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Supporting cancer survivors' participation in peer review: Perspectives from NCI's CARRA program

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Abstract

Purpose—Including cancer survivors in the peer review of cancer-related research is increasingly valued as a strategy for bringing the "patient perspective" to discussions of research merit and human subjects protection. Because integrating lay stakeholders into peer review poses challenges, this qualitative study explored the perspectives of experienced patient advocates to identify programmatic supports for survivors' participation.

Methods—Semi-structured telephone interviews were conducted with a purposive sample of 19 cancer survivors and 6 administrators involved in NCI's Consumer Advocates in Research and Related Activities program. Audio-recorded interviews were transcribed verbatim, and analyzed via thematic content analysis. Participants were highly educated and included survivors of breast, prostate, and blood-related cancers.

Results—Interviewees emphasized the importance of adequately preparing survivors to serve as advocates. Given the intellectual challenge of peer review, interviewees noted the need for intensive and ongoing training on how to review proposals, and they identified mock reviews and peer mentoring as effective strategies to complement didactic instruction. Participants also stressed the need to address social challenges inherent in advocate-scientist encounters. In addition to training for both advocates and scientists, participants reported that opportunities for informal social interaction were important for facilitating collaboration. Finally, participants recommended structuring advocates' role so as to give them a voice via equal voting privileges and protected opportunities to speak.

Conclusions—Programs that seek to include cancer survivors in peer review can prepare advocates' for the intellectual and social challenges of working with scientists through careful attention to training, networking, and programmatic design.

Implications for cancer survivors—Cancer survivors have been leaders in developing a role for patient advocates in the peer review of research. As the concept of patient-centered outcomes continues to gain currency, lessons learned from early programs for patient inclusion in peer review can help to inform future efforts aimed at giving patients a voice in shaping agendas for health-related research.

Keywords

cancer; survivor; consumer participation; patient advocacy; peer review; research

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INTRODUCTION

Patient-centered outcomes research, which seeks to evaluate healthcare from the perspectives of patients themselves, is guided by the principle that patients should have a voice in all aspects of research, including the allocation of research funding [1]. The recent establishment of the Patient-Centered Outcomes Research Institute (PCORI) has spurred renewed interest in understanding how patients, as non-scientists, can be incorporated most effectively into scientific processes such as peer review [2, 3]. Although many scientists would agree in theory that the patient perspective is relevant to the appraisal of research merit and human subjects protection, the actual practice of giving patient advocates a meaningful role in peer review is far from straightforward given the highly technical nature of those discussions [3]. As patient inclusion in peer review becomes more common, fledgling programs may benefit from lessons learned by early adopters of this practice.

Cancer-related research is one area in which the inclusion of patient advocates in peer review has a fairly long tradition, due in large part to the success of the breast cancer advocacy movement. In 1991, the National Breast Cancer Coalition led a grassroots campaign that resulted in a congressional allocation of more than $200 million for the establishment of the Breast Cancer Research Program (BCRP) within the U.S. Department of Defense [4]. In addition to securing research funding, the coalition instituted a policy for the inclusion of breast cancer survivors in the peer review of research proposals funded by BCRP [4]. In this capacity survivors were meant to bring the perspective of breast cancer patients to the review process in order to ensure that funded studies were feasible, ethically sound, and in keeping with the priorities of patient communities [4–6]. Although initially controversial, the program was well-received by scientists and advocates, and to date, breast cancer survivors have served as voting members on all peer review panels [5, 6].

Based on the success of BCRP's program, the practice of patient inclusion in peer review has spread in various forms to other cancer research funding organizations. Non-profit organizations, including Susan G. Komen for the Cure, have incorporated cancer survivors in peer review [7]. Perhaps most importantly, the practice has also been adopted by the nation's largest funder of cancer-related research, the National Cancer Institute (NCI). Since 2001, NCI has recruited and trained cancer survivors through its Consumer Advocates in Review and Related Activities (CARRA) Program, an initiative which serves as the programmatic context for this study (NCI, 2011a) [8]. Although patient involvement in peer review remains unusual with regard to some diseases, in the area of cancer-related research, the practice is relatively well-established.

This qualitative study investigated the practice of patient inclusion in peer review from the perspective of cancer survivors participating in NCI's CARRA program. More specifically, this study aimed to explore programmatic supports that survivors identified as facilitating their work on peer review panels. By investigating the practice of patient inclusion in the context of a well-established program, this research aims to inform future efforts to expand the voice that survivors of cancer, and many other diseases, have in guiding health-related research.

METHODS

Programmatic context

Established in 2001, CARRA maintains a pool of over 100 advocates drawn from across the U.S. To select advocates, CARRA staff members first solicit nominations from cancer advocacy organizations, and nominated individuals are then invited to submit an application. Staff members select advocates from among these applications with an eye toward

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representing different advocacy communities in terms of cancer type, racial/ethnic background, and geographic location. Unlike programs such as BCRP's, CARRA does not require advocates to be cancer survivors in the sense of having had a personal cancer diagnosis. Instead, eligibility is extended also to those who have experience as a caretaker of a person with cancer.

Before joining peer review, CARRA advocates participate in a multi-day workshop. Advocates are instructed in the "anatomy" of a grant proposal, and they are trained in how to critique and score proposals. Other topics include human subjects protection, the inclusion of underrepresented populations, and basic research design concepts such as randomization. The role of the advocate is set forth as the provision of "the patient/public perspective in the assessment of scientific excellence." Advocates are discouraged from presenting a "personal or political agenda," but rather are asked to "represent the collective views of people affected by and at risk for cancer." The workshop, which was developed with input from practicing advocates, culminates in a mock review.

CARRA advocates are invited to participate in the review of clinical and translational research, including research project (R01) grants, small project (R03) grants, research program project (P01) grants, and cancer center (P20/30/50) grants. The process of matching trained advocates to peer review panels begins with the scientific review officer managing the panel in question. The officer requests advocate participation and may specify a preference for advocates of certain backgrounds (e.g., experience with a certain type of cancer). CARRA staff then select and contact advocates to invite their participation.

Once matched to a review panel, advocates receive grant proposals to review off-site. Although the procedure varies, advocates typically submit a written critique of each proposal and then travel to face-to-face meetings of the entire review panel. Advocates are invited to comment on each proposal after the primary and secondary scientific reviewers have made their statements. Advocates participate in peer review panels as voting members, and their scores carry the same weight as those of scientist members.

Participants

The primary study sample consisted of CARRA advocates who had participated in peer review in the previous four years. Eligible advocates included cancer survivors who had experienced a personal cancer diagnosis as well as those who had been the caregiver of a family member or friend with cancer. Using the program's volunteer registry, a CARRA staff member recruited advocates using a recruitment script sent via email. With the goal of achieving maximum variation, this study employed a purposive sampling strategy so as to include participants of four different cancer advocacy interests: breast, prostate, blood-related, and other cancers. Of 43 advocates who were initially contacted, 29 indicated interest in the study, 21 received invitations to participate, and 19 ultimately completed interviews. The final sample size was determined by thematic saturation [9], which occurred in this study when the final four interviews yielded no information that substantively changed the analysis.

To contextualize advocates' perspectives, a secondary study sample consisted of CARRA program administrators. Administrators were interviewed to provide additional information about program history, policies, and procedures as well as an organizational viewpoint on facilitators and barriers to advocates' participation in peer review. These participants included current and former CARRA staff members as well as consultants who had contributed to the development of the program. Using a snowball sampling strategy, 11 program administrators were identified, 6 received invitations to participate, and all completed interviews.

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Data Collection

In 2010–2011, participants were interviewed by phone using a semi-structured interview guide. Open-ended questions explored how participants became involved in CARRA, their experience of cancer and cancer-related advocacy, and their participation in peer review. Of greatest relevance to the present study was a section of the interview guide that asked participants to reflect on CARRA training as well as other programmatic factors that facilitated or hindered their participation in peer review. Participants also provided demographic and other background information including educational attainment, race/ethnicity, and survivorship status (i.e., personal cancer diagnosis versus caretaker of a person with cancer).

Prior to beginning the interview, participants reviewed a study fact sheet and orally indicated informed consent. Interviews ranged from 20 to 90 minutes, with the average session lasting approximately 45 minutes. Interviews were audio-recorded with permission and transcribed “clean verbatim” (i.e., without nonverbal utterances such as “um”). The Institutional Review Board of the Johns Hopkins Bloomberg School of Public Health approved the study protocol.

Data Analysis

Data were analyzed in iterative cycles of content analysis in the manner described by Patton [9]. In the first, inductive phase of analysis, initial transcripts were read multiple times in their entirety and analyzed through a process of open coding aimed at identifying broad topics of discussion. As codes were identified, subsequent interviews were structured so as to explore areas of interest in greater depth. Over time, codes were refined as they were applied to additional transcripts and through consultation with other investigators. Finalized codes were organized into a codebook, and then applied to the data systematically using ATLAS.ti Version 6.0 (ATLAS.ti Scientific Software Development GmbH, Berlin, Germany).

In the second, deductive phase of analysis, data were considered code-by-code to identify areas of convergence and divergence [10]. Data were compared within codes by participants’ area of cancer interest as well as by role (i.e., advocate versus administrator). Emerging patterns were described thematically, and quotations were selected to be representative of thematic descriptions. Transcripts were then re-read to test identified themes and to check for dissenting views, or exceptions to overall themes, that might require additional analysis or discussion. Unless otherwise stated, quotations presented in the findings are from CARRA advocates.

RESULTS

Sample characteristics

The primary sample of CARRA advocates consisted of 10 men and 9 women, all of whom had experience in peer review (Table 1). Participants were highly educated with all but one holding a graduate degree. In terms of survivorship status, 11 participants had personally received a cancer diagnosis, while the remaining 8 had served as a primary caretaker of a family member or friend with cancer. In terms of racial/ethnic background, 12 participants described themselves as white or Caucasian, 4 were black or African American, and 3 indicated another background or chose not to answer. When asked to specify their primary advocacy interest by cancer type, participants most often reported breast (n=5), prostate (n=4), and blood-related (n=4) cancers.

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The secondary sample of CARRA administrators consisted of the program's current and former staff members (n=3) as well as consultants or others involved in developing the CARRA program (n=3). Demographic characteristics of the secondary sample are not reported to protect participants' identities.

Training and mentorship

Theme 1: Comprehensive training to address both informational and social aspects of peer review is crucial for advocates' success—All interviewees emphasized the importance of training advocates to meet the challenges of participating in peer review. They noted the importance of introducing advocates to the structure of grant proposals, the basic principles of research design, and the procedures of peer review. Several advocates also mentioned the value of participating in a mock review session, which gave them an opportunity to apply what they had learned.

For some, training on the social aspects of peer review was even more important than the procedural and informational orientation, and interviewees identified two competing challenges in this regard. First, interviewees noted that, given the highly technical language of peer review and the scientific expertise of other reviewers, advocates could easily become intimidated. For this reason, one goal of training should be to foster confidence:

> [The CARRA training includes] a whole session on how to participate in peer review, and the purpose of that is to get people accustomed to speaking up. Because our [societal] training has always been "the scientist knows best." Well, the scientist may know best about 99 percent [of the proposal], but our 1 percent, we really know best.

At the same time, some advocates and all administrators stressed the importance of teaching advocates how to present their critiques in a "fashion that's acceptable to the panel." In this regard, the goal was a professional tone achieved by presenting critiques in a brief, non-confrontational, and emotionally-neutral way and by avoiding the discussion of experiences or viewpoints deemed to be personal. Thus, one perceived purpose of training was to foster within advocates a careful balance between assertiveness and restraint that would allow them to contribute to peer review without alienating scientist panel members.

Theme 2: Peer mentoring provides an opportunity to extend advocates' formal training—Advocates who had participated in CARRA training uniformly praised the program, and had relatively few suggestions for how the sessions might be improved. Two advocates who had participated in other peer review programs in addition to CARRA, however, suggested trainees could benefit from peer mentoring. Specifically, based on their experiences in other programs, these interviewees found that opportunities to shadow an experienced advocate provided a useful transition into the program.

Theme 3: Researchers also need training so as to better understand advocates' role—Several interviewees noted that researchers also needed orientation:

> You need to train the researchers how to treat the patient advocates and what to expect and what they'll bring to the table.

Although CARRA provided online resources for researchers interested in learning more about working with advocates, CARRA administrators related that researchers' training often happened informally. For example, scientific review officers were perceived as valuable intermediaries who could facilitate advocates' involvement by introducing the chair and other panel members to their role.

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Programmatic structure

Theme 1: Advocates need ongoing support and a clearly-defined role to effectively manage the burden of participating in peer review—In addition to training, interviewees noted the importance of ongoing supports for advocates as they faced the daunting task of reviewing lengthy grant proposals. For example, advocates appreciated that they could contact CARRA staff members with questions:

> They're always available by phone when it comes to the "fun" part of wading through the mounds and mounds and mounds of paper.

In addition to this ongoing technical assistance, advocates found CARRA's periodic conference calls to be a good way to connect with other advocates and to stay abreast of current issues.

Other supports included tools for conducting the reviews. For example, some advocates found it helpful to have an "assignment," or a list of panel-specific prompts that focused their attention on certain aspects of the proposal, such as the protection of human subjects or the recruitment of under-represented populations. For these interviewees, such supports made the review more manageable by reducing the amount of material to be reviewed.

Interviews with other advocates, however, suggested that defining advocates' role was far from straightforward. While some advocates endorsed a fairly narrow role for themselves as human subjects reviewers, others hoped to speak more broadly about how meaningful the proposed research would be to improving patients' quality of life. These advocates tended to feel an obligation to review the grant more holistically:

> I like to read the entire proposal. They keep telling me that it's not necessary, that I should just read the confidentiality statement and the recruitment statement and that's all I need. I don't believe that's true. I need to see this thing for me.

In this way, interviews with advocates reflected some degree of disagreement about the nature of their role and, in turn, their interpretation of supports to guide that role. Guidelines that were helpful to some seemed to others to risk co-opting or "pigeonholing" advocates' voice.

Theme 2: Advocates' participation should be structured so that their voice is equal to researchers'—Advocates noted several aspects of CARRA's organization that facilitated their role. Of particular importance was their status as voting panel members:

> Your vote [as an advocate] is equal to their vote [as a researcher]. You are just as important to the peer review panel as an MD or a PhD is. That helped me gain quite a bit of confidence in terms of participating in the discussion.

In addition to voting privileges, advocates also appreciated that they were always assigned to be one of several primary reviewers and, therefore, had a formalized opportunity to write and present critiques to the panel. Thus, several aspects of the program's structure were important in helping advocates gain entrée into panel discussions.

Theme 3: Including multiple advocates on each review panel enhances their ability to participate effectively—CARRA advocates typically served on peer review panels in pairs, but some advocates had also served alone. A few noted that this experience was less than ideal:

> I really think there should never be less than two [advocates on a panel] because you need the support. In [another peer review advocacy program], there will be several advocates mixed in with the scientists and that helps.

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In addition to easing the perceived power differential between advocates and scientists, several interviewees noted that having multiple advocates on a panel was useful for introducing a multiplicity of advocacy perspectives.

Theme 4: Matching advocates to opportunities is challenging—When reflecting on whom they wished to represent in peer review, advocates expressed the view that they hoped to speak for all cancer survivors. Nevertheless, some felt that they could make special contributions with regard to the types of cancer and populations they knew best. Several advocates and all of the administrators noted that matching advocates' expertise, interests, and peer review experience to the needs of the panel was difficult. One administrator explained:

> It's really hard to turn somebody into fields in a database that can be searched and used to match [advocates] appropriately [to peer review panels]…. Being an advocate---it's sort of a challenge because the community is so diverse.…. To assess someone's skill set and then determine whether they're a good fit for [a panel] can be very challenging.

Program administrators noted that finding advocates with experience with particularly stigmatized or deadly cancer, such as lung cancer, was especially hard. These interviewees emphasized that ongoing recruitment was crucial for maintaining a diverse volunteer pool and for introducing "new blood" into the program.

Social interaction and networking

Theme 1: Opportunities to engage with researchers informally help advocates establish relationships and legitimacy—As previously noted, many advocates described the social environment of peer review as challenging. Researchers were not only highly trained scientists, but they also shared a language, research interests, and sometimes a history of collaboration that bound them together. Some interviewees reported that social events, such as group dinners or even cab rides, offered a valuable opportunity to connect with researchers outside of the rigid confines of the panel meeting:

> With the [panels] that are two days or three days, generally everybody goes out to dinner, and I think that's so valuable…. It allowed me to relax with people. [Researchers] have a lot to talk about with each other, but we don't. But that loosens up, and some of them are extremely interested in the advocacy work we do.

For advocates, such interactions were important not only for "becoming comfortable with each other," but for helping researchers to understand advocates' backgrounds and, in turn, how they could contribute to the research process. Several advocates observed that panel meetings held via conference call were difficult precisely because the disembodied nature of the conversation reduced the opportunity for personal connection and exchange.

Theme 2: Opportunities for advocates to engage with one another strengthen their practice by broadening their perspectives—Several advocates also noted the value of interacting with one another. Because they aimed to represent the patient perspective most broadly, these advocates found interactions with other CARRA members important for gaining exposure to issues pertinent to other cancer advocacy communities:

> By serving on these different panels, I come in contact with persons who have different specialties as it relates to cancer. Therefore, I'm able to learn a lot more about the needs of cancer survivors, caregivers, and other persons with different forms of cancer other than the one that I may be focusing my attention on.

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In addition to serving on peer review panels together, advocates reported connecting with each other through CARRA conference calls and by arranging “meet-ups” at professional conferences. Table 2 summarizes programmatic recommendations drawn from interviews.

DISCUSSION

The findings of this qualitative study suggest that, given the challenges cancer survivors face as non-scientist participants in peer review, successful programs for patient inclusion require careful attention to training, programmatic structure, and networking. While interviewees emphasized advocates’ informational needs, they were also adamant about preparing advocates for the social environment of peer review through strategies such as peer mentoring and the provision of opportunities for social interaction. These findings support prior research that suggests that patient inclusion, while valuable, is also difficult; lay participants need supports as they learn to navigate the unfamiliar professional culture of peer review [4, 11–13].

CARRA advocates described their experience with the program’s multi-day training in highly positive terms. This finding is encouraging and suggests that CARRA training materials may serve as a useful guide for new programs for patient inclusion. In addition to their initial orientation, interviewees noted the importance of providing ongoing training opportunities via conference calls or meetings. Overall, findings indicate that, to be successful, program planners should expect to devote significant time and resources to the goal of training.

This study suggests that one challenge to planning programs for patient inclusion may be the difficulty in uniformly defining advocates’ role in peer review. Although some CARRA advocates appreciated programmatic efforts to structure their critiques of research proposals, others found these tools to be overly restrictive because they envisioned their role as extending beyond any single section of the proposal. Given different expectations for participation, advocates’ role in peer review is likely a topic that merits ongoing discussion among program administrators and advocates themselves. Although advocates must tailor their role to the needs of the funding organization as well as their own constituencies, recently developed tools to guide patient inclusion in peer review may prove useful by suggesting a more holistic approach to critiquing proposals [14].

The findings of this research should be interpreted in light of several limitations. First, this study privileged the perspectives of CARRA advocates so as to understand the practice of survivor participation in peer review from the standpoint of those who practice it; although CARRA program administrators were interviewed to contextualize advocates’ comments, topics that were discussed only by administrators (e.g., program evaluation), but not by advocates, were not included in this report. Second, the study sample was limited to a relatively small number of participants from a single advocacy program. This approach facilitated an in-depth exploration of a prominent and well-established program that draws from a number of cancer advocacy communities, but findings may be less transferrable to patient inclusion efforts in disease areas other than cancer. Finally, this study was limited to active CARRA advocates; additional insights could no doubt be gained from former advocates, particularly if a lack of perceived programmatic support motivated their departure from the program.

In conclusion, cancer survivors have helped lead the way in developing a role for patient advocates in peer review. As innovative programs have matured and become institutionalized, the time is ripe to assess the benefits and challenges that attend this work. This study aimed to describe programmatic supports for patient inclusion in peer review,

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including those related to training, program structure, and networking. These and other "lessons learned" may help new programs developed by PCORI and other funding organizations as they work to expand the opportunities patients have to shape agendas for health-related research.

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Table 1

Sample characteristics

	n (%)
Sex	
Male	10 (53)
Female	9 (47)
Educational attainment	
High school degree	1 (5)
College degree	0 (0)
Graduate degree	18 (95)
Survivorship status	
Personal cancer diagnosis	11 (58)
Caregiver	8 (42)
Race/ethnicity[a]	
White/Caucasian	12 (63)
Black/African American	4 (21)
Other	2 (11)
Primary cancer advocacy interest	
Breast	5 (26)
Prostate	4 (21)
Blood-related	4 (21)
Other	6 (32)

[a]One participant chose not to specify race/ethnicity.

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Table 2

Summary of programmatic recommendations

Training
• Hold mock reviews during training to allow advocates to apply didactic instruction
• Arrange for newly trained advocates to shadow a more experienced peer mentor
• Host periodic conference calls to provide training updates and opportunities for networking
• Engage the panel chair or other administrators in orienting scientist panel members to advocates' role
Programmatic structure
• Define advocates' role as clearly as possible
• Provide advocates with guidelines for reviewing proposals while avoiding narrow or prescriptive rules
• Give advocates equal voting rights and protected opportunities to speak during panel meetings
• Assign multiple advocates to each panel
Networking and social support
• Organize meals or other opportunities for advocates to interact informally with scientists
• Prioritize face-to-face panel meetings over conference calls
• Hold "meet ups" at conferences or other venues to encourage advocates to interact with each other