INNOVATIONS IN EDUCATION AND CLINICAL PRACTICE

Promoting Signing of Advance Directives in Faith Communities

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OBJECTIVE: To develop a participatory educational program implemented in faith communities that would increase discussion and signing of two types of advance directives—living will and durable power of attorney for health care decisions.

DESIGN: Longitudinal study with four annual cycles of program implementation, evaluation, and revision incorporating a program that fostered the discussion, signing, and/or revision of advance directives. The program involved an educational workbook and ongoing support by parish nurses.

SETTING: Seventeen faith communities in Wichita, Kansas. Faith communities included several predominantly white congregations, as well as several primarily African-American and Hispanic congregations.

PARTICIPANTS: Seventeen faith communities, their pastors, and 25 parish nurses worked with 361 self-selected residents, living in community settings, to participate in the program as members of their faith communities. Congregations were recruited by the executive director of a local interfaith ministries organization and parish nurses.

MAIN RESULTS: Two hundred forty-eight (69%) of the congregants who started the program completed it. Of the program completers, 83 (33%) had a directive prior to the program and 140 (56%) had a directive after completion. One hundred eighty-six of the completers discussed directives with family members. Overall, 89 (36%) of the 248 program completers revised an existing directive or signed one for the first time. Age was positively related to having signed/revised a directive prior to the program. Fear that advance directives would be used to deny medical care was negatively related to signing both prior to the program and after program completion, and contributed to participants' reluctance to sign directives.

CONCLUSIONS: Educational programs implemented by parish nurses in faith communities can be effective in increasing rates of discussion, revision, and/or signing of advance directives.

KEY WORDS: advance directives; faith communities; parish nurses; stages of change.

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Completing advance directives (ADs) has been a goal of federal health policy since the passage of the Patient Self-Determination Act (PSDA) in 1990. Since then, decision making around end-of-life health care has emerged as a significant social issue in the United States.^{1–3} Despite the passage of the PSDA, it is generally agreed that only 15% to 20% of persons have signed an AD.⁴ In response to the PSDA, many educational programs have been implemented, although only about 10% of healthy outpatients respond to such interventions for reasons that are poorly understood.⁴

Clinical research indicates that ADs are often not effective in practice. Advance directives sometimes fail to have an impact on physicians' knowledge of patients' treatment wishes or on the aggressive end-of-life treatments patients receive.⁵ Other research suggests that ADs are not effective ethically in extending patient self-determination to future states of medical incapacity. Surrogates' accuracy in anticipating patients' preferences for specific medical treatments is little better than what would be expected by chance, sometimes even after educational programs.^{6–8} Perhaps legitimate concerns contribute to general reluctance to sign ADs.

There is good evidence, however, that ADs are worthwhile. Tilden⁹ and Rosenfeld¹⁰ have demonstrated that ADs can lower the stress of decision making for surrogates. There is therefore a need to develop alternative settings and methods to encourage wider discussion and completion of ADs.

One such program is Hammes and Rooney's¹¹ public education campaign, which resulted in an 85% AD signing rate. These researchers used trained intermediaries in churches and community groups. A second community-based approach by Clarke and Evans¹² involved recruiting participants from membership organizations and providing them with a workbook and ongoing telephone support.

The primary goal of our study was to develop and evaluate an educational project in faith communities to

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increase the rates of discussion and signing of ADs. In this paper, we describe the community coalition members, the program model and conceptual framework, the recruitment of participants, and our use of an action research approach to evaluate and modify the program annually. We present prepost outcome data regarding the number of participants who revised/signed an AD and findings regarding demographic and belief variables associated with AD completion. We also highlight lessons learned that will be useful in future community programs.

METHODS

Community Coalition

During the fall of 1997, we formed a coalition which included the manager of a parish nursing program, the executive director of an interfaith organization, the executive director of a health ethics educational organization, and two university professors.

The coalition developed a program to train a small group of parish nurses in the legal and medical aspects of ADs. These parish nurses then trained members of their congregations and provided ongoing support regarding ADs.

Parish nurses are especially appropriate community educators because they are registered professional nurses and also members of the ministerial teams of their faith communities. There are 6000 parish nurses in the United States.¹³ Their mission focuses on empowerment and emphasizes individual responsibility for health. Ideally, parish nurses are holistic, addressing the needs of mind, body and spirit.¹⁴ Although some are paid, 60% are volunteers.¹⁵ In Wichita there are parish nurses, mostly volunteers, in 60 congregations with more than 20,000 congregants.

The faith communities within which parish nurses work made them desirable community educators. Religious institutions traditionally offer congregants rich systems of belief, meaning, and ritual for coping with illness, loss, and death.¹⁶ They are effective and accessible sites for health promotion and illness prevention programs.^{17,18} The Robert Wood Johnson Foundation funds a number of community coalitions promoting education around end-of-life issues in faith communities.¹⁹ Therefore, the use of parish nurses in AD educational programs has great replicability.

Program Model

We titled the program *Caring from Generation to Generation* because 3 focus groups, prior to program implementation, told us that they were motivated to sign ADs in order to reduce decision-making burdens for spouses, children, and parents.

We organized the program into steps: the first involved obtaining the commitment of clergy for congregational participation. During the first year, the executive director of the interfaith organization identified and recruited clergy based on knowledge of the pastor's interest in end-of-life

issues, with the goal of recruiting a diverse sample. An usually large number of congregations participated during the first year because, unexpectedly, all 7 pastors agreed to participate. In later years, parish nurses recruited the clergy of their congregations. Fewer congregations participated in years 2 through 4: 4, 2, and 4 congregations, respectively. These smaller numbers were appropriate, given our limited resources.*

In step 2, we trained parish nurses in legal and medical aspects of ADs, and in playing a facilitator role. Step 3 was a recruitment meeting at each congregation, generally in October. Attendees were given an overview of the program, watched a 15-minute video, which was part of the Hammes and Rooney program,²⁰ and were invited to participate. We also asked them to complete a preprogram questionnaire regardless of their decision to participate. Congregants who decided to participate received a 32-page educational workbook plus value clarification exercises, e.g., "(is life worth living) if I can no longer recognize family."²¹

Step 4 involved an educational meeting at each congregation, generally in November. Kansas Health Ethics staffers reviewed important legal and medical aspects of ADs and answered participants' questions. The fifth and final step was a 5-month period from November through March of the following year, included because of Clarke and Evans' observations that many participants took several months to make AD decisions (Susan Evans, personal communication by conversation, April 1998). An important part of the program model was the contact parish nurses were expected to have with participants during this period. Nurses provided information about additional resources and encouragement if people were experiencing difficulties starting the conversation. The program ended before March for participants who had already decided to sign (or not) an AD.

Consistent with a collaborative, community-based approach, we encouraged each congregation to implement the program based on their strengths.²² In several congregations parish nurses or clergy made home visits. Other congregations created supplementary educational health materials, e.g., on caregiving.

Conceptual Framework

During the first 2 years, we used the *theory of planned behavior* to predict AD revising/signing.²³ This theory has been widely used as a basis for health behavior interventions. Its primary assumptions are that intentions (e.g., to sign ADs) are the best predictor of behavior (e.g., actually signing an AD); and that, in turn, attitudes (e.g., believing that ADs are helpful), perceived behavioral control (e.g., believing that one can learn the information necessary to complete an AD), and subjective norms (e.g., believing that family members will approve of one's signing an AD) are

* We were funded \$30,000 for 4 years and it was difficult to coordinate more than 2 or 3 congregations per year.

the best predictors of intentions. Beliefs about the consequences of behavior (i.e., if I sign a directive it will be used to deny me medical care) predict attitudes. We selected the educational workbook, in part, because it included content which the theory of planned behavior suggests would change attitudes and therefore promote signing, e.g., informational resources that reinforce beliefs that individuals have the capacity to make informed decisions about ADs.

We used an action research approach—a cyclical, iterative process—to evaluate and annually revise the *Generation to Generation* program.²⁴ Consistent with participatory research, coalition members shared the evaluation information and collaboratively decided to revise the program based on the feedback.²² Because the assumptions of the theory of planned behavior were not supported during the first 2 years, we decided, at the beginning of the third program year, to use Prochaska's²⁵ "stages of change" model as our conceptual framework. We adopted it because it better mapped the *Generation to Generation* program model and because it has been widely used in health behavior interventions. The theory assumes that behavior change occurs gradually in stages. Typically, a 6-stage model is utilized, including: *negative precontemplation* (e.g., "As far as I'm concerned I don't need an AD"), through *precontemplation*, *contemplation* (e.g., "I've been thinking I might want to sign an AD"), *preparation*, *action* (e.g., "I've signed an AD"), and *maintenance* (e.g., "I'm interested in revising my directive").

The stages of change model also assumes that behavior change is associated with cognitive "decision rules."²⁶ The theory assumes that as people move toward adopting new behaviors, the balance of their beliefs shifts toward the positive, rather than the negative, consequences. Regarding ADs, a relevant positive belief would be: "by signing an AD now I will relieve my family of any future burden of having to make difficult medical decisions on my behalf without knowing my wishes." A relevant negative belief would be: "discussing ADs with my family would make them uncomfortable."

Knowledge of people's beliefs about the positive and negative consequences of behavior change is the basis for "motivational interviewing" counseling techniques.²⁷ Counselors are trained to reflect back to people their ambivalent beliefs in ways that motivate them to adopt new behaviors. During the fourth program year, we trained parish nurses in motivational interviewing techniques, to encourage participants to read the workbook and have family discussions about ADs.

Evaluation Materials

Research Questionnaires: The Theory of Planned Behavior (1998 to 2000). At the preprogram recruitment meetings, participants completed questionnaires about their demographic characteristics, including their health status, prior completion of directives, and prior discussions with family members about end-of-life issues. The survey included

items which operationalized the different components of the theory. The intention to revise/sign ADs was assessed by the item: "I intend to revise/sign a directive during the next 6 months." Participants responded on a 7-point Likert scale ranging from 1 (very unlikely) to 7 (very likely). Attitudes about directives were assessed by a 6-item scale, e.g., "at the present time, my completing a directive would be," to which participants responded on a 7-point semantic differential scale ranging from 1 (helpful) to 7 (harmful). Perceived behavioral control was measured by a 3-item scale, e.g., "if I wanted to I could easily complete an AD." Beliefs about how significant others would react to their signing an AD were assessed via a 9-item scale (e.g., "my spouse would approve of my signing an AD"). Beliefs about the consequences of signing a directive were measured by an 11-item scale (e.g., "completing a directive would increase my chances of having some control over the medical care I would receive if I were to become critically ill"). Seven-point Likert anchors were used with items from these last 2 scales, which ranged from 1 (strongly disagree) to 7 (strongly agree).

Participants completed postprogram surveys regarding whether they discussed directives with their spouse, whether they revised/signed a directive, and the extent of their participation in the program, e.g., whether they had contact with a parish nurse, read the workbook, and/or completed the value clarification questions in the workbook.

Research Questionnaires: Stages of Change (2000 to 2002).

During the third year, we used 6 multi-item subscales to determine participants' stage of change: 1) precontemplation negative, e.g., "I am satisfied not having a directive"; 2) precontemplation, e.g., "I am aware of the importance of a directive but I can't do it now"; 3) contemplation, e.g., "I have been thinking that I might want to sign a directive"; 4) preparation, e.g., "I have set aside time to talk about directives"; 5) action, e.g., "I have signed a directive"; and 6) maintenance, e.g., "I am interested in revising my directive." Five-point Likert scales were used with each item and ranged from 1 (strongly disagree) to 5 (strongly agree). The internal reliability of the scales constructed to categorize participants into stages was acceptable, with Cronbach's α ranging from 0.67 to 0.84. These stage of change scales were reduced from 22 items to 12 items in the fourth program year. Their internal reliability was slightly higher, with Cronbach's α ranging from 0.76 to 0.93.

Two 5-item scales were created during the fourth year to assess participants' decision rules. A sample of an item assessing positive beliefs was: "by signing an AD now I will relieve my family of any burden of having to make difficult medical decisions on my behalf without knowing my wishes." Three of the five pro items referred to benefits to family and two items referred to gains in personal autonomy and control. A sample of an item assessing negative beliefs was: "if I sign an AD now I'm afraid it would be used to deny me medical care in the future if I were to become

critically ill.”[†] Two of the con items referred to increased family burden and three to increased personal burden. Participants responded to each item on a 5-point Likert scale (1, strongly disagree, to 5, strongly agree). Each scale had acceptable internal reliability: Cronbach's α were 0.84 (positive beliefs) and 0.74 (negative beliefs), respectively. These findings have been corroborated (M. Base, unpublished manuscript, Wichita State University, 2002). All program procedures and materials were reviewed and approved by Wichita State University's IRB committee. Research procedures guaranteed the confidentiality of program participants.

There were no potential conflicts of interest during this study between the authors, the funders, or the study participants. The study funders reviewed and approved our study proposals and monitored the study's progress through our annual reports. The authors accept full responsibility for the integrity of the data and the accuracy of the data analysis.

RESULTS

The participating congregations represented a variety of denominations including Baptist, Catholic, Jewish, Lutheran, and Methodist. Two congregations were predominantly African-American, one was predominantly Hispanic, and the others were predominantly white. The congregations ranged in size from 37 members to 8,500: 8 had 1,000 members or more, 5 had approximately 500 members, 2 had approximately 150 members, and 2 had 50 or fewer.

Program Participants

Each year we recruited a new group of congregations and, because of limited resources, asked each to recruit between 20 and 50 participants. Across all 4 program years 481 congregants completed preprogram questionnaires. This was 5% of the total membership of the participating faith communities. Of these 481, 75% opted to participate in the program. Table 1 describes the demographic characteristics of the 361 who began the Generation to Generation program across the 4 program years. Participants were predominantly middle aged, Caucasian females who were married and had some college education.

Baseline AD Completion Rates

Baseline data included the responses of those who began the *Generation to Generation* program. Prior to the program, approximately 29% of congregants had completed an AD; in contrast, 63% had financial wills. Advance directive completers were older than those without advance directives (62 ± 14.2 vs 52 ± 12.9 years, $P = .01$). More whites had completed an AD (28%) than African Americans

Table 1. Demographic Characteristics and Prior Advance Directives of Participants in Generation to Generation Program (N = 361)

Mean age, y (SD)	55 (14.5)
Female, %	60
Married, %	81
Race/ethnicity	
White, %	93
African American, %	3
Hispanic, %	4
Some college, %	74
Prior planning documents	
Advance directive, %	29
Financial will, %	63

(9%) or Hispanics (8%), although this difference was not significant.

Participants who believed that “advance directives would be used to deny me medical care” were less likely to have an AD ($F[1, 248] = 3.9$, $P = .05$). Age was negatively correlated with the belief that ADs would be used to “...deny me care”: $r(246) = -.19$, $P = .01$.

Program Completion and Impact

In 4 years, 361 different participants started the program and 68.7% ($n = 248$) completed it, each within the 5-month program period. The analyses of program impact are based on the responses of the 248 congregants who completed postprogram questionnaires. A total of 186 of the program completers discussed directives with their spouse, and 89 (36%) newly signed a directive or revised an existing one. Prior to participation 83 (33%) had a directive; after completion 140 (56%) had a directive. Additionally, 32 (39%) of the 83 completers with a prior directive made revisions. Nonsigners were more likely to believe that “...advance directives would be used to deny me medical care” than signers. There were no statistically significant differences between signers and nonsigners in terms of sex or marital status. None of the questions concerning participants' health status were related to whether or not they revised/signed a directive.

In terms of program participation, there were several statistically significant differences between signers versus nonsigners. Signers and revisers were more likely than nonsigners to have 1) had contact with a parish nurse—43% versus 26%, respectively; 2) read the workbook—43% versus 11%, respectively; and 3) completed the quality of life exercises in the workbook—52% versus 28%, respectively.

In the third program year, we use the stages of change model. The construct validity of the scales used to assess stage of change was supported by the finding that the decisional balance was significantly more positive for participants who were initially categorized into the action stage than for participants categorized into the contemplation

[†] This item was relevant to both the theory of planned behavior and the stages of change model and was used across program years.

Table 2. Congregants Who Completed the Generation to Generation Program Comparisons of Non-Signers/Revisers Versus Signers/Revisers*

Non-Variable	Sign/Revise (N = 159)	Sign/Revise (N = 89)	Non-P Values
Mean age, y (SD)	56 (14.7)	57 (12.8)	.44
Married, %	80	87	.182
Female, %	42	42	.98
Belief: will be denied medical care because of advance directive, mean (SD)	0.338 (.87)	-0.111 (1.03)	.004
Decisional balance Scale: positive minus negative beliefs, mean (SD)	1.54 (.68)	2.39(.87)	.01
Program participation			
Contact with nurse, %	62	78	.02
Read workbook, %	68	93	.001
Complete exercises, %	48	72	.004

* Participants in the "Non-Sign/Revise" category neither signed a directive for the first time, nor revised an existing document. Participants in the "Sign/Revise" category either signed a document for the first time, or revised an existing document.

† Scores were standardized because participants responded to this item on a 7-point Likert scale during the first 2 years and a 5-point Likert scale for the last 2 years. Standardizing scores involves subtracting each score from the mean and dividing by the standard deviation. This produces a common metric with a mean of 0 and a standard deviation of 1.

‡ Scores ranged from 0 to 3.6.

stage: $F_{5,94} = 12.09$, $P = .01$ (R. Patrick, unpublished data, Wichita State University, 2002). In the fourth year, the predictive validity of the decisional balance scale was supported by the finding that scores of revisers/signers were significantly higher than those of nonsigners: $F_{1,40} = 2.73$, $P = .01$ (M. Base, unpublished manuscript, Wichita State University, 2002). We noted that participants endorsed the five pro items equally strongly: the means were between 3.9 and 4. Therefore, participants were equally strongly motivated to sign/revise a directive by their desire to reduce family burden and by their desire to increase personal autonomy and control. The differences between signers and nonsigners are summarized in Table 2.

While the differences in the signing rates were not statistically significant in terms of racial identity, it was striking that collectively African Americans and Hispanics revised/signed ADs at a higher rate than whites: 47% versus 35%. It is likely that the high rate of signing among Hispanics (45%) and African Americans (50%) was due to home visits made by the Hispanic pastor and the African-American parish nurse.

Predictors of Signing ADs During First Two Years: Theory of Planned Behavior

During the first two program years, we used the theory of planned behavior to predict AD signing. However, the findings indicated the level of intentionality among congregants who signed an AD ($M = 5.51$ [SD = 1.55]) was not significantly higher than the level of intentionality of those who did not sign ($M = 5.14$ [SD = 1.59]): $F_{1,156} = 1.68$, NS. These findings did not support the fundamental theoretical assumption that intentions predict behavior. The theory of planned behavior was not used in the third and fourth years.

DISCUSSION

The primary goal of this study was to develop an educational program that would increase discussion and signing of ADs. The findings suggest the effectiveness of our community-based participatory research in faith communities. One promising finding was the high signing rates in the African-American and Hispanic congregations. Because the intervention processes vary between congregations and across years, it is problematic to identify effective elements in the program. Therefore, the bulk of this discussion concerns lessons learned which will be useful in refining future community-based approaches.

Community-based Participatory Research (CBPR)

Our program utilized many aspects of a CBPR approach.²² We engaged people as members of their faith community, and engaged faith communities on the basis of their commitment to their congregants' health. We took a collaborative approach and modified the program each year based on discussions with coalition members. In the following paragraphs we discuss the lessons learned.

Tension Between Service and Research. The need to resolve tensions between service and research was a continuing theme. During the first program year, we allowed congregations to implement the program in unique ways in order to increase their participation. These variations made it difficult to identify the effective parts of the intervention. After the first year we standardized the program. This helped the research and was a practical way of minimizing the work of the congregations.

Using the Stages of Change Model. Our evaluation data from the first two program years did not support the

assumption of the theory of planned behavior that intentions are the best predictors of behavior, probably because 5 months elapsed between the measurement of intention and of behavior. We adopted the stages of change model because it better mapped onto the Generation to Generation program. It gave us the idea of encouraging participants to sign/revise as soon as they were ready, and enabled us to develop a more appropriate role for parish nurses.

Negotiating the Role of Parish Nurses as Health Promoters.

The role of parish nurses changed during the 4 program years. In the first year, parish nurses were expected to contact their congregants monthly (5 times) until the end of the program. Because they expressed discomfort with so many contacts, we asked them to make two contacts in succeeding years.

During the first 2 years, parish nurses were expected to function as AD experts, which discomforted them because of insufficient training. Our adoption of the stages of change model during the last 2 years enabled us to shift them from AD expert to facilitator of personal change. During the fourth year, parish nurses received training in motivational interviewing techniques and information concerning positive and negative beliefs about the consequences of signing ADs. The nurses found this material useful.

Challenges Faced. The fact that only 20% of the population has signed ADs, despite federal law and public education campaigns, indicates that people are reluctant to engage in advance health care planning and makes it important to understand better people's mixed motivations. We found that participants were as motivated by reducing family burden as by needs for individual control and autonomy. This finding suggests that future efforts should place more emphasis on motivations to reduce family burden.

The findings here also document participants' lack of trust that health care professionals will implement ADs in ways that are in their best interests. Whether such concerns are local or more widely shared should be determined by future research.

Faith communities proved to be appropriate settings for the Generation to Generation program. However, 13 of the 17 congregations with which we worked consisted of 500 or more members. The generalizability of our experiences to smaller congregations needs to be explored because most congregations are smaller than 500.²⁸

Limitations of the Research

The findings of this study need to be replicated in other cities using representative sampling techniques. Participants self-selected into the program and there was some attrition. Especially in need of replication are the positive and negative beliefs identified by the program participants here. It would be important to test the relevance of these decision rules with groups of people who are less interested in revising/signing ADs; such groups, especially if they are

not drawn from congregational settings, may have other concerns.

The fact that we used a nonrandomized, noncontrolled design makes it impossible to assess the directionality and causality of the changes in participants' signing behavior. Participants who had contact with parish nurses and read the workbooks may have done so because they were highly motivated initially, rather than because these program elements motivated them to take such preparatory steps.

Future research using a stages of change model with experimental designs will be necessary to identify effective educational materials and motivational interviewing techniques.

In summary, our results indicate that educational programs promoting the discussion and signing of ADs can be successfully implemented by parish nurses in faith communities. The results also suggest that a nontraditional, community-based coalition can succeed in making such a program work if it engages in a collaborative, action research approach.

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