
A Case Study in Planning for Public Health Education: The Organ and Tissue Donation Experience

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Synopsis

The chasm between the supply and demand of donated organs and tissues continues to grow despite widespread public awareness of transplantation and numerous efforts to educate the public about organ donation. It is fast becoming a significant public health problem in this country. The need for more effective public education is well documented in the literature on transplantation and is a primary

objective of organizations in the transplant field.

In response to this need, the Division of Organ Transplantation in the Health Resources and Services Administration of the Public Health Service initiated a project to examine the nature and scope of donation education initiatives throughout the country, to identify shortcomings, and to suggest ways the Federal Government could contribute to the effectiveness of public education in organ and tissue donation.

The project resulted in the development of a protocol that also is applicable to other health education programs. Its major steps consisted of assessing the status of donation-related public education in the United States, identifying existing needs in donation education by applying principles learned from other public health education programs, and identifying roles that could be assumed to help strengthen the American public's commitment to organ and tissue donation. These roles, which could be adopted by any transplant-related organization, were as broker of knowledge, producer of educational strategies, energizer through communications research, and catalyst by bringing together other groups.

This approach to needs assessment and planning may provide useful insights both for those concerned with transplants and for professionals conducting education campaigns related to other public health issues.

LITERALLY THOUSANDS OF LIVES are lost each year because of a critical shortage of organs for transplantation. With more than 35,500 patients waiting for an organ and only about 4,500 donors each year, a serious gap has developed between supply and demand. For African Americans and Hispanics, the gap is particularly severe (1).

As a consequence, education of health professionals as well as the public at large as a way to increase donations has become an especially high priority for all those individuals and organizations concerned with transplants. This need is reflected in several major studies and reports that have called for

more and better efforts at donation education (2-4) and a 1989 unpublished report of the American Council on Transplantation, "An Assessment of Public Awareness Initiatives Promoting Organ/Tissue Donation and Transplantation: Findings and Recommendations." The issue also has been the focus of national and regional transplant meetings and the 1991 Surgeon General's Workshop on Increasing Organ Donation.

In anticipation of intensifying its efforts to educate the American public about the critical need for organ and tissue donation, the Health Resources and Services Administration (HRSA) of the Public Health

Service, which is the Federal agency with primary responsibility for carrying out the provisions of the National Organ Transplant Act, initiated a project to develop a strategy for taking a more active part in public and professional education. An important consideration was to identify roles that would take into account existing efforts of other key players in the transplant community and to develop an expanded role for HRSA that would complement, not duplicate, these activities.

The recommendations to HRSA from the project have been described in an unpublished report, "Organ and Tissue Donation Education: Assessment, Recommendations, and Plans for the Division of Organ Transplantation," developed by the University Research Corporation in 1992. The purpose of our paper is to describe the needs assessment and planning process employed in the project. The process, which could be useful to other health education initiatives, is unique in two ways. First, the needs assessment was based on indicators of effectiveness, that is, program design elements that have been associated with success in other health education programs (strategic planning, evaluation, and other important components). Current efforts in donation education were assessed for their incorporation of these elements. The absence of one of these elements in any program was viewed as a need.

Second, the planning phase of the project focused on roles. Once needs were established, the project identified specific activities that could meet these needs. These activities were grouped under four potential roles that HRSA—or various other organizations—could play in public education. The process and the resulting conceptual framework are presented here for their applicability not only to the transplant community but also to public education efforts in other health fields.

The process consisted of three steps—(a) status assessment, examining the status of donation-related public education in the United States; (b) needs assessment, identifying needs in donation education by applying indicators of effectiveness from other health education programs to the information gleaned in step *a*; and (c) future planning, identifying potential roles that HRSA, or any major transplant-related organization, could assume to advance the American public's commitment to organ and tissue donation.

Assessing the Status of Donation Education

The methodology used to assess the overall level and scope of donation education activities consisted

of two parts, a literature review and in-depth interviews with leaders in the field. Project staff members reviewed recent surveys and reports of educational programs (3–8), the 1989 American Council on Transplantation report, and other reports of the preceding 10 years.

Interviews were conducted with representatives of national and local organizations. Interviewees included key decision makers in major national organizations concerned with organ donation and directors of selected organ procurement organizations (OPOs) that had received HRSA grants between 1989 and 1991. (Organ procurement organizations are community-level agencies that coordinate organ and, in some cases, tissue recovery and distribution in defined geographic areas and are also among the organizations that conduct donation education for the public and for health professionals.) OPOs were selected to provide a mixture of those with high and low donation rates, rural and urban areas, geographic locations, and target audiences.

The interview protocol encompassed six categories—(a) mass media and community-based initiatives, (b) target audiences, (c) educational materials and messages, (d) channels of communication, (e) collaborative programs, and (f) evaluative data.

Interviews and reports provided evidence of a large number and variety of educational activities, especially at the local level. For example, the American Council on Transplantation found that many local organizations had developed "a rich variety and quantity of materials to promote public awareness," that they used a multiplicity of communications channels, and that most had ongoing, rather than one-time, efforts (unpublished report, 1989). Interview data confirmed this finding (9).

Interview data also indicated that current activities continue to be varied and may be growing in number. As examples, several national organizations became involved in major new initiatives during 1990–92. These included a national print campaign by the Association of Organ Procurement Organizations (10), an Olympic-style national sports event sponsored by the National Kidney Foundation (NKF); an annual awards program for public education initiatives sponsored by the North American Transplant Coordinators Organization; and a program sponsored by Dow Chemical aimed at minority students. Further, many public and private transplant-related organizations grouped together to form the Coalition on Donation, a national consortium for public education. Since the time of our study, the Advertising Council has agreed to work with the Coalition on

Applying Indicators of Effectiveness to Organ Donation Education

Needs in organ donation education were determined by applying eight indicators of effectiveness to current programs. This process yielded the following profile of strengths and weaknesses (needs) in this field.

Strengths

Use of multiple channels. Interviews suggested that local programs were using a mixture of mass media, interpersonal, and community channels to reach the public, a finding backed by a previous survey, the unpublished report of the American Council on Transplantation (ACT), 1989. For example, local groups reported successful efforts to place stories in the media, take part in health fairs, and distribute information through motor vehicle bureaus, churches, and schools.

Involvement of other groups. Interviewees mentioned numerous examples of ad hoc committees and more formal consortia made up of representatives of community groups, local hospitals, motor vehicle bureaus, and others. Although collaboration at the local level appears common, a need exists for more information exchange among education programs nationally, according to the ACT 1989 report, and Davis (5).

Needs

Formative research. The ACT survey found that only 4-5 percent of programs responding to its survey conducted research, such as target audience needs assessments, in preparation for program planning. Interviewees confirmed that formative research (through focus groups or community advisory committees) was used to some extent but was not widespread.

Strategic planning. Only one program covered in interviews, the District of Columbia Organ Donation

Project, began with a strategic plan. Among professional education programs, a 1985 survey found that 18 percent had measurable goals and objectives (19). The ACT survey and others (4) have concluded that strategic planning is lacking among public education programs.

Audience-based strategies. Interview data indicated that many programs are not targeted to any particular audience (youth, families, African-Americans, and Hispanics should be key audiences for donation education [3]). Both ACT and Oberley (4) confirm that programs and materials do not seem to be designed to meet the needs of defined audiences, nor do they incorporate cultural or ethnic considerations. Both reports also conclude that written materials tend to be at a reading level too high for the general public.

Appropriate messages. Experts in transplantation (3,4) have recommended that messages address common fears and misconceptions about donation; suggest specific actions, such as signing a donor card or having discussions of organ donation with family members; and convey the knowledge that transplantation does save lives. Both the literature review and interview data indicated that most materials and programs do not consistently convey these messages.

Evaluation. The ACT survey found that few organizations involved in public education perform outcome evaluation. A survey by the National Kidney Foundation found that 54 percent of its affiliates and 69 percent of organ procurement organizations included some form of evaluation in their programs (5). However, interviews indicated that evaluation, when it did occur, was informal and sporadic and more often related to process (the number of donor cards distributed, for example) than to outcome (the number of donor cards that were signed as a result of a public education effort).

Donation to develop a national media-based campaign encouraging organ and tissue donation.

In addition, HRSA has supported donation education through a grants program and other activities since the passage of the National Organ Transplant Act in 1984. In 1991, HRSA's Division of Organ Transplantation organized a Surgeon General's Workshop on Increasing Organ Donation that focused attention on public and professional education and other strategies to increase donations.

Identifying Indicators of Effectiveness

To identify the gaps and shortcomings in current donation education activities, HRSA turned to the

experience of other public health education and communication programs. The last three decades have yielded a solid body of literature and a broad consensus about the elements of successful public health education programs, especially in areas such as smoking, cancer, high blood pressure, and alcohol and other drug abuse.

A systematic review of this literature yielded eight elements of effectiveness that could be used to assess donation education efforts. They are the use of formative research, strategic planning, appropriate messages, audience-based strategies, multiple channels, collaboration with other groups in a community, evaluation, and coordination and information exchange in the transplant field (4,5,11-18).

The body of literature that constitutes the source for these elements of success covers a wide range of public health education programs and strategies. For example, Atkin examined the evidence of mass media campaign effectiveness across a variety of programs (12). In a review of the national educational efforts on smoking, blood pressure, and cholesterol, White described the importance of research-based planning, targeting messages, and use of multiple channels along with the benefits of synergistic partnerships (13). The Stanford Three Community Study demonstrated the importance of combining mass media with community-based and interpersonal communications to promote cardiovascular health (14).

Recent reports on health communications have presented guidelines for program planning based on the experience and literature of the last three decades. Backer combined an exhaustive literature review and interviews with more than 50 recognized experts in this field to develop a comparative synthesis of communication strategies for health behavior change (15). His analysis emphasizes the importance of formative research, the development of appropriate messages, and evaluation, among other elements. A planning process that includes market research, the use of multiple channels to reach an audience, and evaluation is described in a widely used communications manual published by the National Cancer Institute (16).

The literature specific to organ and tissue donation education includes several recent reviews that also suggested indicators of effectiveness. DeJong (17) and Arkin (18) reviewed the literature on health communications, applied the lessons learned to organ donation education, and developed recommendations for audience-based strategies, market research, evaluation, and involvement of a wide spectrum of groups. Davis (5) reviewed programmatic needs in public education, emphasizing the role of localized materials and information exchange. Oberley and coworkers (4) examined barriers to donation and assessed educational materials and programs, concluding that grassroots, community-based programs were essential to supplement mass media efforts and that well-researched campaigns targeted to specific audiences were also key elements to success.

Strengths and Needs in Donation Education

When the eight elements of effectiveness were applied to the current situation in donation education, strengths and weaknesses became apparent (see box). Among the strengths were the use of multiple educational channels and the development of local

consortia or groups of agencies working together to educate the public about the need for donation.

Weaknesses included the lack of market research or audience-based strategies, strategic planning, targeted messages, and evaluation. Further, although many groups reported the development of local consortia, coordination on the national level was only beginning to take place.

Identifying Roles to Meet Needs

The third step in the planning process was to identify ways to meet the needs identified in the previous step. Any number of activities might be considered. For example, to meet the need for audience-based campaigns, HRSA or another organization could (a) produce its own campaign, (b) replicate another group's campaign on a wider scale, (c) provide technical assistance to groups in developing their own campaigns, (d) provide a mechanism for exchange of information about audience-based strategies that are effective or hold promise, and (e) support research on effective, audience-based strategies and disseminate the findings.

How might a national leadership organization such as HRSA select from among these activities? It must first identify the role or roles that it could appropriately play vis-a-vis other organizations and activities in the field. Clearly this role should be one that complements rather than competes with the efforts of local organizations or other key activists promoting organ and tissue donation. As this and other studies have shown, local programs are involved in numerous educational activities. What role, then, can a national leadership organization take that will build on these capabilities in order to strengthen its overall success? The various ways in which other Federal agencies have been involved in health education programs suggest some promising models. Four distinct roles can be identified from these models:

1. *As a broker of knowledge, information, and communications strategies and skills.* Resource centers and clearinghouses operated by numerous Public Health Service agencies are common manifestations of this role. Within the transplant community, this role responds to the need for greater coordination and information exchange among programs.

2. *As a producer of educational strategies, messages, and materials.* The National Cancer Institute, National Heart, Lung, and Blood Institute, and the Office on Smoking and Health are examples of organizations that play this role by creating educa-

tional campaigns, often including public service announcements and print materials. This role responds to the transplant community's need for audience-based campaigns including production of prototype materials for localization.

3. *As an energizer, through sponsorship of market research, educational model development, and demonstration programs.* This course of action would include technology transfer and capacity-building activities, such as training and technical assistance, to ensure that results reached programs in the field. While this role is less common, the Center for Substance Abuse Prevention, for example, funds demonstration programs through its communications grants program. The energizer role responds to the need in organ and tissue donation education for more market research (qualitative and quantitative evaluation to assist in the development of concepts for public education) and other evaluative data.

4. *As a catalyst, serving as the consensus builder and coordinator of a national strategy.* This role implies the creation of an agency-supported consortium that brings together major groups in the field. The activities of such a consortium could include all or some of those projected by the first three models. The National High Blood Pressure Education Program, coordinated by the National Heart, Lung and Blood Institute, is a well known example of this model. Federal agencies have also played this role in creating the Healthy Mothers/Healthy Babies Coalition, the National Eye Health Education Program, and others.

The choice of role depends on an organization's mandate, mission, and constituents, existing initiatives or others planned by groups in the field, and available resources. Although it may be preferable to focus on one role initially, the roles identified need not be completely separate tracks. Indeed, they could begin to overlap in function as they are expanded and would, if resources permitted, merge into an ideal model for public education.

Discussion

Needs assessment and planning are essential first steps in developing any communication program. The public health community's 30 years of experience in health education and communications have resulted in a consensus concerning some broad general principles. By using these principles to establish indicators of effectiveness and systematically applying those indicators to existing activities, it is possible to determine needs in a particular field, such as donation education.

Lessons learned in other health education programs can also be brought to bear in planning. In particular, the four roles identified previously that were drawn from the experience of other Federal agencies are useful as the basis for conceptualizing approaches to meeting identified needs without overlapping or interfering with the valuable work of other organizations.

Planning within the framework of potential roles has several advantages. First, the transplant community, like most other sectors of public health, consists of many kinds of organizations—public, private, national, regional, statewide, and local. Planning based on potential roles enables an agency to take into account its relationship to these other groups as well as its own goals. Second, planning based on roles provides an opportunity to concentrate resources on a few related objectives, maximizing impact in relation to dollars spent. By concentrating on a specified role, an agency can establish an identifiable presence; by focusing on one set of objectives, it can position itself to make a distinct contribution to its field.

After looking at the needs and ongoing initiatives identified in the study of donation education conducted by the University Research Corporation, HRSA was able to identify which roles it might adopt for its education-related functions. To complement existing efforts in the transplant community most effectively, HRSA has opted to focus its resources initially in the role of "energizer."

Examples of ways in which HRSA is playing energizer include exploring the funding a large-scale evaluation of a national donation education campaign being developed by the Advertising Council and the Coalition on Donation, of which HRSA is a member. In addition, HRSA has initiated two long-term projects to increase the effectiveness of OPOs to raise the level of organ and tissue donation in their respective service areas, and to hire, retain, and make maximum use of minority procurement staff. Both of these are capacity-building (energizing) efforts.

To assist public education professionals to plan, develop, and evaluate education interventions at the community level better, HRSA has contracted for the development of a detailed communications manual related to donation education that will be made available to the transplant community. HRSA staff members, in conjunction with the Coalition on Donation, are exploring the possibility of a national registry of those who indicate intent to donate on the driver's license and to promote more actively donation education through motor vehicle bureaus.

In another energizer function, HRSA-funded grants

and contracts enable the development of educational models in donation education. A current project at the University of Rhode Island, for example, involves the development and evaluation of a multi-pronged campus-wide initiative to encourage donation decisions among staff, students, and faculty.

As a secondary function, HRSA also conducts activities related to the catalyst and broker roles. With respect to the former, HRSA has made funds available to the United Network for Organ Sharing to build on its resource center of public and professional educational materials and to strengthen its capacity to serve as a national clearinghouse. In a catalyst role, HRSA sponsored a "Public Education Forum" in February 1994 which is expected to become an annual gathering of public education specialists to share ideas and plan nationally-coordinated community education interventions.

Conclusion

This assessment and planning project has demonstrated that needs in a particular field can be assessed by applying established principles of health communication to a specific health education topic. In addition, it suggests the importance of role planning when selecting among the numerous activities that public health groups use in meeting needs. This approach to assessment and planning may be applicable to other health education and communication programs.

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