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# Community participation in population-based non-insulin dependent diabetes mellitus control program: A paradigm

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**Effective control of chronic diseases in developing countries remains a major challenge in developing countries of the world where low levels of literacy, conflicting notions of disease etiology and low belief in self-efficacy operate jointly to render populations at risk of diseases like non-insulin dependent diabetes mellitus (NIDDM) hopeless. Even as declared by the WHO, the public health challenges of NIDDM have become a serious priority that the organized health care systems of many countries lack the capacity to address the problem effectively without seeking innovative ways beyond what is currently practiced. A paradigm for community participation in population-based non-insulin-dependent diabetes mellitus (NIDDM) control program being used in rural south-eastern Nigeria is presented. The paradigm features the use of area primary health care district health committees as community-based diabetes control implementation committees (CDCICs). It also calls for the deployment of village health workers/volunteers as community-based diabetes control workers (CDCWs) with responsibility for suspect case search, community mobilization, blood-sugar monitoring and referral, and health education. The model integrates population-based NIDDM into area primary health care system. It also aligns control activities with traditional authority hierarchies and political processes of rural communities. Experience from the implementation of the paradigm in five communities in South-eastern Nigeria is presented. Implications for achieving long-term sustenance, relating diabetes control to prevailing socio-cultural norms and practices as well as for demystification of diabetes control are discussed.**

**Key words:** Non-insulin dependent diabetes mellitus (NIDDM), community participation, community-based diabetes control workers, community-based diabetes control implementation committees, diabetes control, primary health care.

## INTRODUCTION

Community participation in health program can be defined as purposive program to empower members of community to exercise self-initiative, responsibility and direction in the planning implementation and control of programs to promote the health and well being of its members. Most applications of the principles of community participation in the prevention and control of diseases in developing countries have been in respect of infectious or communicable disease. However, there is no reason to believe that they cannot be applied to non-communicable diseases. Certainly non-insulin dependent

diabetes cannot be an exception. This disease is gaining significance due to its growing prevalence in population groups previously thought to be little affected by it. It is estimated that about one in every five Nigerians are either diabetic or at risk of developing this disease (Diabetes Foundation, 1999). Increase in the prevalence of the various complications arising from poor control of the disease also makes it significant. Because of the high prevalence of poor blood sugar control among diabetic persons in rural communities, this disease is a leading cause of morbidity and mortality in rural communities of

South-eastern Nigeria.

In a resolution on the prevention and control of diabetes mellitus adopted at its Forty-second World Health Assembly (WHA, 42.36), this world body invited member States "...to implement population-based measures, appropriate to local situation, to prevent and control diabetes". The assembly further called for the strengthening of prevention and community control of diabetes and its complications (WHO Handbook, 1993). The benefits of a community-focused diabetes control initiative have long been recognized (WHO, 1985). King et al. (1995) have described the potential scope of programs to control diabetes in communities detailing which activities are undertaken at the primary, secondary and tertiary levels. However, there has been no reported program of planned community participation in the planning and implementation of population-based non-insulin dependent diabetes mellitus control programs. If the experience of previous population-based control efforts for other diseases and health problems is anything to go by, effective control of non-insulin dependent diabetes mellitus in communities will depend, to a large measure, on the extent to which community members participate in such control programs. The diabetes foundation is a non-governmental organization that is working through members of communities to control non-insulin dependent diabetes mellitus in parts of Nigeria. This paper describes some fundamental aspects of a paradigm to promote community participation in a population-based pilot program to control non-insulin dependent diabetes mellitus (NIDDM) in Ezinihitte LGA, Imo State, Nigeria.

### **Major underlying assumptions of community participation in the control of non-insulin dependent diabetes mellitus**

In the application of the principles and methods of community participation to population-based diabetes control program in communities of developing countries, especially in the African setting, certain assumptions about the disease, the community and its processes, human behavior and disease control are pertinent. To the extent that these assumptions are valid, one would expect such community participation schemes to lead to effective empowerment of rural communities and their members to assume much more increased responsibility in the detection and control of NIDDM. These assumptions, derived from known empirical facts or from theoretical constructs that are strongly built on such facts, are hereby reasoned to be applicable to NIDDM and its control in the community context.

A fundamental assumption is that non-insulin dependent diabetes mellitus and its complications constitute a community health problem, the resolution of which can be sought within the context and scope of

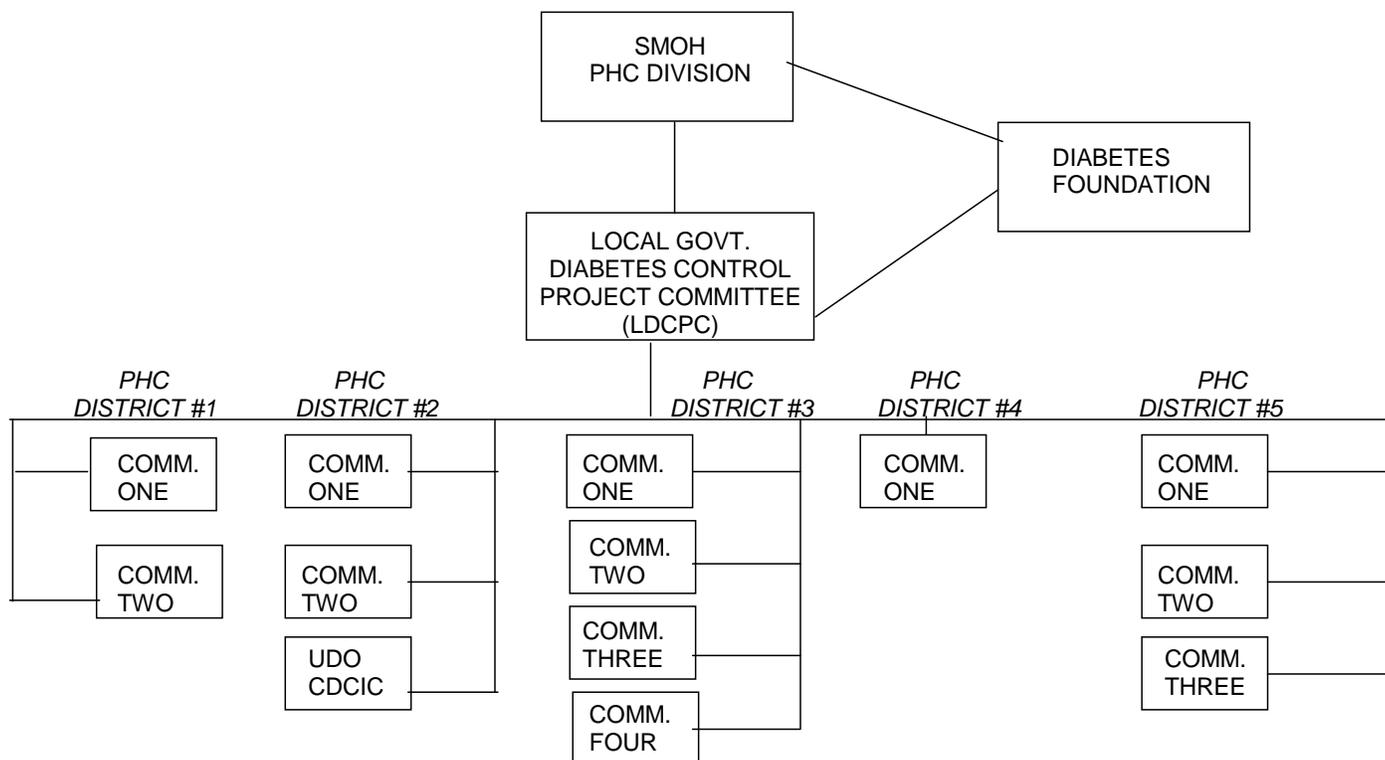
community resources and processes. In making this assumption, it is recognized that the public health implications of diabetes and the rationale for its community-based control, derive from its impact on the patterns of morbidity and life expectancy of the population. It also derives from the implications of diabetes for personal and aggregate productivity, as well as, for optimization of social well being. Further public health implications of diabetes can be argued from the point of view of the financial burden of utilization of diabetes treatment services on the overall cost of health care services.

Another important assumption is that the community can be a necessary and, perhaps indispensable partner in sustainable population-based control of non-insulin dependent diabetes mellitus and the attendant complications of poorly controlled diabetes that afflict members of communities. The active participation of communities in NIDDM control activities, therefore, requires that its members be organized, educated, sufficiently mobilized, as well as, meaningfully empowered to be fully involved in all of the stages of needs assessment, planning and implementation, as well as in monitoring and evaluation of such control programs. These priorities are assumed to be attainable.

Although, community participation is a matter of scope of involvement, participation leading to empowered ownership and control of programs in the long term is considered most ideal. Thus, it is assumed that, in a true sense of partnership, the community can be further empowered to fully exercise self-reliance, self-initiative, self-control, self-responsibility and self-direction in the planning and implementation of diabetes control programs on a population-wide basis.

Non-insulin dependent diabetes, being a disease whose etiology and prognosis has strong behavioral implications, is influenced by the customs, values norms and behavioral patterns of affected persons' communities. Community participation can therefore, facilitate the identification and appreciation of the scope of these factors in the diabetes disease processes. It can furthermore, engender the acceptance of the need as well as, modalities for necessary changes in customs, values, norms and behaviors to bring about the prevention and control diabetes.

The success of any community participation scheme depends to a large extent on the availability within or at easy reach of the community of resources critical to its implementation. Community-based resources whose availability can promote and sustain participation in population-based NIDDM control program include among other things, manpower and material resources, intrinsic leadership structure, values and norms, as well as communication processes and channels. An important assumption, therefore, is that once the proper manner of approach and organization are applied, these potentials can be optimally mobilized to develop and sustain a



**Figure 1.** Organogram for community participation in population-based NIDDM Control.

population-based diabetes control program in which the community is sufficiently motivated to assume responsibility for attainment program goals.

High levels of community focus and of participation in decision-making for diabetes control is assumed to be a realizable goal. Community members, through statutory participation bodies, can therefore become meaningfully involved in the organization and running of diabetes control projects. Beyond the more usual roles of choosing persons who will be trained as community based workers or contributing meeting venues, community members can take on the roles of planning, supervision and mobilization, hence taking decisions on the work of community-based workers. This assumption implies that the real challenge, therefore, is to create an organizational capacity for communities to perform these decision-making roles. Indeed community mobilization activities provide unique opportunities to identify and develop such organizational capacity.

In the socio-cultural milieu of the target communities, and indeed across the entire South-Eastern Nigerian communities, indigenous social structures and traditional patterns of leadership and/or cooperation are easily recognized and understood. They can be integrated into local non-insulin dependent diabetes mellitus control program. To the extent that members of communities accept these existing traditional structures as legitimate, it is safe to assume that they remain veritable instruments

of social mobilization and for transmission/communication of NIDDM control messages. They will also influence the conferment of social legitimacy on NIDDM control activities.

**Basic organogram for community participation in a population-based NIDDM control**

The paradigm for community participation in population-based non-insulin diabetes control programs of the diabetes foundation is developed with due consideration of the assumption discussed earlier and is presented in Figure 1. As readily evident, the actual implementation of the project is by the community diabetes control implementation committees (CDCICs). This committee exists in each of the thirteen communities in the pilot project area. Each is under the chairmanship of a community member who oversees the District Health Committee activities in that community. The district health committee is an organizational component of the area primary health care system. This use of CDCICs facilitates the integration of diabetes control activities into area primary health care systems as recommended by the World Health Organization (WHO, 1985).

Table 1 shows the roles and composition of committees participating in population-based NIDDM control program. As shown, the other members of the CDCIC include the

**Table 1.** Composition and functions of committees in population - based NIDDM control program by communities.

<b>Level/Committee</b>	<b>Composition</b>	<b>Functions/roles</b>
State Diabetes Control Task Force (PHC Division) State Ministry of Health	<ul style="list-style-type: none"> <li>i. Director of Primary Health Care</li> <li>ii. Diabetes Control Program Manager</li> <li>iii. State Diabetes Control Team Members</li> </ul>	<ul style="list-style-type: none"> <li>i. Policy formulation and review</li> <li>ii. Program monitoring and review</li> <li>iii. High level advocacy</li> <li>iv. Inter-agency coordination (ICC)</li> <li>v. Maintenance of state diabetes register</li> </ul>
Local Government Diabetes Control project Committee (LDCPC)	<ul style="list-style-type: none"> <li>i. LGA Primary Health Care (PHC) Coordinator (Chairman)</li> <li>ii. Supervisory council for health</li> <li>iii. Local (Govt.) Diabetes Control</li> <li>iv. Team Members (LDCT)</li> </ul>	<ul style="list-style-type: none"> <li>i. Project management</li> <li>ii. Monitoring and supervision</li> <li>iii. Advocacy roles</li> <li>iv. Information, education and communication (IEC) role</li> <li>v. Maintenance of local diabetes disease register</li> <li>vi. Maintenance of referral network.</li> </ul>
Community diabetes Control Implementation Committee (CDCIC)	<ul style="list-style-type: none"> <li>i. Community/District PHC Committee</li> <li>ii. Chairman (Chair)</li> <li>iii. Elected Ward Councilor from Community</li> <li>iv. Representative of Community Development Union</li> <li>v. Representative of Eze-in-Council</li> <li>vi. Community – Nominated Diabetes Control Workers (CDCWs)</li> <li>vii. LDCT Program facilitator for community</li> </ul>	<ul style="list-style-type: none"> <li>i. Community mobilization</li> <li>ii. “Case” detection</li> <li>iii. Blood sugar monitoring</li> <li>iv. Referrals</li> <li>v. Health education</li> <li>vi. Diabetes case follow-ups.</li> </ul>

democratically elected councilor from the community who represents that community in the legislative arm of the local government area administration. His presence on the committee provides the necessary linkage with the local government policy-making body. Also, representing the views and interests of the LGA Primary Health Care System is a member of Local Government Diabetes Control Team (LDCT). This LDCT member is a staff of the LGA with professional preparation in nursing, community health education or public health. Though not member of the community, he or she is assigned to a specific community and sits on their CDCIC

as a designated facilitator and technical consultant to guide that community in the implementation of the NIDDM control protocol.

Each community in the pilot project area has a two-prolonged leadership/administrative structure comprising the community development union on the one hand and the traditional rulership structure on the other hand. The community or town development union is an assembly of all members of the community headed by an elected executive under the leadership of a designated town (community) union president. The role of the town union is to initiate, implement and monitor community development projects. The traditional

rulership organization essentially comprises of the Eze-in-Council, a body of eminent persons who have various traditional titles and work closely with the community are represented on the CDCIC.

By far the bulk of the work of the CDCIC is carried out by a special cadre of trained lay persons known as Community-based Diabetes Control Workers (CDCWs). These are members of the community, nominated by the community for training and development in service of their people. In majority of the cases, they are already engaged in the delivery of various primary health care services as trained village health

workers (VHW). Their roles as community-based volunteers (CBVs) in lay surveillance for the poliomyelitis eradication initiative and as community-directed distributors (CDDs) in mass Ivermectin distribution for the control of Onchocerciasis have been described elsewhere (Abanobi, 1993, 1999; Abanobi et al., 1999). Many are rural housewives and several others are retired teachers and public service employees. They live and have lived in the communities for quite a long time, know the community members on a personal basis and are well accepted by the people.

The CDCWs undergo a three-day training program on the diabetes disease: what it is, the risk factors, its complications; interviews for suspect-case identification; blood sugar control methods, community mobilization, and reporting. One or more CDCW(s) is/are responsible for a specified sub-population of the community which often conforms to their village boundaries. In some cases, however, it may comprise an aggregate of two or more contiguous village or kindred units. In any case, the span of coverage of the CDCW is consistent with prevailing patterns of community control/administration and community cooperation. The selection and control of the CDCWs by the community leadership is thought to promote a sense of empowered ownership of the control program on the part of the community. It makes the CDCWs accountable to the community.

### **The roles of the community-based diabetes control implementation committee (CDCIC) in NIDDM control program**

This body is responsible for the overall implementation of the project activities within the community. They appoint and supervise the community-based diabetes control workers (CDCWs). They also initiate and supervise mass mobilization of the community membership for diabetes control activities including high risk group screening activity, suspect case identification and community health education. They also identified and mobilized resources available within the community for the support of diabetes control activities and ensure that the periodic summary of activities are reported by the community-based diabetes control workers to the local government diabetes control project committee.

The community-based diabetes control implementation committee (CDCIC) is accountable to the leadership and people of the community. However, The Local Government diabetes control project committee which has technical and managerial jurisdiction over the community control program can, in consultation with the CDCIC introduce policies and decisions intended to achieve greater efficiency and effectiveness in the implementation of the control project. While the functions of the CDCICs can be said to be primarily managerial and supervisory, actual implementation of the

population-based diabetes control activities beyond the direct responsibilities of the afflicted persons rests with the community diabetes control workers (CDCWs). These special health volunteers are responsible for mobilization, case finding, initial suspect case identification using simple and easy to complete risk appraisal instrument, follow-up of cases with reminders to comply with recommendations on control of their condition, etc.

The scope of the community mobilization functions of the CDCIC is critical to both the meaningful participation of the community as a whole and groups in the community who are in positions to influence the process of community empowerment for the control of NIDDM disease. It also takes the form of population-based, mass campaigns of a general nature. In the case of the later, community forums are utilized to deliver relevant mobilization messages.

The setting-up of the CDCIC itself is a result of various high level advocacy activities involving a series of meetings and visits with community leaders, policy makers and high level decision makers to sell and promote community-base control of diabetes. The Foundation and the Primary Health Care Unit of the local government jointly undertake these. The target audiences for these advocacy activities usually include government functionaries (Local Government Council Chairman, Councilors, Headship of the Primary Health Care Department, LGA medical officer and others). Others included are the respective traditional rulers of affected communities and their palace secretaries; town union leadership; other non-governmental organizations operating in the area, particularly those that may in one way or the other be affected by community-based NIDDM control program.

The strategy employed for the mobilization functions of the CDCIC is more of a mass phenomenon approach. It can be characterized as community mobilization or as social mobilization. This involves activities undertaken by the CDCIC to elicit support and compliance of all hierarchies of the community in the effective implementation of the community-based diabetes control program. The target audience generally includes various strata of the community membership particularly those that incorporate known critical and at risk groups in community control of diabetes. Community mobilization for the control of diabetes usually starts with establishment of contact with the traditional rulership and members of the palace cabinet of the areas covered by the program. During such visits, the purpose and scope of the diabetes control program are explained to them in simple and clear terms. The expected benefits as well as expected obligations on their part are spelled out early in the course of these mobilization contacts.

The organization of primary health care systems, which is the bed rock of community-based disease control programs, provides opportunities to work with and through specific bodies with responsibility for directing

area primary care services initiatives on behalf of the community. These, the community/district health committees, are well established in the pilot area where, the Bamako initiative program is also well on the ground. Where the community/district health committees are not in existence, the protocol for the program calls for mobilization of the town union organizations and community development associations to serve that purpose. These and similar bodies are big assets in community mobilization since their membership is almost always representative of the various kindred, villages, secondary strata and other sub-units that make-up the community. Once mobilized, members carry the essential message of the non-insulin dependent diabetes control program to their various groups.

Mass mobilization of community members is often achieved through presentation in churches, schools and at village (Aladinma) meetings, during cultural festivals, and staged rallies, etc. The mobilization message is usually conveyed in the local vernacular that is readily understood by most community members. The native language of the communities is sometimes combined with "Pidgin-English" to broaden its appeal. Illustrations and examples are usually taken from things and situations that community members relate to on a day-to-day basis. The involvement of credible and respected community members, such as retired professional persons and civil servants, is used to facilitate acceptance of the program and to confer reasonable social legitimacy.

#### **The Local Government diabetes control project committee (LDCPC)**

This committee, under the chairmanship of the Primary Health Care coordinator, is responsible for the overall coordination of diabetes control project in their respective local government council areas. Specifically, the Local Government diabetes control project committee, through the Local Diabetes Control Team, sees to the strict implementation of the diabetes control guidelines with respect to planning, management, monitoring, supervision and evaluation of the population-based diabetes control activities. The monitoring and supervision functions of the LDCPC are accomplished through the members of the Local Diabetes Control Team (LDCT) who act as technical facilitators for the various CDCICs.

The LDCPC maintains a diabetes-specific health information system which forms part of the overall diabetes disease register. The basic data for the diabetes health information system is derived from forms completed and collated by the Community-based Diabetes Control Workers (CDCWs) and reported to the central registry through the LDCPC. It is further responsible for the execution of the IEC (Information, Education and Communication) aspects of the project, including the packaging and formulation of community mobilization

messages to fit local idiosyncrasies. Part of the IEC role of the LDCPC is accomplished during the many advocacy activities within and outside the communities, across the hierarchies of Government, as well as with other organizations whose activities in one way or another influence or are influenced by population-based diabetes control activities.

The LDCPC sends periodic project reports to the Diabetes Foundation, which acts as technical consultants, following guidelines stipulated in the detailed implementation plan (DIP) for population-based NIDDM control. Periodic reports are sent to the State Ministry of Health, which monitors diabetes control activities along with other primary health care programs implemented at the community level by the local government.

#### **DISCUSSION**

Community participation in activities for health promotion has long been advocated (Djukanovic and Mach, 1975; UNICEF/WHO, 1977; Read, 1957; Sidel, 1975; WHO, 1976). Indeed, several health and development programs, with varying degrees of success have applied aspects of the basic principles of community participation in one or more stages of the program development and implementation (Sidel, 1975; Hendrata, 1976; Rao, 1972; Stromberg, 1975) and various rationales have been adduced for this. They include, among others, the need to achieve grassroots acceptance and to facilitate effective mobilization of material and human resources available in the community. Other rationales are the creation of public awareness and social mobilization as well as, to promote self identification/assessment of health needs and barriers by community members. Community participation is also thought to enhance effective demand and utilization of program services, to engender sustainability of programs and potentiate the realization of desired changes in client behavior (WHO, 1976; Gish, 1975; Fournier et al., 1975).

Community participation is believed to be most meaningful when it results in reasonable empowerment of the community to assume responsibility for and commitment to the community to assume responsibility for and commitment to the attainment of community health program goals and objectives. Sustainable community participation schemes tend to have built-in mechanisms for longitudinal continuity and to mitigate dependence, whether technical or managerial, on exogenous sources of assistance as is often the case with several NGO-initiated programs. This implies that plans for devolution of control to the community are important part of community participation. Ad hoc schemes, in contrast tend to have a high propensity for failure in the long term. Also, community members often interpret them as being piece-meal and, as in extreme cases, exploitative.

It is important to keep in view, *ab initio*, the fact that

there exists in every community, traditional ways derived from indigenous values and norms of coping with health and diseases. These, in part, form the essential characteristics that define the community and can be basic to their claims of community character. For a community-empowered diabetes control program to enjoy sustained success, it has to give thought to the fact that there exist elaborate and deeply rooted responses to the health needs and preferences of host communities. A population-based diabetes control program with strong elements of empowered community-participation in its planning and execution should purposefully address such needs and preferences.

For communities to participate meaningfully in implementing diabetes control activities, their beliefs and behavior patterns relating to diabetes and its control must be taken seriously and not brushed aside as indigenous traditions and customs which constitute obstacles to promotion of optimal health. In principle, there should be an uncompromising need to learn about and from the indigenous norms and values about health and illness as they relate to diabetes and associated health problems. The use of knowledgeable members of host communities who understand the community and their customs and socio-cultural values is an asset in this regard. In an effort to understand the host communities, critical assessment of proper knowledge, attitudes and health practices that have identifiable implications for the risks of NIDDM and associated complications should not be compromised. In this regard, special attention is paid to the unique circumstances of the rural communities comprising mainly of the functionally illiterate, the not-so gainfully employed, women who are often disadvantaged in health and other respects by traditional patterns of division of labor and social subordination. While these people are not necessarily at higher risk for diabetes, the prognosis of this disease is often worse for them as a result of poverty and ignorance. They are also prone to much gullibility and suggestions based on fads, myths and outright misinformation about diabetes mellitus and its control.

Community empowerment for diabetes control will come when people are fully mobilized to take their well-being into their own hands through a carefully structured program that emphasizes self-initiative, responsibility, reliance and ultimately sustenance. Empowering people for community participation in diabetes control require attitudes and skills that must be learned through specific training and experience. Through mass mobilization methods, specific health education and training workshops, community members can acquire the requisite attitudes, knowledge and skills that build their capacity to develop and sustain a community-based diabetes control program. Because diabetes control involves changes in long-standing behavior, communication with patients and persons at-risk of diabetes and its complications is very important to effective diabetes control. Community participation can

improve communication between the population health workers such that community members become more aware of their own potential contribution to their health status, and to adopt self-help survival skills that lead to ultimate control of diabetes.

In the control of a disease, such as diabetes, where strict compliance to changes in behavior by at-risk persons is important, people have to be given a much greater opportunity to be self-reliant as regards abatement of the risk factors and the proper control of their blood sugar levels. In this respect, participation means in the first place learning – the acquisition and routinization of self-survival skills and widening of understanding about diabetes and its circumstances. This can be expected to free the patient from the shackles of health practitioner domination whereby they depend rather too passively on these professionals to control their blood sugar and reduce their risks.

The nature of NIDDM, specifically its association with several chronic-degenerative diseases and disabling conditions that arise as complications of its poor management, makes it safe to reason that it has the potential to provide an effective entry point in the prevention, management and control of these other diseases and their associated factors. This is well articulated in the WHO technical report on the prevention of diabetes (WHO, 1994). Among diseases and conditions that fit into this paradigm are high blood pressure, coronary artery disease, stroke, chronic kidney failure, atherosclerosis, peripheral neuropathy, complications of pregnancy, gangrene, arteriosclerosis and sexual impotence. These health problems have serious impact on the well being of diabetics and affect the overall health status of communities.

Similarly, community participation in the control of diabetes can also be an entry point in the modification of a number of associated risk factors that are also critical to the control of several contemporary chronic diseases. Notable among these risk factors are inadequate diet, lack of physical fitness, smoking of cigarette, abuse and misuse of alcohol and other drugs, obesity, etc (Abanobi, 1999). These risk factors are also a matter of behavioral choices which can be influenced by enculturation and socialization patterns prevalent in affected persons' communities.

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