Cancer information and support needs of statutory and voluntary sector staff working with people from ethnically diverse communities

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Cancer is difficult for people from ethnically diverse communities to cope with, because there is inequality in getting information and services to meet their needs for prevention, prompt diagnosis, treatment, care and support. Research with black minority ethnic [BME] communities indicates a lack of knowledge about cancer, and a desire for more information, yet research is highly equivocal with regard to health and social care workers’ ability to provide this. The study described in this article aimed to identify the educational and support needs of health and social care workers from statutory and voluntary sectors, working with people affected by cancer in one London borough. Qualitative research methods of one-to-one interview and focus group discussion were used among 33 staff working in various community, organizational and professional settings. Two focus groups were held with cancer patients and carers to gain complementary understanding of their needs for support and information. Health and social care workers are challenged when providing cancer information and support to people from BME communities, even when the worker is of the same cultural background as the person affected by cancer. Interviewees considered that in most respects, the challenges for improving cancer care for people from BME communities are those common for all, and that the difficulty in providing and sustaining improved cancer information and support services to BME communities in their borough lies in poverty, low literacy and social exclusion as much as cultural difference.

Keywords: cancer, information, minority ethnic communities, voluntary and statutory sector.

INTRODUCTION

Research in relation to the black minority ethnic [BME] population is particularly important given the level of ethnic diversity, extent of inequalities and the changing age profile of ethnic communities across London [Acheson Report 1998; Bhui 2002; Coll & Child 2002]. According to the National Health Service Executive, Research and Development Office [2002], almost half of all of the UK’s minority ethnic population live in London. In the London borough in this study, 61% of the approximate 230,000 population are from BME backgrounds [Census ONS 2001], with more than 140 languages spoken. Recently, there has been an influx of asylum seekers to the borough. There are pockets of real deprivation in the borough alongside new up-and-coming areas that have been designated regeneration areas. The borough has a Jarman score of 4.
The unemployment rate is higher than average for the UK, and educational attainment is lower than average.

Reducing the number of cancer deaths and addressing inequalities in health care have been key UK national health priorities since the Health of the Nation targets were set (DoH 1994) and ‘Our Healthier Nation’ was published (DoH 1998). These goals are reinforced in the UK Cancer Plan (DoH 2000) and in local health improvement programme targets. There is accumulated evidence of inequity of access to health services for people in situations of poverty, social exclusion and cultural difference, and considerable unmet needs for cancer information and support for these disadvantaged groups. The prevalence of cancer in the London borough under investigation is higher than the national average and treatment outcomes significantly worse. This is of concern because epidemiological studies show that people from BME populations currently have a lower cancer mortality rate than the majority population in the UK, which may be partly explained by a younger than average age within ethnic minority groups in the UK. However, the mortality rates are expected to increase as the population ages. Breast and lung cancers are the most common cancers among ethnic minority groups, and some BME communities have a higher risk of developing certain cancers, e.g. prostate cancer in Caribbean and West African men and stomach cancer in South East Asians.

With these facts in mind, a 3-year funded local project was initiated to empower people affected by cancer from BME communities by providing them with more information about cancer and knowledge of how to access primary and secondary health care. This empowerment was to be achieved through the development and delivery of a programme that strengthened health and social care workers’ ability to provide information to the local BME community. The first phase of the project involved assessment of local statutory and non-statutory health and social care workers’ cancer information and support needs, first using in-depth interview and focus group methods followed by a wider survey (reported elsewhere). In addition, the needs assessment would determine a focus and direction for subsequent consultation and action with local borough voluntary and statutory sector groups.

BACKGROUND

In the past 30 years, evidence has been accumulating in the general cancer literature that communicating information about cancer not only improves patients’ physiological response to treatment but has a positive effect on patients’ psychological response to their illness (Waitzkin & Stockeckle 1972, Cooper & Watson 1991). Recent studies demonstrate that the majority of patients ask for verification that the disease is cancer and information about: the extensiveness of disease; wider implications of treatment; possible side effects, likely outcomes and physical effects of treatment [Leydon et al. 2000].

Cancer patients generally need more than information, according to Silver and Wortman (1980). They suggest that patients’ ability to find meaning or purpose in the crisis of their cancer illness is very important because it is associated with their ability to adjust to it. Although physical manifestations of cancer illness are the greatest overall source of distress to patients, these correlate closely with their expressions of loss of meaning and social isolation. People need to see their lives as existentially meaningful, and cancer patients seem to have a strong need to interact with others about what life means for them and how they want to go about the task of living with their illness.

Despite the large volume of research in the general cancer population that advocates giving information to people with cancer, an equal amount indicates the apparent inability or reluctance of health and social care workers to do that. Studies identify workers’ self-doubt about exploring emotional issues and giving information to people who have cancer because they worry that they may be asked difficult or awkward questions that they cannot answer [Maguire et al. 1995]. Instead, workers rely on routinized forms of communication, perhaps in anticipation of stereotyped negative reactions from people with cancer [Rogers & Todd 2000]. In doing so, they fail to recognize the seminal work of Glaser and Strauss (1965), who found not only that patients can be helped to make a satisfactory adjustment over time, but that those who sought information – good or bad – were more hopeful than those who wanted little, or only positive, information.

Another important body of work on the nature of cancer information giving and support concerns the troubling reality that despite workers’ best efforts to impart information, e.g. an initial diagnosis, uncertainty often exists about what has been said to whom and when. There is a ‘conspiracy of silence’ surrounding potentially difficult and emotional discussions of poor prognosis and death according to Glaser and Strauss. Their research is very helpful in explaining avoidance processes on the part of health and social care workers as well as cancer patients and their families. It conveys something of the fluctuating grasp of information demonstrated by cancer patients and the difficult often ‘defended’ nature of communications. Glaser and Strauss also recognize that a patient may ask a voluntary sector or social care worker questions he/she would not ask a doctor because it is easier to disbelieve
them if they tell him/her facts that he/she is not prepared to accept.

While these areas of research are all highly relevant to cancer in ethnically diverse communities and so to this study, empirical work exploring cancer and the specific needs and issues for BME communities is limited (Lodge 2001). The few studies that have been undertaken demonstrate that both new and established BME communities require additional support to access primary and secondary health care appropriately (Hoare 1996; Gerrish 1999), and manage their cancer illness effectively.

In order to meet the information needs of cancer patients from black and ethnic minorities, health and social care workers have to know how much and what kind of information patients want (Murphy & Macleod Clarke 1993). A needs assessment of South Asian cancer patients and their carers to establish this (National Cancer Alliance 2002) showed that patients and carers from this community gave highest priority to relevant and clear information from their healthcare team, combined with other information resources, which supplement knowledge of their disease, its treatments and side effects.

A study to assess the efficacy of bilingual health advocacy for cancer patients from ethnic minorities found that there are measurable benefits from providing tailored information and support to meet local community needs (Thomas et al. 2000). Evidence from Rawaf (1996) and the National Cancer Alliance (2002) highlights the important role that health and social care workers in both the statutory and non-statutory sectors have in facilitating communication about the meaning of cancer with people from ethnically diverse communities, the impact the cancer may have on their life and the way they wish to live this.

Aims of the needs assessment

The research aimed to contribute to the BME cancer literature by identifying the:

- educational and support needs of statutory and voluntary health and social care workers involved in meeting the cancer information needs of BME communities living in a multiracial London borough; and
- cancer information and support needs of people from BME communities living in a multiracial London borough.

Ethics

The research project was approved by the local research ethics committee. Participants consented in writing to take part in either the one-to-one interview or the focus group element of the study. Prior to signing the consent form, participants were either posted or given an information sheet about the study and their participation. The information sheets were not translated, but interpreters were on hand to give verbal explanation if needed. Permission was sought from all participants to tape-record the interviews, and this was granted in all but one case. Anonymity was ensured in that no data collection forms identified the respondents by name and individuals were not identifiable by name on tape recordings.

METHODS

Methodology was shaped by an emphasis on the social nature of information and support needs, which must be contextualized in relation to different provider settings and the context of patients' wider lives, most notably their relationships with their family and friends, and their social and material circumstances. What then qualified as need in the project was:

- what, from the point of view of service providers, would make it easier for them to meet the information needs of those affected with cancer; and
- what, from the point of view of patients, would make it easier for them to make decisions and live with the personal and social consequences of their cancer.

Ong and Humphris (1994) argue that the expertise held by users and communities has to be an integral part of needs assessment. Consequently, methods used in this study included: semi-structured one-to-one interviews with statutory and voluntary sector healthcare workers from across the borough, and focus group interviews with people with cancer and their carers.

Semi-structured interviews

Comprehensive borough lists of general practices, voluntary and statutory sector organizations involved with the BME community, and Acute and Primary Care Trust staff were consulted to identify the interview sample. Individuals were purposively selected to represent workers from a range of contexts (Table 1). Interviews lasted 30–60 min and took place in a private room at the health and social care workers' place of work. The interviews enabled exploration of the meanings that participants ascribe to cancer and their subsequent information giving and supportive behaviours (Table 2, interview schedule). Participants were given information sheets outlining the nature and purpose of the research,
and if interested in participating, were required to sign a consent form. The interview questions varied slightly, depending on the role of the interviewee. The recordings were systematically analysed for content through repeated listening, and categories and themes were identified.

Focus groups

Two focus group discussions were undertaken with users and carers from Asian communities accessed through trusted voluntary sector channels. The purpose of the focus groups was to gain a complementary understanding of information and support needs. The first group involved six women who had been living with their cancer for between 18 months and 20 years. The women spoke either Urdu, Hindi or Punjabi. In the second group, there were three carers, two men and one woman, plus one woman with cancer. Gujarati was spoken in common by these participants. Discussions lasted 2–2.5 h and took place in the familiar surroundings of a local community centre. The groups were led by the principal researcher who worked with a translator. Participants were asked in their mother tongue to share their thoughts on their cancer information and support needs and ways in which these could best be met. Immediately after the meeting, field notes were completed after a detailed debriefing with the translator. Categories and themes were derived from systematic analytic engagement with these data as recommended by Bowling (1997).

RESULTS

This article draws selectively from interviews with the health and social care workers and from the focus group discussions. Findings are presented under four main section headings:

- cancer information, educational and support needs of workers;
- what constitutes good practice in meeting cancer information and support needs – users’ views;
- perceptions of current services – users and providers; and
- contributing factors and ascribed meanings.

Cancer information, educational and support needs of workers

The contexts in which the health and social care workers operate are challenging, characterized by organizational instability, variable management support, resource limitations and financial insecurity. For example, within the time frame of the needs assessment, a significant voluntary sector provider of cancer support and information was informed that its funding would end. The role of voluntary sector agencies often varied, but they were generally time pressured, stressful, potentially insecure and characterized by a diversity of problems; for example, a Somalian agency was single-handed. Health and social care workers expressed distress in relation to their work circumstances.

A voluntary sector worker said:

It is very sad sometimes talking with these (cancer) families. What can we do? They come here tomorrow and you would see we do not have enough chairs!

<table>
<thead>
<tr>
<th>Table 1. Health and social care workers interviewed</th>
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<tbody>
<tr>
<td>Job title</td>
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<tr>
<td>Project Officer (housing/services to Asians)</td>
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<tr>
<td>Counsellor (BME with cancer and carers)</td>
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<tr>
<td>Chief Executive (Asian elders and carers)</td>
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<td>Project/Link Worker (health and social needs under 18s)</td>
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<tr>
<td>Cancer Awareness Project Leader (Social Action for Health)</td>
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<tr>
<td>Care Group Coordinator (Asian elders)</td>
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<tr>
<td>Director (services to Hindu community)</td>
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<tr>
<td>After School Club Leader (Asian and African-Caribbean Agency)</td>
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<tr>
<td>Director (BME Language Services and training)</td>
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<td>Training Officer (Asian Women’s Agency)</td>
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<tr>
<td>Health Advocate (Somalian Agency)</td>
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<tr>
<td>Physiotherapist</td>
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<tr>
<td>Occupational Therapist</td>
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<tr>
<td>Clinical Nurse Specialist, Breast Care</td>
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<tr>
<td>Chemotherapy Outpatient Nurse</td>
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<tr>
<td>Cancer Nurse</td>
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<tr>
<td>Health Advocates (general; cancer focused)</td>
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<tr>
<td>Clinical Oncologist</td>
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<tr>
<td>Consultant Surgean</td>
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<tr>
<td>Consultant Physician</td>
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<tr>
<td>Out Patient Services Nurse</td>
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<tr>
<td>General Practitioners (including one serving on Primary Care Trust Executive)</td>
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<tr>
<td>District Nurse</td>
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<tr>
<td>Health Promotion Officer</td>
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<tr>
<td>Practice Nurse</td>
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<tr>
<td>Social Worker</td>
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<tr>
<td>Health Visitor</td>
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<tr>
<td>Community Care Assessment Team Leader</td>
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<td>Imam</td>
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<tr>
<td>Clinical Nurse Specialist, Palliative Care</td>
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<td>Health and social care workers and community nurses.</td>
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The research identified staff providing valuable services, building relations across the healthcare community, and finding inventive ways to address the under-resourcing of their services. For example, one registered charity project established to meet the needs of Asian elders and carers has an impressive record of development work in health, including: drama workshops and talks to raise awareness about breast cancer, and an Asian men’s group, which meets to explore cancer risk and to talk about prostate cancer.

Non-statutory workers and some statutory social care workers considered their main role in relation to cancer information and support was to be accessible, providing information and enabling people to access statutory services. They reported that the issues raised by people affected by cancer from BME communities are a combination of: information needs; personal questions; concerns; anxieties; social situation; problems of service users; and service breakdowns and inefficiencies. These main areas of information and support needs were born out by the patients and carers in the focus group discussions. Below each area of information needs and support is illustrated with an example from the focus group data:

### Information needs

I will have chemotherapy but I do not understand how the drugs they give will help me.

### Personal questions

I have never smoked, how can I have cancer now?

### Concerns

Is it time? Should I ask my relatives to come from Pakistan?

### Anxieties

My daughter does not take part in the family now; I do not want to tell her about my cancer but I know I am sick.

### Social situation

All of my family are unemployed but we need money; we need to buy thick pads to deal with any leaks . . .

### Problems of service users

They said they would send a social worker but my husband will not let that person in the house.

### Service breakdowns and inefficiencies

My GP did not listen when I told him about my pain; he sent me away but a year later they said I had cancer.

Finding answers to these questions and solutions to service inefficiencies means that health and social care workers primarily function to make the existing health and cancer information systems and procedures work better. Face-to-face talk with a person diagnosed with cancer and his/her family is seen as central to this. As one voluntary sector worker said:

The situation can be so tragic you want face to face contact with someone who is going to answer your questions not just once but repeatedly.
In addition, it was clear from interviews with health and social care workers that many perceived cancer to be a fatal illness, a ‘taboo’ that should not be discussed with BME people and they themselves held negative views of cancer and its treatment:

Nothing is going to be all right once you have cancer. That’s it. At the end of the day they are going to die. Maybe their life is prolonged for a few months or a year. But I have never come across a single person who had cancer and survived.

What constitutes good practice in meeting cancer information and support needs – users’ views

In interactions with service providers, patients and their families valued: being treated in a way that was respectful and equal; readily available advice; provision of information about necessary tests and how to manage the side effects of subsequent treatment without having to ask; and healthcare professionals who were judged to be respectful, kind and considerate and willing to answer questions. One patient described a doctor who took particular account of her situation by fitting her chemotherapy treatment around a long trip to India:

I was to and fro travelling backwards and forwards and I told him I had to go home. He said that is important you know and I felt he understood. He said we needed to reach an understanding as to when I would be back so I could have my treatment.

Patients who took part in the focus group discussions clearly stated that they were not aware of services in the community that were relevant to their specific needs. Others stated that they had only found out about services if they had asked. One carer indicated that:

We had to ask about services, but it is difficult. You find out almost when it is too late because you do not know what to ask for. It would be better if doctors and nurses could anticipate what you want. Instead we always had to go and tell them if we had a problem.

Perceptions of current services – users and providers

The role of the general practitioner as gatekeeper to other professional services was perceived to be problematic by some ethnic minority patient and health and social care worker informants, particularly if the doctor was of the same culture and perhaps linked within their community to their families. This led to a lack of trust, and a fear of loss of confidentiality, as they believed that the doctor was likely to disclose personal information to their families. The worry about leakage of a cancer diagnosis within an individual’s community extended to contact with other health and social care agencies. As one patient said:

If outsiders are involved then what is being discussed could leak out and not be good for our family.

Individuals in the focus groups talked about the role of friends, relatives and voluntary sector agencies in informally giving support and advice, particularly when they first suspect they have cancer. Consistently, general practitioners were not identified as effective gateways to receiving professional help. Instead, patients and their carers said that their doctor often failed to listen to their concerns about cancer, failed to take them seriously and were discouraging. The general practitioners themselves recognized shortcomings in their services, as did their medical colleagues:

Ethnic minorities are not well served by a lot of primary care services. They do their best for their patients but we have a long way to go to get people diagnosed early. We have got to start right back at the beginning. If people do not walk through the door because they do not think it is worth doing, then we have already lost the battle. (Acute statutory sector worker)

Contributing factors and ascribed meanings

A central issue for people from BME backgrounds affected by cancer is that there were sometimes few avenues to talk about the distress of the cancer diagnosis within the family. In some cases, there was no common vocabulary between generations with which to properly articulate and discuss concerns. In addition, there was some stigma associated with taking problems outside the family, which has led to the characterization of women being emotionally unsupported in their cancer illness or carer role:

In my experience many people from ethnic minority backgrounds want to talk about it [the cancer]. But sometimes the men try to keep the women ignorant and don’t want the other family members involved; they want to be the decision makers. (Voluntary sector worker)

Service providers recognize that there is a lack of understanding of available services and sometimes few avenues to talk about the distress of cancer within the family. One general practitioner said:
The biggest problem for members of ethnic minorities is they may not understand how the health service works; what is available. They may get services at the last minute particularly because people [service providers] are very stretched and lack resources.

The majority of health and social care workers shared this view. Another general practitioner conceptualized the underlying problem slightly differently:

People exaggerate the importance of religious and cultural belief. What is important is that you are treated equally and get access to a full range of services. It’s a class thing. It’s about poverty, education and knowing the service.

This doctor’s perception reflects a consistent finding from this study that the barriers to reshaping and improving cancer information and support services for people from ethnically diverse communities lie in poverty, low levels of educational attainment and social exclusion as much as culturally diverse values.

Study limitations

The sampling technique used to recruit participants was purposive rather than random, and in particular, relied upon trusted voluntary sector channels to identify patients and carers. Respondent bias is likely with this method of sampling and participants who were known by local voluntary sector community groups perhaps more likely to be proactive in seeking information and support. In addition, some of the voluntary sector workers were recruited from community groups and organizations known to be active in the provision of information and support to people affected by cancer. The sampling technique used was a pragmatic response to the limited time allocated for the needs assessment element of the overall 3-year project.

DISCUSSION

Health and social care workers in this study experienced a range of contextual pressures and the emotional load of individual encounters with people with cancer combine to encourage a ‘sticking plaster’ approach to the issue of cancer information and support to BME communities. A focus on presenting problems, in the context of under-resourced services and in situations of poverty and social exclusion, is not surprising. However, this focus inhibits development of substantive plans, leading to wider organizational and attitudinal changes. Compounding the problem are: a lack of targeted jargon-free cancer information in different languages; inaccessible gateways to services; poor knowledge of cancer services among health and social care workers; and a general lack of awareness of available cancer information and language-specific materials, including information books, videos and websites.

Tucker and Edmondson (2003) distinguish between first-order problem solving (finding a patch or fix) and second-order problem solving (addressing underlying causes). They argue that workload pressures and an individual patient-focused culture combine to encourage first-order problem solving, which may be gratifying for staff and patients but detracts from the need to address organizational system issues, which are more time consuming and seemingly intractable. Health and social care workers in this London borough appear to work in a similar context, facing a range of pressures, that leave them feeling powerless and inhibit them from forming partnerships to develop substantive cancer information and support programmes across the borough. Integrated working practices across localities and healthcare communities are crucial in combating the sense of powerlessness expressed by health and social care workers in this research if headway is to be made to improve cancer information and support to people from different ethnic and cultural backgrounds.

Cultural diversity learning programmes are an important part of substantive plans to enhance health and social care workers’ skill and confidence to provide information and support that is appropriate to people from different ethnic and cultural backgrounds. However, attention needs to be given within them to the exploration of different models of partnership working across the health and social care divide and between statutory and non-statutory agencies. In this case, training should be multiagency, multiethnic and multidisciplinary. Thomas and Dines (1994) indicate that programmes should include ways that health and social care workers can: be involved in health promotion activities for low-income groups; develop confidence to raise the topic of cancer and discuss it regardless of whether it is perceived to be a ‘taboo’ subject or not; and learn how to talk to people with cancer from ethnic minorities when their family members are present.

CONCLUSIONS

Despite widespread recognition that people from ethnic minority communities require additional support to be able to access primary and secondary cancer care appropriately to manage their cancer illness and maintain their
quality of life, evidence from this study confirms that they often face enormous difficulties in doing so. This research also indicates that health and social care workers working with BME communities in one London borough have significant unmet education needs to provide effective cancer information and support.

Practical and emotional support is especially important, given the generally held belief among health and social care workers.

This research demonstrates that emotional as well as practical support for health and social care workers themselves is particularly important, given the generally held belief that the root of the difficulty in providing information and support to people from ethnically diverse communities lies not in ethnic diversity but in poverty, social exclusion and low literacy.

Although this research was undertaken in one London borough, the findings have wider application to healthcare professionals working outside the UK capital and in other countries. Partnership working as part of substantive plans harnessing local effort and enthusing workers will be important if significant improvements are to be made in providing cancer information to ethnically diverse communities.

ACKNOWLEDGEMENTS

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