"Putting Feet to What We Pray About": The Experience of Caring by Faith-Based Care Team Members

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Abstract:
The purpose of this study was to explore the experience of caring by faith-based care team members. Nondirective, in-depth phenomenological interviews were conducted, transcribed verbatim, and analyzed for themes. Participants included 19 care team members who served on faith-based care teams providing in-home support for families with chronic and/or terminal illness. Analysis of the interview texts resulted in the following four themes: "putting feet to what we pray about," "building and sharing relationships," "it makes you more aware," and "because it's a team." Participants expressed a strong reciprocity in their experience; for example, "it's a mutual thing but I think I've gotten a lot out of it." In some cases the caregiving experience was a lesson in survival, "you don't just lie down and die, you get back up." The findings from this study contribute to the limited body of knowledge concerning experiences of participants on faith-based care teams. Keywords: care in the community, care teams, end-of-life care, parish nursing

Article:
The care of the sick, dying, and aged has been a mandate in all major religions for centuries. Congregations have cared for their most needy in various forms, for example assistance with specific tasks such as transportation and home repairs. However, in the early 1980s, the HIV/AIDS crisis propelled congregations to mobilize in a new way to address the grueling demands of the fatal disease, the condemnation of the primarily gay population, and the intolerance inflicted on people diagnosed with AIDS. Several grant-funded groups in the United States began to develop organized networks to train congregational groups to provide in-home support for families with chronic and/or terminal illness. These organized networks developed "care teams."

COMMUNITY INTERFAITH CARE TEAMS PROGRAM
One such care team program is Interfaith Care Links (ICL), which was started in 2000 through the generous support of the Duke Endowment and Carolinas Health Care System. The ICL program is staffed by four full-time community chaplains who are part of the large department of pastoral care and education at the Carolinas Health Care System. Since the ICL program began, more than 100 care teams have been organized and supported, with approximately 65 care teams still serving care partners. Care teams provide in-home support for families with chronic and/or terminal illness. Care teams consist of six to 12 congregants who share the care of one care

partner (care recipient). Care team members provide an ongoing relationship and individualized service to an individual and his or her support system or family. The care partner (care recipient) may or may not be a member of the congregation. Care partners are usually selected by the congregation's primary religious leader with help from an ICL community chaplain, parish nurse, or designated lay leaders. A few care partners have been referred to the program by congregants or healthcare agencies. Each care team member commits to a minimum of 3 hours of service a month: 2 hours of direct service to the care partner and 1 hour in a team meeting. Many care team members contribute additional hours of direct service as the relationship becomes important to them. Families can serve together on an intergenerational team if appropriate for the select care partner. See Table 1 for further clarification.

Table 1 Care Team Terms and Definitions

Term	Definition
Care partner	Persons with chronic illness, long-term disability, or multiple challenges (such as the frail elderly) that overwhelm the family/care givers and/or healthcare providers.
Caregivers	Family members and friends who are in the home and offering basic care services to the care partner.
Care team leader	An individual who serves on a care team and coordinates the services for that team.
Care team members	Individuals who make up the rest of the six to 12-person team that provides services to care partners. Members participate in scheduled meetings and informal networking.
Community chaplain	An individual with pastoral care training who serves as the professional consultant and pastoral caregiver to the teams as they begin and develop.

In the recruitment and training of care team participants, ICL community chaplains emphasize the nature of religious calling to service. The interfaith care team program chaplains rarely if ever refer to care team members as "volunteers." The focus is on the reality that the people

serving on care teams give of their time as members of a faith community that offers opportunities to experience, share, and express their faith. Often what begins as a care team evolves into a genuine religious community.

Care teams do what families have often done for one another. The relationships are the most important exchange, both for care team members and care partners. The concrete services, such as grocery shopping, housekeeping, respite care, or meals, serve as the conduit for the relationships. Care team members use their gifts in the service of someone in need. The care team leader is carefully selected by the congregational leadership with guidance from the ICL staff. The ICL staff remains strategically involved with the care team leader, the care team members, and the care partners throughout the service to shepherd the deepening of relationships.

The acts of providing care invite care team members into a caring relationship with someone who is suffering. The caring relationship with the care partner confronts individuals on the care team with unique human situations that may challenge religious beliefs. These situations are brought to monthly care team meetings, where help, encouragement, and support are offered by others. The care team members are invited in their care team meetings and in their own prayer life to reflect on these relationships as a person of faith. The encouragement to engage in theological reflection begins in the initial orientation meeting. The members on these faith-based care teams contribute time because of their understanding of their faith. What brings them into this type of service? What is their experience of caring? No previous research was found that answered these questions. Therefore, the purpose of this study was to explore the experience of caring by faith-based care team members.

THE STUDY

Aim

The purpose of this study was to describe the experience of caring by faith-based care team members.

Methodology

An existential phenomenological approach informed by Pollio et al [1] and Thomas and Pollio [2] was used to develop an initial description of care team members' experience serving on faith-based care teams. Existential phenomenology attempts to "explicate the essence, structure, or form of both human experience and human behavior as revealed through essentially descriptive techniques."[3(p6)] The phenomenological interview was used to explore and to obtain a rich description of lived experience.

Participants

A purposeful sampling design was employed to obtain participants with varying demographic characteristics who had experience participating on an ICL faith-based care team. Potential participants were recruited through the ICL program. All participating congregations were Judeo-Christian. Participants were included in the study if they had been on a faith-based care team for a year or more and were open and willing to talk about their experience. Participants were English-speaking individuals more than 21 years old. The sample comprised 19 participants (n = 19) aged 36–85 years (mean = 67.1, n = 17); 15 Euro-American (79%), 4 African American

(21%); 3 male (15.7%), 16 female (84.3%); 9 Baptist (47.4%), 5 Presbyterian (26.3), 2 Jewish (10.5%), 2 AME Zion (10.5%), and 1 congregation unknown (5.3%).

Data Collection

Data collection occurred in July 2002 through September 2002. Participants were asked three open-ended questions: (1) "Tell me about your initial interest in offering care to another person"; (2) "Tell me about your experience with your care team's ministry/mitzvah"; and (3) "Sometimes persons on care teams indicate that they have changed in some way, in their faith, or character, or relationships. How has being a member of a care team influenced/affected/changed you?" Follow-up questions such as "Tell me more about [the specific experience]" served only to clarify descriptions. Demographic information was obtained immediately after informed consent was given and before the interview began. Interviews were audiotaped and later transcribed verbatim. All interviews took place in participants' homes, based on mutual agreement. Interview length varied from 45 to 90 minutes.

Ethical Considerations

The study was reviewed and approved by the Carolinas Health Care System's Institutional Review Board. Written informed consent was obtained from those willing to participate. A copy of the informed consent form was given to each study participant and they were informed that they could withdraw from the study at any time. None of the research participants chose to withdraw from the study once interviewing began. There were no monetary incentives offered for participation in the study. Names and references to places were changed to protect the identity of the participants.

Data Analysis

The data were analyzed using the systematic data analysis method described by Pollio et al 1 and Thomas and Pollio.2 The researchers analyzed each transcript for meaning units. Meaning units were read from the part (meaning units) to the whole (entire transcript). The major outcome of these readings was development of a thematic description for each transcript. An initial structure of the experience was then developed and presented to a group of 12 care team members for feedback. The group's feedback was considered in addition to the rereading of all transcripts to finalize the thematic structure. This finalized thematic structure was then presented to a group of seven care team leaders and a community ICL chaplain for validation. The group reviewed the thematic structure and confirmed that it was representative of their experience of caring by faith-based care team members.

FINDINGS

"Putting Feet to What We Pray About"

The experience of caring by faith-based care team members is grounded in the overarching belief that "[we are] putting feet to what we pray about." Another participant said, "I know there are people who don't understand that the church is more than just a Sunday morning thing, or Temple…involves more than just a Saturday experience. But having the love come out of it can happen any time." Participants strongly connected their service to their care partner on a care team with their belief in God. For example, one participant said, "The program represents God." Participants said caring for others "is a part of the church…it gave me a way of knowing that if people needed help…that part of…our church was going out to help them." Many participants

said it was their faith that caused them to initially volunteer for service on a care team: "God already set it up," and "I feel like it's definitely God's plan and God's work, going out to help other people." In addition, care team members' faith helped participants in their service to their care partner: "[I had] trust in God to help me with my care partner" and "it was like a small voice said, trust me in this, I'll take care of it with you…[it was] the Holy Spirit of God."

The caring acts of providing care for a care partner brought participants "close to God through the hardships." Participants thought congregations needed programs such as the ICL program because "we need the ministry of teaching about caring for one another and specifically showing us [by the interfaith care team program]." Participants said the experience of caring deepened their faith:

It's probably made it [faith] stronger in a way; it seems like there is so much out in the world, so much evil and just sad terrible things. It is nice to know that there are still people who have a faith strong enough to help other people even though it may not be the best thing for them…. They are still able to take their faith and share their life back to other people…it is just like having the relationships with the people who have been my care partner have made things less trivial. It's made the world a better place…. The people in my care team who…I would have thought they just came to church on Sunday because I never saw them any other time… [but]…you can see that their faith is more than just on Sunday morning while singing the hymn. So, it gives you a little bit of hope there are other people out there like that who may not wear a big ol' cross around their neck, or even if they do, but it is on the inside as much as it is on the outside.

"Putting feet to what we pray about" is the basis for the experience of caring as part of a faith-based care team. In addition to this overarching belief, analysis of the study data resulted in three dominant themes: "building and sharing relationships," "it makes you more aware," and "because it's a team." In the following paragraphs, verbatim quotations from the transcripts will serve to illustrate each theme.

"Building and Sharing Relationships"
Building and sharing relationships were central to the experience of caring by faith-based care team members. These relationships included (1) relationships with care partners and their families; (2) relationships with other care team members, and their faith congregation; and (3) relationships with care team leaders and interfaith care team program staff. Each relationship was integral to the experience of caring on a faith-based care team.

Central to the experience of caring was the development of a deep relationship with the care partner and their caregivers/family. Participants talked about their relationships as if they were friendships and family: "We're buddies, we're friends," "he's like a family member," and "we have bonded so beautifully. She trusts me. I trust her." Participants experienced intrinsic personal gains from these relationships. For example, "She [the care partner] has done wonders for me…. The benefits have far outweighed anything I have done for her"; and "I get a lot from her…she helps me see that life is funny, it's good and…now I think I am getting more [than giving]." Participants also described building and sharing relationships with other care team members. Participants said, "You get close to them and they get close to you," "the bond is there in this

team," and "we became one big family… the team bonded so well." The team aspect of the experience of caring on a faith-based care team was important in that the care team experience enabled care team members to "get to know the other people in the church." Sometimes the other care team members are from different age groups and interests and, therefore, are outside their "normal circle of friends and acquaintances." As one participant said, "Our group [care team] is a good mix of ages…. I am getting to know people I wouldn't have a reason to get to know…. They are in a different place in their life."

Relationships with the ICL program staff and care team leaders were also significant in the experience of caring on faith-based care teams. Care team members appreciated the knowledge, skills, and experience of the program staff and their ability and willingness to assist the team with various issues. As one participant said, "When frustrations come up you leave it to, like Jean [the team's interfaith care team program staff member], to straighten it out." Another participant relayed the learning that takes place through the relationships with the team, "learning the team's perspective…it's a growth process."

"It Makes You More Aware"
The experience of caring on a faith-based care team served as a learning experience in that "it makes you more aware." Caring for a care partner was experienced as providing many opportunities to learn and grow. The caring experience was described as "a lesson in survival" of "not giving up no matter what"; "It helps me grow as a person. I don't like to consider myself as being a shallow person, and I don't think I am, but it is easy to get wrapped up in your own world, and think that your world is bigger than somebody else's." One participant said of her experience after serving on a care team, "I'm stronger." Another said, "it makes you kind of put things in perspective…that you also need to go ahead and let them go if they are beyond your control and take the help that people want to give you…. I don't beat myself up as much internally."

Participants were made more aware of the suffering of others, of chronic and/or terminal illnesses, and of "what's important in life." Participants expressed "learning about communicating with someone with Alzheimer's [disease]." The learning that care team members experienced through their service to others was transferred to their own friends and families. For example, "Sharing with children and family…makes them aware of other realities in life." A realization of one's own vulnerability was also raised: "It could be me sometime." Another participant described how "being more aware" has helped her to be a better friend:

I don't have the patience for things that are hurtful any more. If someone wants to be critical, that's fine; they can be critical. But I'm not going to have any part of it. I tend more to let people…go if it's not good for me…as you grow, different things become important and different things affect you and make you change or not change…. I think, before, when I would be a friend to somebody, it was on the surface more. Where I am now able to share more of me, but also I feel like I'm a better friend. I feel like I am there more.

The experience of caring brought participants more awareness of "life's blessings" and faith expressed as gratitude. For example, "It makes me more thankful to be able to get up every morning and to be able to do normal things. And to just appreciate, like he [the care partner]

does, watching birds out the window…makes our faith more precious to us," and "It [faith] has deepened… it has gotten stronger." The care given to others through service on care teams "made people aware how very fortunate they are" related to their personal health and their relationships within their own family. As said by another participant,

We appreciate people a little bit more. We appreciate the "hello" a little bit more. And things that you have learned in your life makes you appreciate more, just learning about the needs that people have. I have never taken for granted that I have healthy children, that I have a husband who loves me and still likes to be with me and I like to be with him. But in a way I think I have… [it] makes the struggles that we may have seem more like they are supposed to be there… It helps me appreciate my family more and not wish to change them.

"Because It's a Team"

The team aspect of caring was significant for the research participants, "because it's a team, not one person, it is a joy," "[it was a] good experience to work with others as a group." Participants appreciated that the "caring burden" was dispersed among several care team members. As one participant said, "You have someone to talk it over with that makes the burden much lighter." And as another said, "It takes a little bit of the pressure off to know there's another person who is out there doing it in an organized way."

The care team and monthly care team meetings with team members also provided a place of accountability where people practiced being involved in caring relationships in caring communities. At times, this resulted in disagreement about how particular practices and understandings fit into the pattern of life. This disagreement and engagement in the process of team-based care held the potential to lead to more profound and transforming relationships among care team members and care partners. As one participant said, "It helps a lot…knowing that people out there have the same issues and struggles…it helps. You are not by yourself or alone and hopefully they will get the same feeling back."

IMPLICATIONS
The findings from this study contribute to the limited body of knowledge about the experiences of people on faith-based care teams. This study supports the value of carefully nurtured faith-based care teams and validates information about the benefits of altruistic experiences, gratitude, and social support [4,5] while contributing new insights to the value of faith-based care teams. It is our hope that these findings will help people who establish and manage care team programs to improve the support and structure offered to team members to ensure satisfaction with the caring experience.

The work of "becoming more aware" occurs as care team members "build and share relationships." Care team members in this study sustained their care for more than a year. Other care teams in this program have served the same client for more than 4 years. The findings suggest that the structures of the care team program can begin to develop the "culture" that will be able to sustain the commitment to service and care. Relationship skills are a core part of the care team culture. To support the sustainability of the care teams, the ICL program offers the congregational leadership a "job description" for the care team leaders. This key position requires organizational and relationship skills. Care team members and leaders receive a 2-hour

"orientation" before they begin their service. This training includes such essentials as confidentiality, listening skills, emotional boundary setting, and items specific to the care partner. Hospice and palliative care nurses could recruit others in a congregation or a community and offer this training to care teams.

Part of faith is an experience of the transcendent and the desire to live out that experience in actions. Patients sometimes experience alienation from and disappointment with their congregational communities. Participation in faith-based care teams, by reconnecting patients with the resources of the care team, may also reconnect patients with their own faith. In the context of an ongoing relationship, care team members experience their faith as sustaining their service and giving them meaning. The value of the underlying faith and the group are that they provide the discipline to follow through to sustain them through the caregiving experience.

Hospice and palliative care nurses are encouraged to assess the resources of their patients and intervene by considering support from congregational teams. Nurses could introduce the concept to family members and friends or seek the cooperation of a faith congregation. This study suggests that these teams can be a positive experience for both the givers and the receivers, allowing care team members to "put feet to what we pray about." For patients active in a faith group, one suggestion is to approach the congregational leadership of that faith congregation. Another approach is to explore with the patient any congregations that are associated with family members or that are located in their neighborhood. In addition to those that are faith-based, care teams could also be developed with groups of friends, coworkers, or neighbors.

It is important that the desire to access adequate service for a desperate patient does not lead a healthcare professional to approach people in congregations with unrealistic expectations. Such urgency can interfere with the development of a functional congregational team. The reality is that congregations are not always willing to assist a congregational member through the venue of a care team. Our findings "because it's a team" suggest that in the initial recruitment of care team members, people are more willing to contribute their time and services in a context that is not experienced as demanding. The team structure offered in this program requests only 2 hours a month of service from each care team member, with one more hour in a care team meeting. The community chaplains assist in the intake interview to negotiate a covenant or agreement that is manageable in that time frame and helps participants realistically decide what can be done in 10 to 14 hours of service a month. Our observation is that people often offer more hours of service after the relationship has become more personally meaningful.

Findings from this study raise several questions for future research. This study did not examine the benefit of care team support to hospice and palliative care clients; however, in light of the anecdotal reports from our study participants and through our work with care teams, we believe that care team support does help care partners and hospice and palliative care patients. The patient's perspective of the care team experience is an area that needs further study. Future research questions include: Do hospice and palliative care nurses get the same or similar benefits from caring as faith-based care team members? Does the suffering witnessed by hospice and palliative care nurses make those nurses "more aware"? Are relationships to patients and their families central to the experience of caring by hospice and palliative care nurses?

DISCUSSION
Faith is central to the experience of caring by faith-based care team members. Study participants relate their care team service to their understanding of God. The southeastern city where this study was conducted is located in the "Bible belt" of the United States, where Christian congregations significantly outnumber other traditions. Like other traditions, Christian congregations have a strong historical and scriptural mandate to care for the whole person in ways that embody mutuality and respect.

Findings from this study suggest that care team members discovered a state of healthy humility. Care teams "enable Christians to learn to see the world from the perspective of those who suffer."6(p32) From that view, the illusion of self-sufficiency is shattered by the face-to-face confrontation with human fragility.

Participants on faith-based care teams offered themselves out of a commitment to care. In a study of commitment in public service, Parks-Daloz et al interviewed more than 100 people who had sustained a "remarkable commitment to the public good" and found that "the single most important pattern" in sustaining such a commitment was a "constructive, enlarging engagement…with others significantly different from themselves."7(p63) Care team members are wooed into deeper engagement with a "foreign" person in the strange and vulnerable landscape of illness, which can lead to commitment in a complex world. Parks-Daloz et al documented what they identified as an "unexpected finding," namely, that "religion played an important role in the formation of commitment."7(p63)

The stories of commitment that we heard from our research participants consistently included "important encounters with others significantly different from themselves." This research is consistent with current discussions of ways to counteract the trends of individualism, driven schedules, and consumerism. As stated by Parks Daloz et al, "We described the ongoing life task of composing and recomposing a trustworthy sense of self and world—a process dependent upon communities of belonging that offer developmentally fitting elements and provide the appropriate mix of support and challenge. A critical part of what communities and societies provide—by intention or default—is moral content."7(p141) The challenge is to encourage people toward an "enlarging engagement" that is neither too scary nor overwhelming to participants, particularly in the often insular congregational environment. The findings from this study of the experience of caring by faith-based care team members suggest that care teams offer this type of bridging experience between those with the illusion of health and those suffering from an identified illness or illnesses.

The care team model calls congregational members out of self-absorption and into a particular community that focuses on service and more abundant living. Care team members work side by side with others, often learning to "forget themselves on purpose" through gradually establishing routines of giving of themselves, their time, and unique gifts. They give freely and for no good reason, with no observable compensation or benefit. They experience the "grace of daily obligation."8 This giving is experienced as a powerful witness to faith, especially since care team participation is not tied to any compensation or requirement from the religious sect, without coercion toward any religious tradition. Individuals may have their whole vision of the faith

community changed by the investment of the care team, experiencing moments of unconditional acceptance in the midst of suffering.

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