developmentally disabled persons would continue to add additional such persons to their case loads. In conclusion, the study does acknowledge that gaps in services would be anticipated and that the availability of a service which provided coordination and continuity was essential.

The gaps in services cited by Minihan (1986) were not found in a study by McDonald (1985) on a smaller group of developmentally disabled adults already living within the community. She found that specialty services not available in the institution were accessible in the community. The subjects of this study were 27 severely developmentally disabled who had a total of 215 identified medical conditions. The participants resided in three group homes located in highrise apartment buildings in New York City.

Two of the group homes had 24-hour nursing coverage by an LPN. Additionally, each home employed an RN as health care coordinator.

The 215 medical conditions were extracted from the clients' clinical records with cerebral palsy being the primary physical disability. The mean age of the clients was 23 years old with 48 percent of the group being profoundly retarded. One of the group homes was located in the same building as the primary care provider for that home (McDonald, 1985). Primary health care and specialty services were available to clients in the McDonald study. This may be due to the proximity of services and the advocacy and interest by around-the-clock nursing staff for these clients. Additionally, as mentioned earlier, the Minihan study based its conclusions on projected rather than actual availability.

Although both these studies' conclusions differ on availability/access to medical services, they agree that community-placed developmentally disabled persons are at high risk and their requirements for ongoing medical care are greater than for the average person of the same age and sex (Yankauer, 1986). The experience of many group homes is that health care services are available for acute conditions. However, continuity, coordination, and comprehensive care, which is the most important factor in judging the efficiency of any primary health care services for developmentally disabled persons, is lacking (Crocker, 1989).

Issues Effecting Delivery of Primary Care Services

In general, the experience of developmentally disabled persons has been that primary health care is not readily accessible. Initially, some primary care providers were willing to treat the newly deinstitutionalized developmentally disabled adults. However, the burden of time involved in the indirect care and poor reimbursement by the Medicaid System became prohibitive to continued services. Providers would no longer see new patients and current patients were dropped from case loads (Crocker, et al., 1987).

A group dental practice which provided comprehensive dental services to developmentally disabled adults analyzed actual total hourly dentist--and hygienist--provided services. A net hourly deficit of $18.81 per dentist hour and $9.89 per hygienist hour was found (Gotowka, Johnson, & Gotowka, 1982). The actual cost of providing dental services was based on direct services, i.e., salaries, supplies, laboratory expenses; indirect costs, i.e., capital equipment/expenses; and daily operating costs, i.e., rent, utilities, telephone, maintenance. The services provided were reimbursed via Medicaid fee for service program and was unrelated to prevailing fees (Gotowka, Johnson, & Gotowka, 1982). Likewise, fees to physicians providing primary care services are dramatically lower than the prevailing rates paid by fee for

service and other insurance companies. This provides a powerful disincentive to the integration of low income and handicapped patients into the mainstream of primary care (Master, 1987).

A working conference, held in 1986 in Auburn, Massachusetts to honor Sterling D. Garrard, examined the effects of deinstitutionalization on the adequacy of health care received by developmentally disabled persons. The presenters at the conference highlighted the current health care needs of persons with developmental disabilities and discussed the general lack of adequate primary and specialty health services. Alternative service delivery and funding models were proposed where understanding, knowledge, and sensitivity of providers be combined with coordination, comprehensiveness, and ready access to systems (Crocker, 1987).

Alternative Service Delivery Models

As an alternative to the present reliance on the generic primary care system, other health care delivery models were discussed at the Sterling Garrard Symposium. Crocker et al., (1987) outlined a model with physician/nurse practitioner teams managing ongoing care, allocating resources and integrating specialty rehabilitation, mental health, and hospital care as needed. Cole (1987) proposed the development of a prepaid managed primary health care system which would have six components: 1)

primary care group practice; 2) affiliated specialty and consultation services; 3) case-management of each client's plan of care by mental health staff; 4) staff training programs; 5) state agency coordination, i.e., Medicaid and Department of Mental Health; and 6) nursing practitioners as managers and coordination of health care delivery.

An HMO-managed program of Medicaid AFDC (Aid to Families with Dependent Children) clients in Massachusetts at the time of the symposium was showing positive indications of cost containment. Some minor changes in reimbursement for developmentally disabled persons would result in fundamental changes in where and how care is provided and substantial reductions in the use of hospital services and overall costs (Master, 1987).

At the University of Buffalo Pediatrics Department, a special program with efforts in regard to community health and medical care are focused in two approaches: 1) a fellowship training program for developmentally disabled; and 2) development of a university-based health maintenance organization. The two areas of service and training are seen as critical. The model is based on methods which utilize medical and health-related providers in a coordinated manner (Griswald, Msall, Cooke, 1987).

A working program established by the New Jersey Department of Human Services in a Morristown, New Jersey hospital in 1982

provides primary and specialty care to 729 developmentally disabled persons. Up-front financial support by the Department for salaries, fringe benefits, and supplies allow the hospital some independence and security to continue the program. Reimbursement for all clients' visits is through the hospital's customary Medicaid rate (Ziring, Kastner, Friedman, Pond, Barnett, Sonnenberg, & Strassburger, 1988).

The coordination and referral, in addition to medical and behavioral screening, is done by nurse practitioners. The use of nurse practitioners and the availability of comprehensive specialty services are cited as the most important factor in the success of the program (Ziring, 1987). The nurse practitioners working in this expanded role are most cost effective and provide for coordination, education, and continuity of care, which in all proposals of alternative care are deemed essential for the population of persons who are developmentally disabled (Ziring et al., 1988).

Summary

The literature reviewed highlighted many common problems in the areas of primary health care both from the perspective of client needs and delivery systems needs. Developmentally disabled adults have multiple primary and specialty health care needs and there is a lack of true primary care providers who coordinate and

collaborate with specialty services to treat these needs. Reimbursement via Medicaid is cited as a major disincentive to provision of care. Additionally, lack of familiarity with the special needs of this population is a further barrier for primary care providers.

In order to address these problems, options other than the traditional generic primary care system were discussed. At the center of these proposals, the role of the nurse practitioner was seen as a key element in the provision of care.

In order to facilitate the provider in this type of system, education and familiarity with the needs of this population of developmentally disabled persons is essential. The availability of a specialized assessment tool to highlight potential and current health problems in an easy to use format is seen as a highly desirable clinical option for these providers.

Chapter III

Methods

Overview

In this chapter, an assessment tool to identify current and potential health risks in the physiologic mode for persons with cerebral palsy is presented. The assessment tool is discussed in terms of the proposed methodology for evaluating the tool, the areas in Sister Callista Roy's physiologic mode which are used to make up the tool, and the proposed setting in which the tool will be used.

Purpose of the Project

The purpose of this project is to design and evaluate an assessment tool which will be used to determine the current health status and predict the potential health risks which will give direction to long-term planning and prevention strategies. The population with whom this assessment tool will be used are adult mentally retarded persons with cerebral palsy whose health care is overseen by community agencies and/or community primary care providers.

The following steps were used to develop the instrument:

1. Literature was reviewed.
2. Items in the instrument were developed within Roy's physiological mode, based on the literature and clinical practice.

3. A questionnaire was distributed to a group of nurses to review and provide comments related to clarity, inclusiveness, exclusiveness, appropriateness, and usefulness.
4. All comments were summarized.
5. These summarized comments were used to modify the final instrument.

Roy's Adaptation Model

In order to utilize Roy's adaptation model, an understanding of the basic concepts underlying the theory is essential. The main concepts of Roy's theory are person, environment, health, and nursing. Her theory of adaptation sees man as a biopsychosocial being in constant interaction with the changing environment (Roy, 1976). The human person, the first concept, is seen as an individual and as a member of a group and as such is described as an adaptive system. This adaptive system takes in input (stimuli) and processes this input to produce a response or output. Adaptive behavior is evidenced by effective response to the stimuli while ineffective behavior indicates problems (Andrews & Roy, 1986).

Roy sees the environment affecting the person through his/her perspective of the stimuli--an exchange of matter and energy with the ever-changing environment. Roy names this process the regulator/cognator coping mechanism. The outputs from the

regulator and cognator are effected through the adaptive modes. There are four in number, and are identified by Roy as:

1. The physiologic needs mode.
2. Self-concept mode.
3. Role function mode.
4. Interdependence mode (Roy, 1984).

The physiologic needs mode as described by Roy, is the way the person responds physically to stimuli from the environment. Five needs and four complex processes are identified in the physiologic needs mode relative to the basic need of physiological integrity: oxygenation, nutrition, elimination, activity, rest protection senses, fluids/electrolytes, neurological function, and endocrine function (Andrews & Roy, 1986).

The environment, the second major concept, is described by Roy as the world within and around the person. Adaptation is influenced by the environment and the person's ability to deal with this environment (Roy, 1984). The environmental input is described as a stimulus and may be focal, contextual, or residual. Focal stimuli are those stimuli influencing the current situation. Contextual stimuli are those stressors or factors in situations which contribute to or influence behavior. Residual stimuli are those stimuli which may influence the adaptation level, but whose effect have not been confirmed (Andrews & Roy, 1986).

The third major concept in the Roy model is health. This is defined as a state and a process of being and becoming an integrated and whole person. The opposite of health is lack of integration of the person with the environment, leading to a state of ill health. Roy sees this process of integration as the fulfillment of the person's purpose in life (Andrews & Roy, 1986).

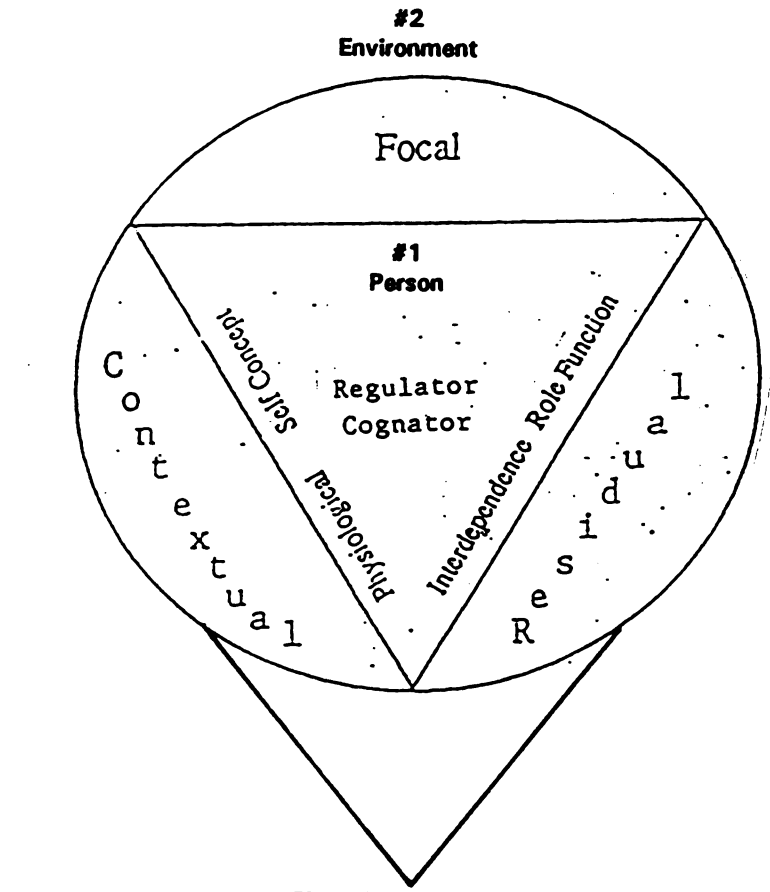
The fourth concept, nursing, is described by Roy as a process and has six steps:

1. Nursing assessment of behavior: nurse assesses how the person is behaving as an adaptive system.
2. Assessment of stimuli: nurse notes the factors of stimuli which are affecting behavior.
3. Nursing diagnosis: based on nursing assessment of behavior and stimuli.
4. Nursing goals: relate to the promotion of patient's adaptation.
5. Nursing intervention: manages the patient's stimuli to promote adaptation.
6. Evaluation: nurse checks to see if planned interventions lead to goal attainment (Andrews & Roy, 1986) (Figure 4).

Having described the basic concepts in Roy's adaptation theory, it is necessary to integrate the person and the condition

Figure 4.

Integration of Roy's Concepts



Physiological Needs
Oxygenation, Nutrition, Elimination, Protection, Activity/Rest, Senses, Fluid/Electrolytes, Neurologic, and Endocrine Functions

↓

#3
Health/Illness

↓

#4
Nursing Process
Assessment of behavior and stimuli through use of assessment tool
Nursing Diagnosis
Goals
Intervention
Evaluation

of cerebral palsy with this theory and assessment tool utilization.

Integration of Roy's concepts in assessing person who has cerebral palsy

The person who has cerebral palsy, due to neurological damage, may have defects of the regular/cognator coping mechanisms. These deficits would be described by Roy as residual stimuli which influence the adaptive behavior. This defect of adaptation would lead to less than total integration of the person and may result in a state of ill health. Additionally, the person with cerebral palsy has varying degrees of neuromuscular damage which modify many areas of adaptation. These deficits could be either focal or contextual stimuli. For instance, the person may present to the provider with swallowing difficulties which are the result of the original disability. In this case, Roy would label this presenting symptom a focal stimulus. However, if this same person returned for treatment of a respiratory infection secondary to aspiration, the swallowing difficulty would be considered a contextual stimulus and the respiratory infection the focal stimulus.

Because of the multiple and often complex manifestations of poor adaptation in the person who has cerebral palsy, many systems may be affected. For this reason, when itemizing the areas under

each physiologic need category in the assessment tool to be developed, only one area will be targeted for any one particular assessment need. An example of this would be the presenting (focal stimulus) of constipation. This would be addressed under the most obvious physiologic need of elimination. However, when addressing the problem of antipsychotic medication or behavior problems under neurologic function this, i.e., constipation, could be considered as a contextual stimulus.

Format of the Instrument

The instrument (Appendix D) which was developed as a result of this scholarly project is an assessment tool directed primarily toward the special needs of persons who are mentally retarded and have cerebral palsy. The assessment tool was evaluated by local community nurses who have expertise in assessment of the target population. These nurses were asked to review the assessment tool and answer a questionnaire related to clarity, inclusiveness, exclusiveness, appropriateness, and usefulness of the instrument.

The instrument consists of nine categories based on the nine areas of assessment in the physiologic mode developed by Roy. Under each category, specific need areas developed by this investigator and based on a review of the literature and personal clinical experience are presented. Each of the need areas is in the form of a question requiring a "yes" or "no" answer. The

questions are asked so that any "yes" answer signifies a problem area. If "no" is indicated, than no problem is present. Through the use of the nine areas as outlined by Roy (1984), a positive response under any main category readily establishes a nursing diagnosis with an alteration noted in this category, i.e., oxygenation with qualifying factor, whichever area has a positive response, i.e., poor lung expansion.

After establishing a nursing diagnosis or diagnoses, the clinician will cluster the various symptoms and prioritize them to establish interventions for changing or modifying the situation. The additional benefit in reviewing all of the items under each category is that the clinician's attention will be called to areas of future potential risk.

Categories of Needs in the Physiological Mode

The assessment tool generated from and influenced by Roy's conceptual framework of adaptation incorporates need areas from the literature which was reviewed and the clinical practice of this writer. These nine categories will be discussed below as they relate to the person with cerebral palsy. Specific need areas under each category are then listed as they appear on the original instrument (Appendix D).

A. Oxygenation Needs:

The process of oxygenation includes the external form of respiration that is associated with moving air in and out of the lungs and the internal respiration that takes place on a cellular level where metabolism of oxygen provides energy to the body. Normal breathing requires:

1. An intact chest cage with functioning muscles to expand and contract it.
2. A patent and intact air passage.
3. Control of the respiratory rate by the nervous system.
4. Elastic properties of the tissue (Rambo, 1984).

The person with cerebral palsy and mental retardation has a known neuromuscular disorder. This often translates into: 1) deformity of the chest cage secondary to spasticity/rigidity of the muscles and poor posture over time; 2) poor swallowing which leads to obstruction of the air passage or aspiration of food particles leading to aspiration syndrome; 3) defects in control of respiratory rate as a result of damage to respiratory center; 4) defects of elasticity resulting from chronic lung disease.

The questions in the assessment tool are directed toward eliciting defects/needs in these areas and are listed as:

Has the client:
1. cyanosis/dyspnea
2. diminished lung expansion

3. diminished energy level
4. esophageal reflux
5. > 3 respiratory infections in a year
6. noisy respirations
7. choking during meals

B. Nutritional Needs

Nutrition is the process of intaking food for the purpose of providing the body's necessary nutrients. In order to obtain all the essential nutrients, a variety of foods must be consumed. Additionally, there must be ability to put food in the mouth, chew, swallow, and digest the food (Rambo, 1984).

Due to defects in the neuromuscular systems of persons who have cerebral palsy, any or all of the areas noted above may be partially or totally dysfunctional. The questions assessing these potential areas of need are:

Has the client had a:
1. > 10% weight gain in past year
2. > 10% weight loss in past year

Does the client require:
3. calorie regulated diet
4. fluid regulated intake
5. a consistency modified diet
6. extra time to eat
7. adaptive equipment to eat
8. staff assistance to eat

9. special positioning to eat
10. upright position after meals

C. Elimination Needs

Elimination is the process of excreting waste materials from the body. In order to do this, lungs, skin, kidneys, bladder, and bowel need to function adequately (Rambo, 1984).

Persons with cerebral palsy may have defects of the kidneys/bladder or bowel due to neuromuscular damage, inactivity, or poor positioning. The questions under elimination will elicit problem areas of urine and feces excretion and are listed below.

Does client have:
1. need of staff assistance with toileting
2. urinary catheter in place
3. frequent urinary tract infections
4. history of bladder deformity
5. history of bladder spasticity
6. difficulty voiding
7. urination: < 4 times a day
8. urination: > 6 times a day
9. < 3 stools a week
10. known bowel disease

D. Activity/Rest Needs

Motor activity is essential for ongoing skeletal function and for carrying out activities of daily living. Conversely, the body

requires rest to restore and repair bodily structures and function. Because of damage to the neuromuscular system, many normal activity/rest functions may be dysfunctional (Rambo, 1984). Questions to assess these need areas are:

Does client have:
1. need of wheelchair
2. need of assistance when walking
3. need of assistance to change position
4. decreased/absence of voluntary movements of upper limbs
5. decreased/absence of voluntary movements of lower limbs
6. diminished head control
7. inability to bear weight
8. drowsiness during the day
9. hyperactivity during the day
10. < 4 hours sleep at night
11. frequent bone fractures

E. Protection

Protection is the process of provision of safety for the human organism. This includes internal safety, i.e., temperature regulation, defense against infection and trauma, immunity and integument integrity. External safety includes a safe home and work environment (Rambo, 1984).

The persons with cerebral palsy and mental retardation may have unique needs in this category because of the central nervous system damage, inactivity, immobility, wheelchair use, and sensory defects. Questions in this category are specifically related to hazards secondary to environment, community, and integument and are listed below.

Does client have: 1. reddened/broken skin areas
2. safety hazards in home/work areas
3. need of antibiotic therapy 3 times/year

F. The Senses

The senses include sight, hearing, taste, smell, and touch. The interaction of the senses with the environment is facilitated by language (Rambo, 1984). Because of neuromuscular defects, secondary to central nervous system damage, persons with cerebral palsy have many sensory defects and communication problems. Questions under senses to elicit needs in this area are:

Does client have: 1. hearing impairment
2. vision impairment
3. speech impairment
4. olfactory impairment
5. pain sensation impairment
6. taste impairment
7. heat/cold sensation impairment

8. temperature regulation impairment
9. cerumen impaction

G. Neurological Function

The nervous system impacts all of the body. The person with cerebral palsy has central nervous system damage. This leads to many dysfunctions of movements, coordination, and regulation in the body. Conditions such as epilepsy and behavior/psychiatric disorders may be present. Questions under neurological function are oriented to eliciting specific problem areas often experienced by persons with cerebral palsy who have brain dysfunction and who may require medication for treatment of these disorders. These questions are:

Does client:

1. have seizure disorder
2. take antiepileptic medications
3. have behavior/psychiatric disorder
4. take antipsychotic medications
5. take lithium
6. have spasticity/rigidity
7. have athetoid movements
8. have difficulty swallowing
9. have mental retardation
10. require assistance to communicate

H. Endocrine Function

The regulation of the hormonal systems of the body are essential for growth and development, metabolic function, and utilization of calcium and glucose. In the person with cerebral palsy, manifestations of hormonal changes are in areas of growth, thyroid dysfunction, and menstrual irregularities. Questions under the category to elicit needs in these areas are:

Does client have:
1. stunted growth
2. excessive hair growth
3. abnormal features/growth
4. low energy level
5. unexplained excessive weight gain/loss
6. absence of/or irregular menses
7. need of assistance with use of pads during menses

I. Fluids and Electrolytes

The balance of fluids and electrolytes is essential for cellular, extra cellular, and systemic functioning. This balance becomes sometimes difficult to identify with persons who have cerebral palsy. They oftentimes are unable to obtain fluids by themselves and dietary modification due to swallowing may affect the intake of electrolytes. Additionally, the use of some medications may deplete or influence how the body utilizes

electrolytes (Green-McGowan, 1985). Questions to elicit needs in these areas are:

Is client:
1. dependent in obtaining fluids
2. dependent in drinking fluids
3. unable to intake adequate fluids
4. showing signs of dehydration
5. taking anticholinergic medication
6. taking any electrolyte depleting/blocking medications

Evaluation of the Instrument by Clinicians

To evaluate the instrument, nine community-based nurses who have expertise with the identified population and who are currently working with persons with cerebral palsy and mental retardation were asked to complete an evaluation questionnaire (Appendix B). These nine nurses have an average of 10 years clinical experience and four of these years were working with developmentally disabled persons. A letter of explanation (Appendix A); a professional/educational profile (Appendix C); a copy of the instrument (Appendix D); and this questionnaire about the instrument was given to these nurses when interviewed as a group by the writer. The nurses were asked to evaluate the instrument in terms of clarity, appropriateness, inclusiveness, exclusiveness, and usefulness by answering the six question's

presented in the questionnaire. The nurses were given clear parameters in terms of the specific population with whom this instrument is to be used, i.e., mentally retarded adult persons with cerebral palsy who are living in community settings and rely on community primary care providers for provision of health care.

During the interview, time was allowed for these nurses to read through the questionnaire and the instrument. The writer answered any questions and clarified issues the evaluators had about the questionnaire and the instrument. The nurses were given 1-2 weeks to complete the questionnaire and the writer was available by phone to the nurses during this time to allow for any further clarification or comments.

The writer met with the nurses to collect the completed questionnaires and instruments on a pre-determined date. At this time, an opportunity was available to these nurses to verbalize any further comments and seek further clarification.

Limitations of this Evaluation

1. Evaluation is limited to one group of nurses.
2. Nurses who are evaluating the instrument are not practicing at the advanced level.
3. The instrument is being evaluated by review only.
4. The instrument is limited to assessment in the physiological mode.

Conclusion

In this chapter, an assessment tool was proposed for evaluation of health risks in persons with cerebral palsy who are mentally retarded. Evaluation procedures, together with the evaluation questionnaire, were discussed. A plan for evaluation of the tool was outlined. The proposed development of the instrument and operationalization of the study variables was presented. In Chapter IV, the results of the evaluation questionnaire and modifications made in the instrument as a result of the evaluation by nurses are presented. Findings of the evaluation will also be discussed in light of Roy's conceptual framework and existing literature. The implications for advanced nursing practice and, in particular, the suitability of the instrument in the primary care setting will be discussed.

Chapter IV

Results and Recommendations

Introduction

An interpretation of the evaluation finding and a discussion of their implications for the nursing profession are presented in Chapter IV. For purposes of the discussion, the chapter is organized into sections related to summary of the problem, information about the nurse evaluators, the plan for screening responses to the questionnaire, the results of the evaluation questionnaire, and the changes made in the initial instrument as a result of the evaluator's responses to the questionnaire. Finally, the recommendations for nursing practice, specifically related to the instrument and Sister Callista Roy's nursing theory with primary care, education, and research implications will be presented.

Summary of the Problem

An assessment tool, for use with persons who have cerebral palsy and mental retardation, was developed and given to nine community mental health nurses for evaluation. This assessment tool was based on the assessment in the psychological mode as proposed by Roy. The tool will be used by health care providers to: 1) address the special needs of persons with cerebral palsy; 2) provide a forum for utilization of information about persons with cerebral palsy and mental retardation; 3) provide a basis for

nursing diagnosis, intervention and education specific to this population; and 4) assist in prevention of disease development as a legacy of the disability by early assessment, education and intervention.

Profile of the Nurse Evaluators

The nine nurses who agreed to participate in the evaluation of the assessment tool are employed by a community mental health center which provides clinical services to approximately 550 adult developmentally disabled clients of whom approximately 10% are diagnosed with cerebral palsy. These nurses are practicing at the staff nurse level but in a non-traditional role which requires independent clinical judgement and decision making. Six of these nine nurses graduated from associate degree programs, one from a hospital diploma program and two from baccalaureate programs. Two of these nurses have a B.A. in health studies and are currently enrolled in masters programs. The nine nurses have had an average of ten years experience in professional nursing with an average of four years clinical experience providing services to persons with developmental disabilities.

Plan for Screening Responses to the Questionnaire

The responses to the questionnaire were evaluated in terms of clarity, inclusiveness, exclusiveness, usefulness, and appropriateness. Specific recommendations suggested certain

adjustments and additions in identified questions. All of the evaluator's responses are noted in the section "Results of the Questionnaire". Changes in the instrument resulting from these responses are documented in the section "Changes in the Initial Instrument".

Results of the Questionnaire

The nine nurses were asked to complete a questionnaire which consisted of six questions about the assessment tool. These six questions were formulated to evaluate the tool in terms of clarity, inclusiveness, exclusiveness, usefulness, and appropriateness. The nurses responses to these six questions are discussed below.

In response to the question on clarity three suggestions were made about words in specific categories which were unclear. The word "frequent", in categories C and D was targeted as unclear. Additionally, the word "difficulty", in category C was felt by one nurse evaluation to be open to interpretation, i.e., difficulty urinating or accessing the bathroom due to immobility? Under category E the use of a broader indication rather than a specific number was seen as necessary. A question arose by one nurse evaluator as to whether behavior as stated in category G was an observation in a diagnosed disorder. This same evaluator questioned using the term, "stunted growth" in category H. At the

initial meeting with the nurse evaluator's they suggested that a clarifier to category I, question 3 was needed.

The second question in the questionnaire asked for additional questions under any category. Four additional questions were recommended. Since many clients have special diets, a question under nutrition to elicit this information was suggested. The daytime activity level, i.e., active or inactive in workplace was recommended for inclusion under activity/rest. The writer, in reviewing the questionnaires felt that a question should be added under category A about chest deformity. Several nurse evaluators wished that the level of retardation be included in category G.

Two similar questions were included in categories A and H related to energy level. The nurse evaluators felt that this question should be deleted from category H. They also recommended that question 7 in category H would be more suitable for inclusion under category C.

The major suggestion for change related to usefulness of the tool was that the format be scaled down to fit on the front and back of a single page. It was also the recommendation of the nurse evaluators that the age of the client be known and that the tool format allow for some patient demographics. In addition to a "yes" or "no" column, it was thought that an additional column was needed for "unknown" or "not applicable".

All nine nurse evaluators stated that they would use the tool for initial assessments. Six evaluators felt they would use the tool when reassessing clients. There were three responses to using the tool for single acute episodes and no response to the question of use at other times.

The tool was seen as most suitable for use with clients who have cerebral palsy. However, many of the nurse evaluators indicated that they might also find the tool useful to evaluate clients with other neuromuscular problems, swallowing problems, clients who are "medically fragile", or with persons who have neuromuscular defects after a CVA. A few evaluators felt the use of this tool would be appropriate as an indicator of functioning level for clients who may be hospitalized or have a change in programs or residences. Additionally the tool could be used as a barometer of improvement or deterioration after a baseline assessment had been completed.

Overall, the evaluation of the tool for use with persons who have cerebral palsy and mental retardation was very positive. The suggestions for change were minor and in general will increase the usability and specificity of the tool when used in clinical practice. Valuable suggestions were made regarding other populations with whom the tool could be used and the

recommendation for format change will definitely increase "user friendliness".

Changes in Initial Instrument

The tool was scaled down and did fit on one backed page. This allowed space for the nursing diagnosis and the plan for treatment. An additional page was added to allow for demographic information on the client. This page also allows for a list of medications the client is currently taking and a column for the date of last blood level and results as indicated (Appendix E).

Questions were added to three categories because of the nurse evaluators recommendation: 1) under oxygenation related to chest deformity; 2) under nutrition related to special diet; and 3) under activity/rest related to inactivity in the workplace. Additionally, to improve clarity the word "frequent" was deleted from the elimination and activity/rest categories. Question 4 under elimination will now read > 3 urinary tract infections in one year and the word "unexplained" will substitute for "frequent" in question 12 of the activity/rest category.

Under the category neurological, question 9 will read: "mild, moderate, severe mental retardation". Question 4 under endocrine is deleted and question 7 under this same category is included under elimination. Finally, question 3 under fluids and electrolytes will have a qualifier added, i.e., for reasons other

than dependency. A footnote will indicate to the user that any question about which information is "unknown" or "not applicable" should have a clarifying note in the comment section. An asterick is requested next to any need which is a new problem. A footnote indicates this. Table 2 identifies the questions under each category, related to the areas of evaluation, about which the nurse evaluators commented.

Recommendations for Nursing Practice

Because cerebral palsy is a chronic non-progressive disorder to which one must adjust in one way or another, the Roy Adaptation Model (1984) was chosen as the nursing conceptual framework for the scholarly project. Cerebral palsy requires adjustments in all four adaptive models. However, for the purposes of the tool development, the physiologic mode only has utilized. Roy's concept of assessing health needs according to the presenting obvious difficulty (focal stimuli), with a probing for contributing factors (contextual stimuli) and additional background less obvious influences (residual stimuli) was used to develop the questions under each of the nine categories. Cerebral palsy with mental retardation certainly typifies a complex nursing assessment.

With the aggregate information from all of the sources available, i.e., the client, physical assessment, clinical record,

Table 2.

Evaluators Comments on Questions Under Each Category Related to Evaluation Criteria

Categories	Clarity	Inclusiveness	Exclusiveness	Usefulness	Appropriateness
A.Oxygenation		Q.3, Q.5			
B.Nutrition		Q.6			
C.Elimination	Q.3, Q.6				
D.Activity Rest	Q.11				
E.Protection	Q.2				
F.Senses					
G.Neurological Function	Q.3	Q.9			
H.Endocrine Function	Q.1		Q.4 Q.7		
I.Fluids Electrolytes	Q.3				

family, and caregivers and a consideration of the relationships among the types of stimuli the nurse can develop specific diagnoses to guide planning and intervention.

Examples of possible nursing diagnoses from the use of the tool would be:

1. Oxygenation deficit related to diminished lung expansion as evidenced by cyanosis.
2. Alteration in oxygenation level as evidenced by noisy respirations, secondary to choking during meals.
3. Alteration in oxygenation level second only to choking during meals as evidenced by > 3 respiratory infections in a year.

The above are three possible nursing diagnoses which may all have a similar set of interventions. The diminished lung expansion and choking during meals may all be helped by better positioning while eating and at other times. Many supportive wheelchairs with special straps and head rests to prevent hyperextension of the neck and forward leaning are available. These wheelchairs promote better chest expansion and increase lung volume capacity.

In addition to the repositioning of the specialized wheelchair, the tool provides a further guide to other related need areas. Contributing to the diminished oxygenation may be the need for a consistency modified diet or upright position after

meals as is noted under nutrition. Additionally, the information under activity/rest that a client may have diminished head control and decreased or absence of voluntary movements of the upper extremities will guide the clinician in appropriate interventions to maximize oxygen delivery, while promoting client independence. This may require the use of adaptive equipment so that the client will be able to feed him/herself or at least assist in the process.

Many times in designing appropriate interventions for the complex health needs of the person with cerebral palsy consultation and cooperation with other disciplines such as occupational, physical, speech, and nutrition therapy will be essential. Additionally, the clinician may require further evidence related to the swallowing problems as is obtainable by a video fluoroscopy. This type of test provides specific information on all areas of chewing and swallowing. These are a few examples of how this tool elicits not only the obvious presenting problem, but the other contributing and background stimuli.

Evaluation of the interventions will take into account the progress made in the major problem and contributing factors. Because of the chronic and long standing nature of these problems, progress may be slow and will only be detected over perhaps many

years. If the major contributing factor to the oxygenation deficit was choking during meals, the frequency and severity of the coughing spells should diminish fairly soon with the modification in diet and positioning changes. However, the hoped for increase in oxygenation level may be more difficult to measure, and expected changes in lung expansion, skin color, and energy levels may take time to be evident. For some of these clients, the goal may be to maintain the current level of functioning rather than any improvement. Alternatively, reduction in the number of episodes of chemical pneumonia, for instance, rather than complete eradication of episodes may be a realistic goal for these clients with severe chest deformities and swallowing deficits.

The clinician working with persons who have cerebral palsy will be greatly assisted in nursing assessment and treatment by a solid knowledge of the multifaceted areas of potential deficits in these clients. A collaborative working relationship with other disciplines and specialties will enhance not only the nursing assessment, but contribute to this knowledge for comprehensive planning, goal setting, intervention, and evaluation.

Implications for Primary Care/Primary Care Providers

The implication for use of this tool to emphasize such health promotion areas as prevention, screening, education, and referral

may include the following activities: 1) using this tool for initial assessment on all clients who have cerebral palsy seen in the primary care office; 2) utilizing the information in the tool to alert home caregivers to potential need areas; 3) including the completed tool in any package of information to referral sources indicating the present functioning level and alerting these sources to potential need areas; 4) educating short term caregivers, i.e., hospital staff to prevent regression and promote maximum independence during the short stay in these facilities; 5) by using the tool at regular intervals alerting the primary care provider to improvements or deterioration in the client's health status; and 6) involving the client, family, and other specialty services in eliciting information to complete the tool.

As the provider of health care services at the advanced practice level, the clinical nurse specialist/nurse practitioner utilizes critical and comprehensive clinical judgement to implement the nursing process. The scope of practice, at this level, is differentiated by the complexity of the developmental and functional needs of patient's with cerebral palsy and mental retardation. The utilization of the tool in the nursing process provides valuable information regarding not only the patient's needs but also strengths. The clinical nurse specialist, in evaluating these findings, will implement strategies which

incorporate the patient's strengths in the plan of care. This may require special advocacy for equipment or money to purchase, for instance, a communication device. In the advocacy process, collaboration and facilitation with other specialties, equipment manufacturers, and caregivers will be necessary.

As the tool is utilized in various situations, the clinical nurse specialist will become more familiar with the multifaceted areas in the provision of primary care for this population. The outcome of this process will enhance communication between health care team members and the patient. The coordination and comprehensiveness of services which should follow will result in improvement in the health status of persons with cerebral palsy and mental retardation, prevent the complications of their disability and reduce, in the long term, the cost of providing services for this population (Rubin, 1989).

Implications for Nursing Education and Research

The curriculum of many nursing schools does not allow for any formal exposure, for student nurses, to the population of persons who have cerebral palsy and mental retardation. Since the deinstitutionalization process began there are no longer institutional settings for admittance, and this population of persons are being seen in local hospitals, clinics, and hospitals.

In these settings the instrument would be a useful guide to both nursing students and practicing nurses related to the current and potential health needs of persons with cerebral palsy. The tool in providing a categorized guide to assessment, allows a more systematized and less threatening interaction to nurses unfamiliar with the developmentally disabled population.

Nurses in advanced practice have the opportunity to teach other nurses through staff development, seminar presentations and peer review. The tool could be used in all of these situations as a basis for education related to the health care needs of persons with cerebral palsy and mental retardation.

The research potential of this tool could include a pilot study to evaluate the clinical appropriateness of the tool in a population of persons with cerebral palsy and mental retardation. Additionally, this type of pilot project could elicit information related to the high, medium, and lower health need areas. Further, categorization of age groups may give useful information about the effects of the disability as persons become older. The tool may also be adapted and piloted for suitability of use with other populations including neuromuscular disorders other than cerebral palsy, swallowing disorders, and residual post CVA defects. As the tool is researched in these situations, the clinical nurse specialist may utilize this information to promote

the development of nurse managed clinics either at the patient's worksite or at a suitable site which would provide ready access in terms of time, location, and environment.

In summary, the nursing education and research opportunities are present but underutilized for persons with cerebral palsy and mental retardation. The main teaching and research focus is dependent on the particular situation. However, nurses should keep in mind the basic principle of nursing assessment, that all persons require a holistic approach to care and this certainly includes education to and involvement of families, home operators, caregivers, other providers, specialists, and professionals.

Summary

The main conclusions drawn from the evaluation of the assessment tool are that: 1) the tool is appropriate for use with the target population; 2) the format would be useful to provide information to caregivers and providers; 3) the tool is readily usable and generates specific nursing diagnoses leading to appropriate interventions; 4) the information gleaned from the use of this tool would help prevent disease development by early assessment, education to clients, caregiver, and providers of health care. The use of the tool, by the nurse at the advanced level, is seen as an adjunct to the role of coordination, facilitation, education, and provision of care for the multiple

health needs of persons who have cerebral palsy and mental retardation.

APPENDIX A

Letter to Nurse Evaluators

1017 Tindalaya
Lansing, MI 48917

March 4, 1991

Dear CSDD Nurses:

I am requesting your assistance in evaluating the attached assessment tool, which will be used with persons who have cerebral palsy and mental retardation. This tool is being developed as a product of my scholarly project to complete the requirements for a Master of Science in Nursing degree at Michigan State University.

The format of the evaluation is a questionnaire about the tool and has six questions. I would like your comments/suggestions on each question in the space immediately below each question. Additional blank pages are supplied should you need more space.

In order to better evaluate the tool, it would be helpful to use it for at least two client-assessments. As you read the tool and answer the questions, please keep in mind your other clients who have cerebral palsy. Should you have any comments elicited by the questions, please use the attached sheet for these. Any additional comments are welcome and, as with your comments on each question, will be used to modify the tool or/and be incorporated into a discussion of the tool evaluation.

There is a short professional/educational profile to be completed. This is very important in terms of your credibility as clinical experts in evaluating the tool.

If as you answer the questions you are in need of clarification on any issue, please call me at work, 887-4320 or home, 321-5623 after 5:30 p.m. I would like to meet with you all in about 2 weeks to pick up the questionnaires and answer any further questions you may have.

My sincere thanks to you all for your help in this project. I hope the completed tool will be useful to you in your clinical practice. I will make the tool available to the agency for use with clients of the agency.

Sincerely,

Nuala Clark

Nuala Clark

APPENDIX B

Questionnaire

Questionnaire

Q. 1. Are the questions under each category clearly stated? If not, suggest a specific alternative.

Q. 2. Are there additional questions under any category which you would add? State category and question number. Give rationale for addition.

Q. 3. Given your clinical expertise, are there questions under any category you would delete? Note these and give rationale. Would you include deleted question under any other category?

Q. 4. Would the format of the questionnaire need to be changed in any way to increase "user friendliness?"

Q. 5. When would you use this tool?

a. Assessment

b. Reassessment

c. Single acute episode

d. Other (be specific)

Q. 6. Given your current caseload, with which types of clients would you most likely use this tool?

APPENDIX C

Professional/Educational Profile

Professional/Educational Profile

Q. 1. What is your highest preparation in nursing?

a. Diploma

b. Associate Degree

c. Bachelor's Degree

d. Master's Degree

Q. 2. What are your professional credentials in nursing and other areas?

a. Certification in any area of nursing

b. BA/BS, MA/MS in field other than nursing

c. Any other

Q. 3. How long have you practiced professional nursing?

Q. 4. How long have you been nursing persons with cerebral palsy and mental retardation?

Q. 5. In your current caseload, describe the number of clients who:

a. Have Cerebral Palsy _____

b. Use a wheelchair _____

c. Take antipsychotic medications _____

d. Take antiepileptic medications _____

e. Take lithium _____

f. Take anticholinergic medications _____

Q. 6. How often in a week/month would you use this tool?

APPENDIX D

Original Assessment Tool

A. Oxygenation:

Has the client had:	Yes	No	Comments
1. cyanosis/dyspnea?			
2. diminished lung expansion?			
3. diminished energy level?			
4. esophageal reflux?			
5. > 3 respiratory infections in a year?			
6. noisy respirations?			
7. choking during meals?			

B. Nutrition:

Has the client had a:	Yes	No	Comments
1. > 10% weight gain in the past year?			
2. > 10% weight loss in the past year?			

Does the client require:	Yes	No	Comments
3. calorie regulated diet?			
4. fluid regulated intake?			
5. consistency modified diet?			
6. extra time to eat?			
7. adaptive equipment to eat?			
8. staff assistance to eat?			
9. special positioning to eat?			
10. upright position after meals?			

C. Elimination:

Does the client have:	Yes	No	Comments
1. need of staff assistance w/ toileting?			
2. urinary catheter in place?			
3. frequent urinary tract infections?			
4. history of bladder deformity?			
5. history of bladder spasticity?			
6. difficulty voiding?			
7. urinate < 4 times/day?			
8. urinate > 6 times/day?			
9. < 3 stools a week?			
10. known bowel disease?			

D. Activity/Rest:

Does client have:	Yes	No	Comments
1. need of wheelchair?			
2. need of assistance when walking?			
3. need of assistance to change position?			
4. decreased/absence of voluntary movements of upper limbs?			
5. decreased/absence of voluntary movements of lower limbs?			
6. diminished head control?			
7. inability to bear weight?			
8. drowsiness during the day?			
9. hyperactivity during the night?			
10. < 4-6 hours sleep/night?			
11. frequent bone fractures?			

E. Protection:

Does client have:

	Yes	No	Comments
1.			
2.			
3.			

F. Senses:

Does client have:

	Yes	No	Comments
1. hearing impairment?			
2. vision impairment?			
3. speech impairment?			
4. olfactory impairment?			
5. pain sensation impairment?			
6. taste impairment?			
7. heat/cold sensation impairment?			
8. temperature regulation impairment?			
9. cerumen impaction?			

G. Neurological:

Does client:

	Yes	No	Comments
1. Have seizure disorders?			
2. Take antiepileptic medications?			
3. have behavior/psychiatric disorders?			
4. take antipsychotic medications?			
5. take lithium?			
6. have spasticity/rigidity?			
7. have athetoid movements?			
8. have difficulty swallowing?			
9. have mental retardation?			
10. require assistance to communicate?			

H. Endocrine function:

Does client have:

	Yes	No	Comments
1.	stunted growth?		
2.	excessive hair growth?		
3.	abnormal features/growth?		
4.	low energy level?		
5.	unexplained excessive wt. gain?		
6.	absence of/or irregular menses?		
7.	need of assistance with use of pads during menses?		

I. Fluids and Electrolytes:

Is the client:

	Yes	No	Comments
1.	dependent in obtaining fluids?		
2.	dependent in drinking fluids?		
3.	unable to intake adequate fluids?		
4.	showing signs of dehydration?		
5.	taking anticholinergic meds?		
6.	taking any electrolyte depleting meds?		

APPENDIX E

Revised Assessment Tool

A Health Needs Assesment Tool in the Physiological Mode
with Cerebral Palsy and Mental Retardation

A Health Needs Assesment Tool In the Physiological Mode for Persons with Cerebral Palsy and Mental Retardation

Name_____ Number:_____
Age _____ Sex _____ Birthdate _____
Address_____
Ht. _____ Wt. _____
Program/Workplace _____

List of Current Medications	Date Last Blood Level	Result Last Blood Level

2. diminished lung expansion?
3. diminished energy level?
4. esophageal reflux?
5. chest deformity?
6. > 3 respiratory infections in a year?
7. noisy respirations?
8. choking during meals?

. Nutrition:

Has the client had a:	Yes	No	Comments
1. > 10% weight gain in the past year?			
2. > 10% weight loss in the past year?			

Does the client require:	Yes	No	Comments
3. calorie regulated diet?			
4. fluid regulated intake?			
5. consistency modified diet?			
6. a special diet			
7. extra time to eat?			
8. adaptive equipment to eat?			
9. staff assistance to eat?			
10. special positioning to eat?			
11. upright position after meals?			

NOTE: Unknown, not applicable, etc. use comment section to explain.

/ problem

2. need of staff assistance with use of pads during menses?
3. urinary catheter in place?
4. > 3 urinary tract infections in one year?
5. history of bladder deformity?
6. history of bladder spasticity?
7. difficulty voiding?
8. urination < 4 times/day?
9. urination > 6 times/day?
10. < 3 stools a week?
11. known bowel disease?

D. Activity/Rest:

Does client have:	Yes	No	Comments
1. need of wheelchair?			
2. need of assistance when walking?			
3. need of assistance to change position?			
4. decreased/absence of voluntary movements of upper limbs?			
5. decreased/absence of voluntary movements of lower limbs?			
6. diminished head control?			
7. inability to bear weight?			
8. drowsiness during the day?			
9. inactivity in workplace?			
10. hyperactivity during the night?			
11. < 4-6 hours sleep/night?			
12. unexplained bone fractures?			

. Protection:
Does client have:

	Yes	No	Comments
1. reddened/broken skin areas?			
2. safety hazards in home/work areas?			
3. need of antibiotic therapy 3x/year?			

. Senses:
Does client have:

	Yes	No	Comments
1. hearing impairment?			
2. vision impairment?			
3. speech impairment?			
4. olfactory impairment?			
5. pain sensation impairment?			
6. taste impairment?			
7. heat/cold sensation impairment?			
8. temperature regulation impairment?			
9. cerumen impaction?			

3. Neurological:
Does client:

	Yes	No	Comments
1. Have seizure disorder?			
2. Take antiepileptic medications?			
3. have behavior/psychiatric disorder?			
4. take antipsychotic medications?			
5. take lithium?			
6. have spasticity/rigidity?			
7. have athetoid movements?			
8. have difficulty swallowing?			
9. have mild, moderate, severe mental retardation?			
10. require assistance to communicate?			

H. Endocrine function:

Does client have:

	Yes	No	Comments
1. stunted growth?			
2. excessive hair growth?			
3. abnormal features/growth?			
4. unexplained excessive wt. gain?			
5. absence of/or irregular menses?			

I. Fluids and Electrolytes:

Is the client:

	Yes	No	Comments
1. dependent in obtaining fluids?			
2. dependent in drinking fluids for reasons other than dependency?			
3. unable to intake adequate fluids?			
4. showing signs of dehydration?			
5. taking anticholinergic meds?			
6. taking any electrolyte depleting medications?			

ASSESSMENT:

PLAN:

SIGNATURE_____

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