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Communication Study

The role of volunteer support in the community for adults with hearing loss and hearing aids

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A B S T R A C T

Objectives: To explore interactions between audiology patients and volunteers, to describe encounters and define the role of volunteers.
Methods: Qualitative ethnographic and interview study of volunteer–patient interactions. Ten volunteer participants from two volunteer schemes in South West England were observed and interviewed. Three patient participants were interviewed.
Results: Analysis of observational data showed that volunteers provided support relating to local services and hearing aids, but did not engage in discussions about hearing loss. Interviews with volunteers identified gaps in audiology provision, including accessible services and clear information and highlighted a need for more support from audiology services to enable them to fulfil their role. Volunteer interactions with patients mimicked a clinician–patient encounter and volunteers employed strategies and behaviours used by professional audiologists.
Conclusions: Audiology volunteers could provide an accessible bridge between health services and the community but their care is limited to focus on hearing aids.
Practice implications: Volunteers enable patients to use hearing aids appropriately and are a core element of current care arrangements. However, volunteers express a need for adequate support from audiology services. Volunteers have the potential to increase service capacity and to bridge the gaps between community and audiology healthcare services.

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1. Introduction

Hearing aids remain the most common treatment option offered for people affected by hearing loss. However approximately 40% of people fitted with hearing aids stop using them over time [1]. This may be due to lack of support, such as emotional and psychological support for adjustment to hearing loss [2] or practical help and assistance with hearing aid use and maintenance [3]. In the UK, volunteers who often have hearing loss and wear hearing aids themselves, have supported National Health Service (NHS) patients’ use of hearing aids; however the nature and impact of the support provided to date has not been investigated in detail.

Volunteering is usually understood as unpaid activity where someone gives their time freely to help an organisation or an individual who is not a relative [4]. Naylor et al. [5] estimate that around 3 million people in the UK volunteer in health and social care; those volunteering through healthcare organisations provide support across a range of settings such as acute hospital trusts, community settings and hospices.

Volunteer activities have the potential to impact positively on public health, patient experience, relationships between health services and communities, and delivery of integrated care [5]. Much of the research on volunteers in healthcare has considered their potential for public health impact and this is likely to be most relevant when considering volunteer support of hearing aid services. South et al. [6] described potential public health roles of volunteers (also termed ‘lay health workers’), including peer education and support. Peer education is defined as communicating information to patients to influence behaviour change [6] and peer support is defined as provision of emotional,
physical and social support based on shared experiences of a condition [7]. However, definition of ‘peer’ remains contested [6] and it is unclear what social characteristics connect individuals. Reviews of effectiveness of volunteer or peer based interventions on health, health behaviours and self-management of chronic conditions show some benefit but the evidence is mixed [8–11]; all reviews highlight the heterogeneity of studies in terms of intervention delivery as well as health condition or behaviour, making generalisation difficult. A key issue when considering the nature of intervention is whether volunteers complement or replace professional support [12]. Kapteyn et al. [13] conducted the only study to compare patient outcomes in an audiology service with or without volunteer support and provided an indication that volunteers reduced “ineffective” hearing aid use.

Glenton et al. [14] carried out a qualitative synthesis complementary to one of the reviews of trials [11]; they explored factors that might influence the effectiveness of peer interventions. Of those trials that included a qualitative component, a common theme was that participants valued characteristics they shared with peers, either relating to social background or health condition. Audiology volunteers may share a range of characteristics with the patients with whom they work, including experience as hearing aid users. This may enable them to provide emotional support for adjustment to hearing loss as well as practical help with hearing aid use beyond that provided by audiology professionals. Before gathering evidence about effectiveness of volunteers in audiology it is important first to identify the nature of the support provided.

1.1. Study aims

We used qualitative methods to define the role of volunteers and explore interactions between volunteers and patients. We use a broad definition for a volunteer consistent with that of Volunteering England [4]: a person who is unpaid and voluntarily provides their time to perform functions related to audiology service delivery, they have no formal training in audiology but receive training specific to their role. This approach allows us to explore whether volunteers are an intervention themselves or whether their role could equally be provided by healthcare professionals.

2. Methods

2.1. Approach

Ethnography enables a detailed examination and description of the social encounter between patient and volunteer in their natural setting. Observations were analysed and themes were linked to provide inductively-generated theory about how interactions were shaped [15]. Following broad observations we use detailed analysis of seven encounters to examine interactions [16]. The analysis of conversation provides further detail about how social roles were played out within encounters. Observational work was supplemented by interviews to explore the rationale behind their choice of behaviours and to gain greater insight into observed activities. Interviews were open-ended to allow participants to lead the direction of conversation; interviews were also tailored as data collection and analysis progressed to enable comparison of comparable experiences between cases using constant comparative analysis [17].

2.2. Ethical approval

Ethical approval was provided in May 2011 by the NHS National Research Ethics Service Committee (East Midlands – Derby 2: 11/EM(0167). We have anonymised the identities of all participants as well as locations at which the research was conducted.

2.3. Setting and participants

Volunteers at two Audiology/Hearing Therapy volunteer services in England were invited to participate in writing by volunteer service co-ordinators. These settings were chosen to provide demographic contrast and variety in the activities undertaken by volunteers. Volunteer service 1 has involved volunteers in service delivery for over 20 years and over 20 volunteers run clinics in community settings supporting hearing aid use and conducting repairs. In addition, the service offers community based information days for hearing aid users and hospital ward based repair services. Volunteer service 2 has a team of six volunteers who provide home visits to support hearing aid use. In this model patients are followed up and supported in their adjustment to hearing aid use by volunteers who visit users in their homes.

Volunteers who took part in the study provided written informed consent before data collection started (Table 1). Patients were invited to participate in the study when they visited a service; they also provided written informed consent.

2.4. Data collection

The researcher (HP) undertook observations of volunteers and patients. In total, 120 h of observations of clinical encounters were completed and interviews were conducted with 10 volunteers and three patients. Observations and interviews continued until there was no additional variation in themes, at which point saturation was achieved [17].

Interactions between Audiology/Hearing Therapy volunteers and patients were observed in clinic locations and patients’ homes. Encounters between volunteers and patients were audio-recorded where acoustics would allow [18]. The researcher also made detailed field notes to record the topic, tone and content of encounters with activity noted down at least every 90 s. Data were collected from June 2011 to March 2012.

Volunteers were interviewed after clinic sessions to provide further detail on their role and their perspectives on the services they delivered. Audio-recordings were transcribed, and anonymised. All names in this article are pseudonyms.

The complete dataset comprised field notes of observations of 125 patient and volunteer encounters, 7 audio-recorded encounters, 13 audio-recorded volunteer interviews (3 volunteers participated in more than one interview) and 3 audio-recorded patient interviews.

2.5. Analysis

The approach for organising and interpreting data was informed by constant comparison and derived from Grounded Theory [17]. Field notes and in-depth interviews were analysed
using open and axial coding techniques; each statement was allocated a code and codes were linked from each data source into themes with variation in properties and dimensions. Following the description of the encounters, the thematic analysis of field notes and interviews was conducted by two researchers independently who compared interpretation of codes and agreed themes. These were then grouped into a model of process or paradigm [17]. The structure of conversation was examined through analysis of recorded interactions between patients and volunteers. This focused on the sequence of encounters, practices engaged in by volunteers and patients, the organisation and comparison of each encounter with subsequent encounters [19]. Interactions were analysed with regard to turn-taking, sequence of discussion and choice of language [16]. The researcher described the observations and participants were invited to correct any inaccurate perceptions of the encounter. The analysis was refined through examination of divergent cases. Contrast occurred within cases where patients and volunteers switched between professional and peer roles during different phases of the encounter. This contrast was used to refine the properties and dimensions of the themes.

Observational themes from field notes and interview transcripts were brought together into a framework designed as analysis progressed (Fig. 1). This approach groups themes into preconditions for the encounter, themes associated with the encounter itself, themes that describe the interactions and direct components of the encounter, and themes that describe the consequences of these [17].

The researcher (HP) is a Hearing Therapist. This enabled her to interpret the purpose and aims of clinical activities undertaken and contextualise the activities within the wider field of rehabilitative audiology.

3. Results

3.1. Overview of encounters

Encounters followed a consistent framework with key phases:

- Openers
- Diagnostics
- Contextual conditions
  - Audiology & Hearing Therapy backroom support
- Strategies (Actions/Interactions)
  - Disclosure of hearing loss
  - Knowledge disclosure
  - Being "hands on"
  - Practical solutions
  - Volunteer-volunteer peer support
- Consequences
  - For the patient:
    - Local service
    - Ease of access
    - Social contact
    - Improved hearing aid use
    - Seamless service
  - For the volunteer:
    - Personal impact
    - Personal satisfaction
    - System satisfaction or dissatisfaction

Volunteers referred to the people they work with as patients regardless of the location of their service (e.g. clinical or non-clinical). Interactions were shaped by standard clinical opening questions like 'what can we do for you today?' or 'what's the problem?' Patients interpreted these as opportunities to define problems associated with their hearing aids ranging from the specific such as: 'I think it's time for a new tube' to the abstract: 'I don't seem to be able to get on with it'. Volunteers then examined hearing aids and asked the patient questions. This afforded the encounter a clear purpose and identified the nature of the support on offer as related to the hearing aid specifically, rather than broader issues of adjustment to hearing loss or social support.

The routine care enacted by all volunteers included cleaning of earmoulds, battery changing and re-tubing the earmould. This activity afforded space in the encounter for more general discussion to fill the time taken by the practical activity. This reinforced the separation between volunteer and patient as they demonstrated practical and technical skills beyond lay knowledge. The practical actions also afforded time to discuss shared local knowledge, recent events or people in common. This revealed contrast in communication styles with informal interactions and shared local knowledge enabling more informal 'peer' relationships.

Advice-giving followed practical care of the hearing aid with patients being advised on access to care services, how to use the aids, how to manage some care procedures (battery changing and cleaning the earmould). The volunteers adopted the language and tone of audiologists in referring to the importance of hearing aid use, use of binaural aids rather than monaural and importance of self-directed effort in using hearing aids. The act of advice giving was used to finish the encounter. This enabled volunteers to determine the topic that the encounter closed with and to control the close of the appointment. It appeared to reassert the volunteer as separated by specialist knowledge which was used to advise and direct the patient at the end of the encounter.

Fig. 1. How volunteers support audiology services.
3.2. Volunteers enacted ‘professional’ behaviours

Volunteers adopted professional codes of speech and behaviour throughout the encounter with patients (Table 2). The volunteers’ speech made a series of references shared by professionals but unfamiliar to patients:

- Directly referring to people they work with as ‘patients’
- Indirect allusions to knowledge
- Direct references to knowledge about hearing aids
- Direct references to knowledge about hearing services

Indirect allusions to knowledge occurred when the volunteers asked questions or referred to aspects of the hearing aid that were not clearly understood by both parties. This also included focused attention, eye contact or handling of the hearing aid. They did not necessarily explain their actions to patients.

Volunteer takes left sided hearing aid and cleans it. He retubes the aid with longer tubing and returns to patient with words it should settle down now. Fieldnote PH01

Volunteers described their role as separate from ‘patients’ and as skilled.

Volunteer Kit: It’s been a way of using a little bit of skill that I’ve had and I love the patients, the staff are lovely and they’re all nice to me.

References to knowledge and experience lent authority to the advice that the volunteer made. Volunteers offered advice as a response to patients’ questions or their own observations.

Patient identifies that the hearing aid isn’t working. Volunteer replies “Let’s have a look… it needs a clean” Fieldnote MK01

Frequently, patients referred to their limited use of hearing aids and were advised that such an approach was ineffective. However, there were no opportunities for patients to expand on their thoughts about how they might wear the aids. Conversation openers were not usually used in these moments and so patients were not encouraged to discuss broader concerns about the use of aids or their motivation to wear them.

Patient’s daughter explains that her mother only uses her hearing aids if she knows that people are coming to visit. Volunteer replies “It doesn’t work like that unfortunately” Fieldnote MK02

However volunteers made use of personal disclosure to encourage patients to change behaviour relating to hearing aids. In order to encourage binaural hearing aid use volunteers disclosed their own preferences with hearing aids.

Patient queries whether it’s worth pursuing with hearing aid. Volunteer advises he should. On fitting the aid he says ‘now you should be hearing better’. Patient then asks about whether he should use two hearing aids. Volunteer says ‘I started with one and went for two and found a great difference.’ Fieldnote CH02/2

| Table 2 |

<table>
<thead>
<tr>
<th>Phase</th>
<th>Volunteer–patient interaction</th>
<th>Stated purpose</th>
<th>Level of patient in discussion</th>
</tr>
</thead>
<tbody>
<tr>
<td>Conversation openers</td>
<td>Volunteer opens the encounter with a standard clinical opener</td>
<td>To elicit purpose of visit in relation to audiology needs</td>
<td>Identifies issues with hearing, Patient leads conversation; volunteer steers conversation back to hearing</td>
</tr>
<tr>
<td>Diagnostics</td>
<td>Patient questions or comments on hearing aids</td>
<td>To elicit information or to report concerns with aids</td>
<td>Patient leads; volunteer responds to patients’ points with advice giving Volunteer leads; patient responds about the hearing aid Little; patient passive in exchange</td>
</tr>
<tr>
<td></td>
<td>Volunteer examines hearing aids and asks patient questions</td>
<td>To elicit information about the hearing aids</td>
<td>Patient leads; volunteer responds to patients’ points with advice giving Volunte lead; patient responds about the hearing aid Little; patient passive in exchange</td>
</tr>
<tr>
<td></td>
<td>Third party accompanying patient informs volunteer</td>
<td>To provide more information for the volunteer and to report on hearing aid use</td>
<td>Patient leads; volunteer responds to patients’ points with advice giving Volunte leads; patient responds about the hearing aid Little; patient passive in exchange</td>
</tr>
<tr>
<td>Routine care</td>
<td>Changing batteries, etc. and casual discussion about shared local knowledge</td>
<td>To repair/improve hearing aid</td>
<td>Discussion around shared local knowledge</td>
</tr>
<tr>
<td>Close</td>
<td>Advice giving</td>
<td>To improve use of hearing aid</td>
<td>Little; passive acceptance</td>
</tr>
</tbody>
</table>
In this example the volunteer used prior knowledge to advise the patient on their hearing aid, providing education rather than support based on shared experiences.

Volunteer Kit: You can see what's going on a little bit. Right, well, that's this one done but it's different so it's no good showing you that one because I don't know much about that. I've switched it on (whistling noise) and it whistles because my hands are near it.
Patient: Yes.

3.3. Peer support was based on shared locality not hearing loss

During the diagnostic and advice giving stages in the clinical encounter volunteers adopted directive roles. Despite this there were moments in which volunteers appeared to relate to patients as peers. However, this peer connection was created through discussion of shared knowledge about a local area rather than hearing loss. In this example the volunteer updated a patient about local news.

Volunteer Roland: Your old next door neighbour got remarried again in October.

Within the data there were examples of differences in emphasis in the topics discussed. The discussions about the hearing aids and their use were predominantly led by the volunteers; during these talks patients did not direct the conversation but listened to advice from volunteers and asked questions about the advice provided. This appeared to limit the interaction between volunteers and patients and contrasted with informal discourse when volunteers were engaged in practical tasks. Patients appeared to emphasise local knowledge and experience as a way of sharing rather than focusing on any shared experience as hearing aid users or audiology patients.


Patient: I think and I'm praying so hard that I get in there [care home] because if I do apparently there's nurses that like ... I'm eighty, eighty two and I don't really want to get any accidents ... oh well. I think it'll be quite nice. They say there's a nice garden.

Volunteers used reflection and summarising to validate patient feedback, and answer enquiries about practical use of hearing aids. However, when a patient’s remarks indicated that they had greater difficulty than the volunteer was able to address, then the volunteer closed that line of discussion with a statement 'you can only do your best'. This illustrates how volunteers shape interaction to fit with their perception of their own level of expertise.

3.5. Volunteers provided access to services

The data shows that volunteers acted as extension of the audiology service by providing a more local service to populations who otherwise find access difficult, particularly older people and those with mobility issues. Volunteers also extended the range of services provided through advice about hearing aids and discussion of hearing aid use. This gave patients greater opportunity to discuss concerns and thoughts about hearing aids and to clarify their decisions to use aids. Volunteers describe the importance they place on understanding patients’ situations and the challenges they face in maintaining their hearing aids.

Volunteer Maureen: I've had a gentleman here, come this morning and this is his second visit in two months, he came along on his first visit, he'd taken a public bus journey from his home in ... into [city] to get down to the centre of [city], he'd then had to catch a link bus from the centre of [city] up to the [the local hospital] and he went in with broken hearing aids, um, because there was no drop in service, they were unable to repair him on the spot, so they supplied him with two tubes and told him to come back to our local clinic,
which is the third Friday of every month. So he came in here with the two tubes and asked if we could fit it up.

3.6. Volunteers provided a bridge between audiology and the community

With local insights and knowledge the volunteers provided vital insights into the needs of the local community. They identified gaps in audiology services and identified what was needed to fill them. They also recognised where information was needed and bridged the clinic and community by providing key information and help. In this example a volunteer describes her perception of the patient and their needs for information.

Volunteer Maureen: Use of his two hearing aids. The other lady that we had this morning, we understand she comes from um no she comes from [name of place], which is a small village outside of here. And she's just been fitted with hearing aids, two hearing aids and she's come down this morning, she doesn’t know how to use them, she's been given no information whatsoever, no booklet.

Volunteers referred to difficulties accessing spare tubes and parts, batteries and administrative forms. They did not refer patients with additional difficulties hearing despite hearing aid wear. There is currently no access to supervision for difficult issues.

4. Discussion and conclusion

4.1. Discussion

The encounters between patients and volunteers were influenced by the presence of hearing aids. The requirements of hearing aids limited the range of communication between volunteers and patients. Hearing aids became the focus of encounters and provoked segregation into roles of 'patient' and 'volunteer expert'.

This lack of shared social identity around hearing loss, which is key in determining the value of the interaction for patients [20–22], means that volunteers are likely to fulfil an extension to audiology services but less likely to provide additional peer support or therapeutic value. Regardless of locality or individual differences, professional identity was consistent. This is in keeping with reviews of volunteer interventions that stress the role of extending clinical service and clinical advice [11] but do not provide specific 'peer' based support [10,11]. Audiology volunteers are providing peer education through provision of advice about hearing aid use and may influence behaviours through this [6].

The role of the volunteer is limited by the clinical focus on hearing aids and so the institutional needs of the healthcare provider and audiology service take precedence over the needs of individual patients who may, for example, wish to explore non hearing aid solutions. Levinson’s definition of institutional interaction involves orientation to a goal with a relatively restricted communicative focus [23]. Communication between volunteer and patients reflects this orientation towards hearing aids as the main focus of the interaction with limited opportunity for patient-led communication or peer support around hearing loss or hearing aids. In interactions, patients appear to have limited opportunity to set the agenda in the encounter. As with earlier studies, hearing aid benefit may be demonstrated through extension of the service [13]. In keeping with findings of G lenton et al. [14], patients related to the social characteristics they shared with volunteers. However these shared characteristics did not facilitate therapeutic support for wider issues around hearing loss.

The questions used to shape discussion focus on the professional remit of the volunteer; the patient is not encouraged to describe experiences that fall outside the volunteer’s agenda. Therefore, questions about the value of hearing aids in difficult listening environments are not addressed. The patient is informed that they should use hearing aids as the treatment for their hearing loss without discussing the compromises that hearing aids involve in accessing sound. The consequences for patients are that long standing additional difficulties are not addressed and hearing help is interpreted as hearing aid use.

This study provided the first in-depth, detailed examination of encounters between volunteers and patients with hearing loss. Data were gathered from complementary methods of observations and interviews to describe and analyse how volunteers function. The role of the observer/researcher might have had the effect of enhancing the ‘professionalism’ on display from volunteers who were conscious of being observed as volunteers. This possibility is the case in much research that involves observation. It is best mitigated by trying to achieve good rapport and a relaxed atmosphere, which the researcher attempted to do. The sample was purposefully selected to provide contrast between demographic location, age, gender and type of volunteer service (including domiciliary/clinic location), and provided contrast in the dataset. The observations revealed consistent patterns of activity within the encounters and the interviews identified themes that became saturated. In keeping with qualitative approaches, the findings cannot be assumed to be generalisable but they define, describe and provide theoretical understanding of the nature of the helping relationship within this context [17]. Although transferability of qualitative findings is still debated [19], the aim is to provide a critical insight and sufficient contextual detail for future researchers to judge the applicability of the findings.

4.2. Conclusion

Volunteers are extending health care capacity in the community. They provide care to individuals who otherwise would find hearing services hard to reach. However, their role brings challenges in terms to their own support and management. In particular, volunteers stressed the need for appropriate support and expressed frustrations when there were problems in support. This highlighted the fact that volunteers are aware of the demands placed on them and require help to meet those demands. This study contributes to the systemic understanding of the way audiological services are delivered and accessed.

4.3. Practice implications

Volunteers have the potential to increase service capacity and to bridge the gaps between community and audiology healthcare services. For their value to be realised, volunteers themselves would benefit from clear management, support and supervision as well as a channel through which they can communicate patients’ needs to Audiology service providers.

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I confirm all patient/personal identifiers have been removed or disguised so the patient/person(s) described are not identifiable and cannot be identified through the details of the story.

References


