

## RESEARCH ARTICLE

# Challenges in Volunteering from Cancer Care Volunteers Perspectives

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### Abstract

The involvement of non-government organizations (NGOs) and support groups has helped strengthen public health services in addressing cancer care burden. Owing to the contribution of volunteers in cancer care, this article documents a qualitative study that examined challenges in attracting and retaining cancer care volunteers as part of the effort to develop a volunteer recruitment model. Data were collected through three focus group discussions involving 19 cancer support group members in Malaysia. Findings of the study revealed that mobility and locality appeared to be significant in Malaysian context, while the need for financial support and time flexibility are challenges faced by cancer support groups to attract and retain volunteers. The findings imply that cancer care initiatives can benefit from more local volunteers but at the same time these volunteers require flexibility and financial support to sustain their engagement.

**Keywords:** Volunteerism - cancer care volunteer - support group - Malaysia

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### Introduction

Cancer is a major killer disease worldwide. According to American Cancer Society, about 1,660,290 cancer cases are expected to be diagnosed in 2013 (American Cancer Society, 2013). In Peninsular Malaysia, the National Cancer Registry registered 21,773 cancer cases diagnosed in year 2006 comprising of 9,974 males and 11,799 female patients. The cancer burden can be reduced through collaborations and mobilization of resources between health services, patient groups and community organized by cancer control programs (Stewart and Kleihues, 2003). Cancer patients need support from family, friends and the community. Thus, volunteers are needed to form cancer-related support groups and non-governmental organizations (NGOs) to join governmental health services in alleviating the cancer burden in Malaysia. A concerted effort between the government, private sector, NGOs and the community is important to reduce cancer case burden and to enhance cancer patients' and cancer survivors' quality of life. Volunteerism is an important component to empower and optimize community participation as organized by the National Cancer Control Program (Lim, 2002). Despite of demands for cancer care volunteers, the level of participation of Malaysian in volunteerism is still low (Azizan, 1993). Cancer care volunteers in this research are those people who helped and cared people with cancer without pay and involved actively in cancer organizations or support groups.

This scenario leads to the question of what are the challenges in attracting and retaining cancer care volunteers. Previous literatures stated that the challenges for people to involve in voluntary work were time and financial constraints (Terry, 2005; Lee et al., 2007). However an empirical investigation is necessary to ensure whether or not such claim is applicable in the cancer-care volunteerism context. In addition to that, most of the documented studies were conducted in the western, developed country. Very limited studies have aimed to study cancer-care voluntarism issues encountered in developing country. Thus, this study was designed to address the challenges of attracting and retaining cancer care volunteers in Malaysia. It is believed that the findings will serve as important inputs to attract and retain more cancer care volunteers.

Gender, marital status and education are among the demographic variables that have been identified as indicators of inclination towards volunteerism. Women are found to be more likely to engage in voluntary work (Lindenmeir, 2008) and more dependable as compared to their male counterparts (Zweigenhattm et al., 1996). Previous studies indicated that those married and having partners, compared to single individuals, were likely to feel rushed and have lesser time to spare for other work such as volunteerism (Warburton and Crosier, 2001; Claxton-Oldfield et al., 2011). Past studies stated that volunteering generally increases with educational attainment where those with higher levels of formal education are more

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likely to volunteer than others and may contribute more hours in volunteering (Hall et al., 2009; Claxton-Oldfield et al., 2011; Wilson and Newman, 2011). Interestingly, they also found that those employed were most likely to volunteer compared to those who were unemployed.

Volunteer work is a noble job. However, not many people want to participate as volunteers. According to Azizan (1993), many volunteer societies have articulated their concerns about the lack of volunteers. Such scenario and previous studies have been able to identify several challenges in voluntarism such as time, financial and mobility constraints (Terry, 2005; Lee et al., 2007; Barbara et al., 2011; Willems et al., 2012 ) as well as issues of limited infrastructure and resources, which will be discussed more thoroughly on the following review of literature.

Many studies have reported time constraint as one of the primary factors that hindered volunteer recruitment and retention. Reports based on findings of Volunteering Strategy Workshops ran by The Voluntary and Community Unit in the Department for Social with the Volunteer Development Agency in early 2007, focused on views and experiences of volunteers and stakeholders to help inform the development of new Volunteering Strategy for Northern Ireland (NI). Reports of the findings gave a comprehensive insight into volunteering from the perspective of individuals and organizations. Volunteers and voluntary organizations were from Newry, Londonderry, Belfast and Cookstown. A written submission was also provided by Northern Ireland Association for the Care and Resettlement of Offenders (NIACRO). According to the report, time management has become one of the barriers to volunteers because people are not aware of short- term volunteering opportunities. They feel that volunteering is a life time commitment. Time constraint is related to volunteers' obligation and commitment towards their work and family. In their study, Stephen and Jane (2012) found that major reasons for people not volunteering were family obligation and work commitment. A research by Cleave and Doherty (2005) indicated that time-factor and scheduling related to the juggling of work-family conflicts influenced both active volunteers and non-active volunteers. Both active volunteers and non-active volunteers referred to time constraint as a barrier in their volunteerism participation. Moreover, Lee et al. (2007) reported that people who are working full time demonstrated high probability for not participating in volunteer activities.

Schedule flexibility is one of the important factors that influence participatory decisions. Some volunteers may have the time to spend for voluntary work but some others may not. Volunteers generally need to fit their working time with the needs of the organizations and when their schedules are determined by the organizations, it leads to lower job satisfaction (O'Driscoll et al., 1992; Browne, 1997; Fitzsimmons and Fitzsimmons, 2003). One of the key factors that attracts and enables volunteerism participation is schedule flexibility. It means that volunteers get to decide when they can volunteer and how much time they will volunteer; the schedule suitability that allows volunteers to manage their own time usually

helps to build up the satisfaction in themselves (Wisner et al., 2005). In short, if the volunteer experience is non-satisfactory, there is a tendency for them to exit from such experience. If they feel satisfied with what they have experienced, they would be more loyal and remain as volunteers.

A report by Hager and Brudney (2004) indicated that one of the common challenges in managing volunteers is the lack of funds to support volunteer administration. Barbara et al. (2011) also stated that the issues in volunteerism included lack of adequate financial resources to support volunteer involvement. Meanwhile, previous studies emphasized that in social trends of volunteering; the issue of mobility is becoming more common among volunteers (Allen, 2000; Barbara et al., 2011). In addition, the Volunteering Code of Good Practice (2009) and a report of the Volunteering Strategy Workshops (2007) stressed that, the constraints that volunteers may face are those related to restrictive transportation and cost. Volunteering Code of Good Practice has been developed by the Cambridgeshire Compact Group that seeks to, "i) set out the key principles that underpin volunteering activities, ii) understand the scope and potential of volunteering, iii) identify barriers that prohibit volunteering, iv) set out good practice that reduces barriers and thereby encourages more people to volunteer". The Cambridgeshire Compact Group aims "to developing, promoting and celebrating volunteering as an expression of both active citizenship and the basic human rights of freedom to assemble and associate".

Locality or spacing for doing activities is part of the barriers in volunteerism. Volunteering Strategy Workshops (2007) reported that the lack of infrastructure within the organization and lack of resources may limit individuals from becoming volunteers. It may also contribute to the problem of retaining existing volunteers. Another workshop carried out in Volunteering Code of Good Practice (2009) also emphasized on the issue of locality. It was stated that locality or spacing for doing activities is an important part in volunteerism. Hence, inadequate space or comfortable facilities may hinder volunteers from enjoyment in their activities. It would also disturb their effort to plan appropriate activities for fund raising.

## Materials and Methods

Data for this qualitative study were collected via three focus group discussions involving a total of 19 informants (respondents) from cancer support and NGOs in the south, north and middle Klang Valley, Peninsular Malaysia. The qualitative research strategy was employed to obtain richer and subjective perspectives on the challenges in recruitment and retention of volunteers. In the qualitative study, the researchers played the role as instruments in both data collection and analysis. Besides, an interactive with the research context, sensitive to non-verbal aspect during the focus group discussions and continuously processed and analyzed the data until the end of the research process (Guba and Lincoln, 1981).

For this particular study, the informants were selected based on two criteria. The first is active voluntary

participation in cancer support group or associations. The second criterion is the participant's ability to converse in either Malay or English language. Informants were given individual consent form but no formal approval was obtained from the university or the organizations as the research did not involve patients or employees of the university or organizations. Informants were given a form to complete with details on their personal background and basic voluntary activities. Questions involving basic voluntary activities are; *i*) Whether any closed family also involved in volunteerism; *ii*) who encourage them to volunteer; and *iii*) what are their status while getting involved in voluntary work. The focus group discussion was recorded on digital recorders. The use of the digital recorders has also facilitated the researcher's work in managing and transcribing the data into verbatim transcripts. Each focus group discussion is guided by interview guide. The guide helped the discussion to stay focused on the study objectives. The study result was reported in descriptive manner based on analysis of transcribed wordings from subjects.

Data analysis was conducted simultaneously during the data collection process guided by the constant comparative method (Glaser, 1978). The data was saturated by the third focus group discussion. The transcripts were viewed and read not less than two times. Categories were formed according to the identified data recurring patterns. Different codes were then designated to different categories. The data were analyzed for clues and categorized according to the identified themes (Merriam, 2009). The coding process was carried out at two levels. During the first level, the theme on challenges in volunteerism recruitment and retention was generated. Subthemes such as time constraint were then constructed at the second level of coding. Subsequently, all the recurring phrases or sentences which indicated identified themes and sub-themes from the verbatim transcripts were underlined and marked with stickers labelled with themes' and sub-themes' numbers. All the data were labelled and saved into a Microsoft word file named 'themes and sub-themes'.

#### Ethical considerations

All informant received a copy of participation information sheet which provided details of what was required of the, that participation was voluntary and that all data would be treated confidentially. The information sheet also confirmed that ethical approval was gained from University Putra Malaysia. The information was available in English and Malay and included the contact details of researcher. The study protocol was approved by the Medical Research Ethics Committee of Faculty of Medicine and Health Sciences, Universiti Putra Malaysia.

## Results

A total of 19 informants participated in the focus group discussions. Most of the participants were women (84.21%). Their age ranged from 50 to 59 years old. Most of them were married (78.95%), 15.79% single and 5.26% widowed. Majority informants were Chinese (57.89%),

while 36.84% were Malays and 5.26% Indians (Appendix 1).

In carrying out the voluntary work, an individual may face challenges which may stop or sustain her or his volunteers. The issues were: *i*) time, *ii*) financial, *iii*) mobility constraints and; *iv*) infrastructure and resources.

#### Time

These study findings are in line of past researches that identified time constraint as a factor that limits the number of volunteers' recruitment and retention. Due to family constraints, volunteers had limited time for voluntary activities and those with extended family need more time to focus on them. Majority of the volunteers were of middle and late age. At this age, they are preoccupied with their own grandchildren. One of the volunteers commented that although she likes to help others, her intention to actively join any groups is curbed by time constraint: *I like it.....because I have a personality like that... energetic, love to help others. But I do not like to get involved in any group. That's because I have limited time. It is difficult for me to join any group* (G205, Female, 50s).

Several other volunteers also highlighted time as a hindering factor for them to be more active in volunteering since they are working. Majority of the volunteers were busy with their own working life which need their full commitment and attention. An informant reports;

*After the dinner event [organization dinner], I am so busy. I did not come to report. Early this year, I started to meet them again. So, I miss many activities because I have many things to do. I just cannot make it...* (G302, Female, 30s).

#### Financial

Financial was another challenge that limit the volunteer participation. Informants comment that with more funding, more can be done to help cancer patients. Furthermore, retired or jobless volunteers will no or less income, limit their participation. A retired informant reported that she did not have money to get involved in voluntary work: *Every time I comes I takes taxi, RM15, so how many times I can come a week, right? One time is fifteen dollar, what about going back...?* (G201, Female, 50s).

#### Mobility

In cancer care, majority of the women volunteers do not have the transport facilities. Thus mobility constraints affect volunteers from joining the activities or events. Some volunteers did not have any transportation to go to the centre or places where activities event were held. It also makes it difficult for them to move around to give support to cancer patients who were in need. One of them illustrated the limited chances for volunteers to participate in activities due to transportation issue: *Last month, we have Workshop A at KL. They did it twice. One in mid February and the other on February, 28<sup>th</sup>. We have volunteers in both workshops, and all the survivors came to KL. We provide one car to go to KL. The transportation is all given to survivors because they are the priority. But, if any volunteer want to go, they have to arrange*

**Table 1. Background of the Informants**

| ID   | Gender | Age | Ethnic  | Marital Status | Working     |
|------|--------|-----|---------|----------------|-------------|
| G101 | Female | 70s | Chinese | Married        | Working     |
| G102 | Female | 60s | Chinese | Married        | Working     |
| G103 | Female | 50s | Malay   | Married        | Working     |
| G104 | Female | 50s | Malay   | Married        | Working     |
| G105 | Female | 50s | Malay   | Married        | Not working |
| G106 | Female | 60s | Chinese | Married        | Not working |
| G107 | Female | 60s | Chinese | Married        | Working     |
| G108 | Female | 60s | Chinese | Single         | Working     |
| G109 | Male   | 60s | Chinese | Married        | Pension     |
| G201 | Female | 50s | Chinese | Married        | Pension     |
| G202 | Female | 50s | Chinese | Married        | Working     |
| G203 | Female | 40s | Malay   | Married        | Working     |
| G204 | Female | 30s | Malay   | Single         | Working     |
| G205 | Female | 50s | Malay   | Married        | Working     |
| G206 | Female | 50s | Chinese | Married        | Working     |
| G207 | Male   | 40s | Indian  | Married        | Working     |
| G301 | Female | 40s | Chinese | Single         | Working     |
| G302 | Female | 30s | Malay   | Divorced       | Working     |
| G303 | Male   | 60s | Chinese | Married        | Pension     |

themselves and no transport is provided. Free transports are for the survivors. Only, if there are extra spaces, then volunteer can go (G302, Female, 30s).

Usually, people at late ages are jobless, have no income and transportation and difficult for them to move around and actively involved as volunteers. Another volunteer seconded the statement: "...last time, I have to be a passenger with A, B right...Then, if not, she need to take bus" (G103, Female, 60s).

#### Infrastructure and resources

Others challenges that volunteers face during voluntary work are locality and infrastructure. Both play important roles to provide suitable and comfortable place for volunteers to run their activities. Non-government organizations (NGOs) on cancer is not well. Lots of comments by the informants were made about not having enough space, facilities, and proper place to run their activities. One woman said "Yes, there are quarters, but they are all full..."

Another comments that, "It is hard. We can give our time but without a proper place to organize our meeting that can used to convene and share with my friends every week, it is difficult" (G206, Female, 50s)

Volunteers do not only have problems with their own limited time but also have no proper place to run their voluntary activities. The volunteers voiced their difficulty in getting approval to use the facilities from the hospitals authority to run their activities.

For example: "At Hospital A, the biggest problem is that of space. The constraint is to get a place or space to organize activities. To conduct any activities, it takes time to get green light (permission)..." (G203, Female, 40s)

Another volunteer emphasized the importance of appropriate centres for their volunteerism activities: "Yes. And place to actually meet. Here, the mammogram and all treatment are free because this is a teaching hospital. Where can you get such facilities...So, must start more centres like that in the hospital, in the university." (G301, Female, 40s).

## Discussion

This finding is congruent with a previous study indicated that women's higher inclination towards voluntary work than men (Lindenmeir, 2008). According to Zweigenhatt, Aimstrong and Quitis (1996), women are usually more dependable volunteers than men. The study showed that almost 60% were Chinese contradicting previous literature that emphasized the insignificant affect of ethnicity onto helping behaviour (Marrow- Howell et al., 1990). Even though a previous research indicated that those married and having partners were likely to have lesser time to spare for other work (Warburton and Crosier, 2001; Claxton-Oldfield et al., 2011), findings of this study showed that majority informants are married (78.95%), with their average age being 55 years old. This may be explained by their middle age's phase of life which is marked with lesser responsibilities in handling dependent, young children. It was also found that most volunteers have received at least secondary education certification (52.63%).

Findings revealed that volunteers have limited time for volunteering due to other commitments such as family and career. It was supported by Mjelde-Mossey et al. (2001) that family and career commitments are the major reasons for volunteer not doing voluntary work. The findings of this research also supported previous literatures on financial constraint as a deterrence for an organization or support group to plan activities and program that could attract and retain more volunteers (Hager and Brudney, 2004; Terry, 2005). Challenges such as mobility and lack of resources have also a negative impact on volunteer involvement. Having own space and centres of activities for the volunteers would provide them the sense of freedom to conduct their own activities as well as the comfort to socialize and interact with each other. However, there are many cases where organizations could not provide adequate and, suitable place and facilities for volunteers to conduct their activities. The lack of space or equipments restricted and demotivated the volunteers continuous involvement.

Mobility impact the volunteers involvement. Volunteers need transportation. The public transportations are inadequate. Most volunteers are middle age young women, who need someone especially male counterpart to drive them to run the activities. The number of men in voluntary works are small, as in the study only 15.78%. The constraints affect woman volunteers' mobility. Without vehicle or support from others, their involvement in volunteering will be restricted. Such restricted movements would definitely affect their sense of empowerment as well.

The volunteers involved are mostly working with limited time left. On the other hand, those volunteers who have retired spent their retirement time with their family and grandchildren. Time constraints is the most consistent reason given for nonparticipation in many studies (Martindale and Drake, 1989). Past literature also show that beside time, financial constrains, lack of comfortable space, infrastructures and other resources as challenges or deterrents that hindered volunteers from being more active

in conducting their activities (Hager and Brudney, 2004; Terry, 2005; Volunteering Strategy Workshops, 2007; Volunteering Code of Good Practice, 2009).

In conclusion, challenges come in various forms for volunteers to help others. Mobility has been found to be the unique challenge that affects volunteers' involvement. This shows the need for volunteers to organize and manage their mobility in voluntary work. To help this, it needs to recruit more volunteer among male gender who can ease transport and driving problems. The other challenges that influences volunteers' involvement is the time constraint. It shows the need for volunteers to manage their time wisely since they need to manage their family, career commitments and voluntary work all at the same time. Apart from these challenges, financial and locality aspects have also been identified as crucial issues in recruiting and retaining more volunteers. And last but not the least, this study has also identified middle-age women with no or lesser dependent children as those who were most likely to turn up as volunteers.

Based on these findings, several recommendations are proposed. One is to identify different tasks for different categories of volunteers. For example, volunteers with tight family or work commitments may help with tasks and skills that do not really need them to be at the centres. In the contemporary era of technology, some of the volunteers could actually communicate or contribute virtually. This would include virtual meetings in the process of organizing events, online help for cancer patients, fund raising activities through e-business and so on. Meanwhile those volunteers that have more flexibility in their time arrangement could be involved in activities that require them to be more mobile such as visiting cancer patients at the hospitals, conducting recreational activities for cancer survivors at the centres, or putting exhibitions of cancer awareness at public premises. Besides that, it would also be useful for the voluntary organizations to promote effective time-management skills among their volunteers. Support group can be more active in establishing affiliations with other governmental and private agencies in the effort to raise more funds to build better activity centres. More funds and better locality would make it possible for more conducive environment and better activities or program to attract and retain more volunteers.

As more middle-age women with no or few independent children were identified to have more tendencies in volunteerism, voluntary organizations as well as support groups are recommended to focus in drawing these women to participate in their activities. This could be done by word of mouth, peer influence, and set-up booths for registration in shopping complexes. Most important of all, prospective volunteers are made to understand the purpose of the voluntary organizations and given clear explanations on the activities that they might be interested to join.

The implications of the study could be divided into three aspects which are institutional-financial, personal-financial and mobility, time and spacing and locality. The implications for institutional and financial aspects are more support for home-based NGOs due to the lack of funds to separate and run programs; leadership and fundraising

training for volunteers and must be creative in fundraising (jamboree sale, arts and crafts sale, annual sale, table sale). Besides, financial and mobility are important elements in to develop social network among volunteers, so that more are willing to help and share travel/registration cost by members (e.g. trust fund). As for time aspect, clots timetabling is very important to ensure time sufficiency and time management (for hospital or centre-based). Such practice is also essential, to increase the awareness as well as motivation of volunteers so that they would make time. Lastly, having enough space and locality are important to create centres for cancer volunteers such as Cancer Resource Centre (CRC), Putrajaya and to take into account the social needs of volunteer such as to have fun, sociable and interesting activities.

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