Building successful coalitions to promote advance care planning

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Abstract

This qualitative study explored the challenges and successes of an advance care planning (ACP) coalition formed at the University of Wisconsin called Life Planning 2000. Data were obtained from key informant interviews (n = 24) and grounded theory. Major themes included commitment (the need for leadership, recruitment of key persons, and funding); cohesiveness (disparate groups collaborating toward a common purpose); and outcomes (including educational tool development). Coalitions need to define short-, intermediate-, and long-term goals that result in measurable outcomes and an evaluation process. Resources must be commensurate with goals. Results indicate that strong leadership, paid staff, adequate funding, and the collaboration of diverse groups working toward a common goal are essential if a coalition promoting end-of-life (EOL) care planning is to be successful.

Key words: advance directives, advance care planning, palliative care

Introduction

Advance care planning (ACP) is gaining widespread acceptance as a means to determine goals of care and treatment choices, and to assign a surrogate decision maker if a patient is incapacitated and unable to make such decisions. These goals are consistent with patient-centered care.1 Advance directives (ADs) are valuable tools for patients to express their wishes and include the assignment of Power of Attorney for Healthcare, the Declaration to Physicians (living will), and other documents, such as do-not-resuscitate (DNR) orders. Many efforts in the past have focused solely on AD completion, forsaking the importance of ACP as a process. These efforts have been nominally successful, and the challenges associated with the completion and honoring of ADs have been well-studied.2-7 The Study to Understand Prognoses and Preferences for Outcomes and Risks of Treatments (SUPPORT) highlighted that, even if ADs are completed, they are not necessarily honored by physicians.4 One notable exception to these findings is Respecting Choices, a successful comprehensive program instituted in LaCrosse, WI, to promote ACP. Respecting Choices involves a systems approach emphasizing all aspects of ACP through a community-wide educational program in a well-defined healthcare system.8 Despite the widespread dissemination of the program, however, its success on a larger scale has not yet been demonstrated.

Despite all the research on the challenges of instituting ACP programs, little research has focused on AD coalition development. What are the elements of successful programs to promote the completion of ADs, to support meaningful discussions about end-of-life (EOL) care choices, and to honor ADs when they are executed? An understanding of the challenges such coalitions face and the process of their development is valuable in promoting an evidence-based approach for future community and statewide ACP endeavors.

This qualitative study investigated a statewide coalition created in Wisconsin and modeled after the Respecting Choices program. The
objective was to determine the key elements of successful ACP coalition development. The study followed the Life Planning 2000 Program (LP2000), a Wisconsin State Bar Association (WSBA) initiative undertaken in partnership with the Wisconsin Medical Society (WMS) and the Wisconsin Health and Hospital Association (WHHA). The coalition consisted primarily of lawyers, doctors, and other healthcare professionals. LP2000 was a unique program in which doctors and lawyers partnered on an issue having both legal and medical implications for the citizens of the state. Its goals included educating Wisconsin’s health and legal professionals about ACP and developing partnerships among them, equipping them with the knowledge and skills to promote the completion of ADs within their communities, and developing a tool to use in ACP. Key participants and components were as follows:

- Participants: lawyers, doctors, nurses, social workers, Respecting Choices representatives, and ethicists from communities statewide;

- Components: educational seminars (panel presentations by legal and healthcare representatives aimed at educating other professionals on ACP with continuing legal education credits provided for participating attorneys);

- Bar association activities: “How to Implement” guides distributed to all county bar associations, which included timelines, suggested activities, sample press releases, bullet points for newspaper editorials, sample events calendars, and a roster of county organizers;

- Other activities: skits, open houses, television programs, and other public presentations within communities;

- Organ donation information: packets regarding organ and tissue donation were distributed at all educational seminars;

- Consumer guide: “A Gift To Your Family” contained state forms designating power of attorney for healthcare, a living will, information on organ and tissue donation, and frequently asked questions; and

- Publicity: a proclamation recognizing Life Planning Week was signed by the governor; and public service announcements, newspaper ads, billboards, and press releases were distributed to the media.

**Methods**

Data were collected through key informant interviews (n = 24). Informants were selected from several WI communities based on their association with the LP2000 coalition. Participants included eight lawyers, four doctors, eight persons designated as healthcare professionals (nurses, social workers, clergy, and ethicists), and four healthcare administrators.

Selection of participants was through identification of key members in the coalition by public record and from those originally identified as key members of the LP2000 team. (One participant agreed to an interview but could not be reached to make an appointment despite repeated attempts at contact.) After obtaining University of Wisconsin Institutional Review Board approval, informants were invited by letter to participate in one-hour interviews conducted by one of the investigators. The interviews were audio-recorded, transcribed, and numerically coded with participant identifiers removed to ensure confidentiality. The interviewer used a semistructured interview format consisting of broad questions followed by prompts. Data saturation occurred after 15 interviews. Data analysis was conducted shortly after each group of four to five interviews was completed so that emerging questions and themes could be further explored in subsequent interviews.

Using a grounded theory approach, the transcripts were analyzed individually and then collectively by the investigators (two family physicians and two medical students) using the editing analysis style described by Miller and Crabtree to determine emergent themes. Responses were compared with records, news reports, and other publications when applicable.

**Results**

Major themes associated with the development of effective community initiatives were identified. These themes included 1) commitment (the need for leadership, recruitment of key persons, and funding); 2) cohesiveness (disparate groups collaborating toward a common purpose); and 3) outcomes (adoption of ACP as a process as well as legal and educational tool development).

**Theme 1: Developing commitment through leadership, recruitment of key members, and funding**

The idea to create a coalition to improve ACP planning was first envisioned by leaders of the WSBA and the WMS. It grew through their ability to create a sense of commitment to the project through leadership, membership, and tangible resources.

The coalition was lead by the presidents of the WSBA and WMS, who recruited staff within their organizations to act as secondary leaders.
These second-tier leaders planned and supervised committee meetings and were responsible for coalition operations. Paid staff leadership was essential, providing continual guidance and support for all members. This was especially important considering many members of the coalition were volunteering their limited time.

Selection of coalition members determined the potential impact of the group. The second-tier leadership and paid administrative staff were responsible for membership development and recruited AD experts from several healthcare professions (nurses, social workers, administrators, e.g.). Members were recruited from across the state to enrich the diversity and knowledge of the group. The membership was particularly enriched by the participation of representatives from Respecting Choices, who shared their experiences and vision of ACP with the group.

Funding for the campaign also demonstrated commitment by the organizations involved. The coalition considered many sources of funding including hospices, hospitals, health insurance agencies, and local advocacy groups. Specific challenges associated with funding included competition between entities, how the funding source would impact the image of the campaign, and the ability to match objectives with actual commitment of resources. It was necessary for all major players to contribute equitably to avoid any divisive competition between entities.

**Theme 2: Cohesiveness through development of a shared perspective, skill set, and common objectives**

After the initial investment stage of coalition development, the group was challenged to work together effectively despite personal and professional diversity. Several factors contributed to the cohesiveness of the group. To develop a shared perspective on ADs, the coalition focused on education. Leaders identified a lack of understanding regarding different perspectives on ADs as the reason for lack of coordination among doctors, lawyers, and other professionals on this issue. A specific aim of the campaign was to develop a common skill set for ACP to share among members and for physicians and lawyers to work as a team. This was achieved through continuing education seminars and “How-to” handbooks distributed by the WSBA and WMS.

Beyond developing a shared perspective, the coalition was challenged with creating a common objective and a unified approach to communicating this objective to the larger community. The coalition attempted to duplicate the success of Respecting Choices by developing a common language and unified message that could create a viable standard of care for ACP within the community. The message was broadcast through billboards, news bulletins, and a consumer guide, all of which promoted “Life Planning” as the common language of the coalition.

**Theme 3: Outcomes—process, collaboration, and creating a tool for ACP**

Despite the lack of quantifiable outcomes evaluated by the coalition, such as comparing the number of ADs completed before and after the interventions or measuring the increase in ADs honored by physicians following the initiative, there were three important results of the LP2000 efforts as identified by key participants. A formal evaluation process to determine the impact of the interventions is a subject for further research.

The effect of LP2000 included a shift in paradigm among coalition members from thinking solely about AD completion to thinking about the overall process of ACP. Through LP2000, professionals involved with the coalition became increasingly aware that ADs are useful tools within the larger context of ACP—one of the core values to emerge from the campaign. The greatest collaboration within the group was the formation of partnerships between physicians and lawyers, uniting them in a mission that both groups felt strongly about and creating unprecedented cooperation between two historically competing professional entities. This resulted in development of the “Consumer Guide,” a printed booklet reflecting the perspectives of both. The booklet contains educational information for the public on ADs and organ donation as well as easy to follow and understand documents on AD to complete. Initial distribution of this guide was free to all healthcare and consumer groups that requested them. Formal evaluation of the use and impact of this tool has not yet been done.

**Discussion**

Many programs intended to promote ACP fail to reach their goals, yet little evaluation has occurred to determine why. Several models of AD promotion focus on the single outcome of AD completion. Yet by focusing so narrowly, little impact is made on the larger process of changing attitudes and ingrained practices with respect to EOL care. The Respecting Choices model promotes not just completion of ADs; it also encourages comprehensive, systemic changes that permeate all levels of community care as relates to EOL care planning. This includes encouraging discussions about goals of care, patient wishes for future care, completing appropriate documents to communicate those decisions, and the final step of honoring those wishes in the hospital. Respecting Choices took place in a small community with sufficient diversity.
resources, commitment, staff, leadership, and evaluative practices to measure the effects of their efforts. Whether this model can be applied to larger communities, as was attempted with LP2000, is not yet known. Although Respecting Choices has shown to be very successful, it did not engage lawyers from the community, who often are in a position to address completion of directives. This was an important aspect of the LP2000 coalition and a potential essential element of future advance-planning coalition efforts.

In assessing community initiatives, it is helpful to adopt a framework for evaluation. Florin et al.11 describes such a framework as consisting of initial mobilization, establishing organizational structure, building capacity for action, planning for action, implementation, refinement, and institutionalization. This framework can be applied broadly to coalition development through the logic model,12 which describes development via three core components: input, output, and outcomes. Using the logic model, the results of this study can be understood in terms of what the coalition invested, how effectively it worked together, and the outcomes of its efforts. This framework provides the basic elements to create and evaluate successful future coalitions in ACP.

Commitment must be sufficient for the coalition to overcome initial barriers and consistent enough for sustainability. To develop a successful working group, leaders are important in recruiting effective members and securing funding. Leaders and secondary leaders must be paid to ensure commitment and continuity. Too many programs are based on volunteer time, and these are doomed to failure especially if they rely on unpaid professionals who have too many other responsibilities and little free time. Adequate funding and resources are essential from the start of the project. Good intentions are not enough. What is necessary is creativity in the acquisition of funding from sources that may have a vested interest in ACP; e.g., senior centers, advocacy groups, grant organizations, public health organizations, hospitals, hospices, churches, or insurance companies. In this study, the coalition had effective leaders and could attribute most of its success to paid staff. Stipends should be considered for all individuals investing their time in these efforts. For LP2000, funding accomplish goals that could be realized within one year of initiation of the project.

Respondents also alerted us to the need to be attentive to the agendas of funding parties, since their objectives could derail the program’s goals by expecting to influence them. Agendas of contributing parties need to be aligned with the objectives of the coalition. Multiple legal and healthcare-related sources of funding in LP2000 abrogated project ownership and competition among funding sources.

The ability of a group to work together effectively is referred to as group cohesion.13,14 The development of a sense of community, as described by McMillan and Chavis,15 consists of the development of membership, the influence each member possesses within the group, the fulfillment of needs, and the development of a shared emotional connection between members.

Cohesiveness involves the delicate balance of creating a shared perspective of common language, values, and messages yet honoring diverse interests and perspectives. A skill set must be developed that bridges these diverse values. LP2000, taking its cue from Respecting Choices, focused on developing consistency of language and message.8 The initiative leaders found that, similar to an advertising campaign, the message needed to be recognizable wherever it was encountered in the community. This cohesive message was broadcast through billboards, newspaper articles, and radio bulletins advertising a consistent theme (i.e., life planning). The information was not focused exclusively on the medical or legal aspects of ACP, thus promoting equal footing and shared responsibility among coalition members.

In order to determine the success of a program, outcome measures needed to be determined and evaluated. LP2000 had the short-term goal of initiating collaboration between doctors and lawyers and creating an educational booklet to facilitate ACP. Their efforts on these points were successful. There was no evaluation of the impact of the coalition’s other efforts, such as lawyer-doctor seminars, the booklet, or related community projects. Evaluation measures and tools need to be incorporated into the planning of a program so that, at its end, concrete evaluation data can determine its success and provide direction for future activities. Lack of a formal evaluation process to measure the impact of the program was a major weakness is this education effort.

The collaborative lawyer-doctor teaching team model used by LP2000 brought together diverse interests and skill sets, and a shift in perspective occurred among participants, especially lawyers, who had previously viewed ACP as a matter of completing documents. Without lawyer-doctor collaboration, ACP continues to be fragmented by profession within the community. The consumer guide embodied this collaboration and is the coalition’s most tangible success, providing a valuable tool for discussing ACP from both a legal and healthcare perspective and including information on organ and tissue donation. The booklet provides a lasting way for the coalition’s efforts to reach those in the community not directly involved in
the program.\textsuperscript{10} Future research could be done to determine the impact of the guide on communities where it was disseminated.

Our qualitative study cannot be generalized to other settings but highlights important considerations for future local and state coalitions in terms of what makes such cooperative efforts successful. LP2000 was unique in its collaboration of legal and healthcare professionals. ACP is complex, and programs to merely increase the number of signed ADs are not enough. ACP requires a comprehensive systems approach as epitomized by the Respecting Choices program. Yet, success in a local community is difficult to translate to a state level, which has more challenges to overcome. Coalitions wishing to promote ACP need to define short-, intermediate-, and long-term goals. Potential funding is available through many sources, which should be in line with the goals of the coalition. Leadership, paid staff, and the collaboration of diverse groups working toward common goals are the basic needs of a successful local or state coalition. Common language, values, and messages need to be established. Outcome measures and a formal evaluation process must be delineated from the beginning. Evaluation of outcomes to determine the impact of the program and identify changes for future efforts is crucial. ADs are not the sole responsibility of health professionals, and lawyers must be included in multidisciplinary efforts to incorporate ACP into the care of all patients.

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References


