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To cite this article: Thomas Parkman, Joanne Neale, Ed Day & Colin Drummond (2017): How Do People Who Frequently Attend Emergency Departments for Alcohol-Related Reasons Use, View, and Experience Specialist Addiction Services?, Substance Use & Misuse, DOI: 10.1080/10826084.2017.1285314

To link to this article: http://dx.doi.org/10.1080/10826084.2017.1285314

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Published online: 03 May 2017.

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How Do People Who Frequently Attend Emergency Departments for Alcohol-Related Reasons Use, View, and Experience Specialist Addiction Services?

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ABSTRACT

Background: People who frequently attend emergency departments (EDs) for alcohol-related reasons, cost health systems greatly. Although specialist addiction services may be more appropriate for their needs, drinkers often experience barriers accessing specialist alcohol-related support. Objectives: This study explores how people who frequently attend EDs for alcohol-related reasons use, view, and experience specialist addiction services. Methods: We conducted semi-structured interviews with 30 individuals recruited from six EDs across London, United Kingdom. Data relating to participants’ socio-demographic characteristics and service use were systematically coded using qualitative software, and analyzed following the Framework. Results: ED usage over the last 12 months was high, whereas current use of specialist addiction services was low. We found little evidence that structural barriers were preventing participants from attending specialist services; rather, participants seemed not to require help with their alcohol use. When asked what support they desired for their drinking, only 11/30 participants identified alcohol-specific treatment. More commonly, they wanted help relating to mental health problems; social contact; paid or voluntary work; housing-related issues; or gym access. Women were more likely to be receiving, and to have support from a specialist addiction service. Conclusions/Importance: People who frequently attended EDs for alcohol-related reasons expressed low levels of interest in, and motivation for, alcohol-specific treatment but desired broader psychosocial support. Case management and assertive outreach appear to be valuable models of service delivery for this population (particularly for men). However, further qualitative and quantitative research is now needed to verify these findings in different countries, regions, and health care systems.

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of higher socioeconomic deprivation (Curran et al., 2003; Dent et al., 2010; Hansagi et al., 2001; Moore et al., 2007; Williams et al., 2001).

Several studies have also suggested that people who regularly attend EDs for alcohol problems have high rates of attendance at other health services, including community-based psychiatric services, outpatient clinics, and doctors’ surgeries (Hansagi et al., 2001; Rockett et al., 2005; Williams et al., 2001). In spite of this, one qualitative study based on in-depth interviews with 10 adult patients who repeatedly attended the Huddinge University Hospital in Sweden found that patients who were referred from the ED to a psychiatrist did not continue with this treatment. This study (which did not explicitly focus on drinkers) concluded that patients wanted urgent medical care and felt stigmatized by ED staff who did not treat their symptoms seriously or who classified their use of ED as inappropriate (Olsson & Hansagi, 2001). Information (quantitative or qualitative) on the use of specialist addiction services by people who repeatedly attend EDs for alcohol-related reasons is not reported in the literature. Nonetheless, it has been suggested that some drinkers use EDs when specialist addiction services would be more appropriate for their needs (Hunt, Weber, Showstack, Colby, & Callaham, 2006).

Reasons why individuals experiencing drink-related problems may not attend specialist alcohol services have been widely documented and attributed to a range of factors. Common structural factors include lack of service provision (Probst, Manthey, Martinez, & Rehm, 2015); lack of information about services (Harris et al., 2013; Probst et al., 2015); costs, including travel and childcare costs (Grant, 1997); service inflexibility, particularly in relation to opening times (Cummings, Wen, Ritvo, & Druss, 2014; Kaufmann, Chen, Crum, & Mojtabai, 2014; Mojtabai, Chen, Kaufmann, & Crum, 2014; Rapp et al., 2006); and lack of community outreach (Grant, 1997; Saunders, Zygowicz, & D'Angelo, 2006). More individual barriers to accessing alcohol treatment include perceived feelings of stigma, shame, and embarrassment (Browne et al., 2016; Fortney et al., 2004; Grant, 1997; Keyes et al., 2010; Probst et al., 2015; Wallhed Finn, Bakshi, & Andreasson, 2014); problem denial or ambivalence to change (Edlund, Booth, & Feldman, 2009; Edlund, Unutzer, & Curran, 2006; Grant, 1997; Mojtabai & Crum, 2013; Probst et al., 2015; Rapp et al., 2006; Saunders et al., 2006); fear and concerns about disclosing private information (Rapp et al., 2006); lack of confidence in treatment services (Grant, 1997); and a misperception that treatment requires abstinence (Wallhed Finn et al., 2014).

In addition, there is evidence that female drinkers find it more difficult to access alcohol services than men. For example, women may be less able to utilize alcohol services because they have less money to pay for treatment in countries where support services are not publically funded (Brady & Ashley, 2005). Women are also more likely to have family responsibilities, including childcare, so they may be reluctant to attend services if this means taking children with them or they may be unable to attend services (particularly residential services) if children are not permitted to stay with them (Brady & Randall, 1999). Similarly, women can be reluctant to enter addiction treatment because of fear of losing custody of their children (Allen, 1995) or because they experience greater feelings of stigma, shame, and embarrassment relating to their alcohol misuse than men (Thom, 1987). Further, it has been argued that female drinkers are more likely to attend primary health care services, such as EDs, than men, because specialist alcohol services are insensitive and unresponsive to their needs (Weisner, Mertens, Tam, & Moore, 2001).

In recognition of—and in response to—these various barriers, there has recently been a growing acceptance that professionals working in the alcohol sector need to do more to engage and support people experiencing entrenched drinking problems, and this has led to the development of a range of innovative treatment approaches. Examples include employing alcohol health workers in hospitals to screen patients, conduct brief interventions, and refer patients onto more intensive treatment and detoxification services (Baker & Lloyd, 2015); involving family members in care planning (National Institute for Health and Care Excellence, 2011); and initiating case management approaches which recognize that substance users experience a variety of associated problems and, therefore, need access to a range of health and social services (Substance Abuse and Mental Health Services Administration, 1998). Lately, assertive outreach—a model of care originally developed for people with severe mental health problems (Marshall & Lockwood, 2011)—has been adapted for use with problem drinkers (Gilbert et al., 2012). Assertive outreach is based on small practitioner caseloads; input from a multidisciplinary team; regular brief contacts outside of service settings; a focus on both health and social care needs; persistent and repeated attempts to contact individuals who do not respond; a flexible focus on patient goals even if these do not directly relate to drinking; and extended periods of care (Gilbert et al., 2012).

This article seeks to fill a gap in current knowledge by providing insights into how people who frequently attend EDs use, view, and experience specialist alcohol services. Findings are discussed with reference to ED usage; the existing literature on barriers to accessing specialist addiction services; and the opportunities offered by new models of service provision, such as case management and
assertive outreach. We draw out potential implications for service providers and policy makers who want to ensure that those who have complex drink and drink-related problems secure the help that they need and do not utilize very expensive forms of ED support unnecessarily or inappropriately. Strengths and limitations of our analyses are also reported.

**Methods**

**Data generation**

Data are based on a qualitative study of 30 people who were dependent on alcohol and regularly attended EDs. Inclusion criteria were as follows: “Any patient aged 16 or over who attends any Accident and Emergency (A&E) department 10 or more times within a year or 5 or more times within a 3-month period for an alcohol-related condition” (Information Services Division Scotland, 2014). Participants were recruited from six EDs located in hospitals across south and west London, United Kingdom. Ethical approval for the research was secured from a UK NHS research ethics committee (REC reference number: 14/LO/1251).

Alcohol liaison nurses and specialist alcohol workers employed within the six participating hospitals identified potential participants through their patient records. The same staff then approached individuals, explained the study to them, and provided details on what participation in the research would involve. If individuals were interested, the hospital staff asked them for permission to pass on their contact details to the study researcher (Dr. Thomas Parkman [TP]). TP next contacted every interested person by telephone, again explained the study, re-screened them for eligibility, and arranged a time, place, and date to conduct interview. Of all the contacts that TP received from hospital staff, only three could not be contacted and one declined an interview. All those contacted were eligible to participate.

Prior to commencing the interview, TP provided written information about the study with further verbal explanation, and secured written informed consent. Nearly all the participants were interviewed in their own home. For those who did not have stable housing or who expressed a desire not to be interviewed in home, an appropriate alternative location was found (e.g., hostels, hospitals, GP surgery, restaurant, or a nursing home). Although some participants had drunk prior to the interview and/or drank during the interview, all were sober enough to consent and engage positively with the questions and discussion. Interviews took place during the day, lasted from 60–120 min, and were conducted using a semi-structured topic guide. The topic guide covered the participants’ socio-demographic characteristics; past and present alcohol, drugs, and tobacco use; contact with specialist addiction services; contact with wider health and social services; details of their most recent ED attendance; details of previous ED attendance; and types of support/treatment desired for alcohol or other problems. Participants were given a £15 voucher in recognition of their time.

**Data management and analyses**

Interviews were audio-recorded, transcribed verbatim, and entered into the qualitative software program MAXQDA™ (version 10) for systematic coding. A coding frame was developed based on deductive codes, derived from the topic guide, and inductive codes that emerged from the transcribed interview data. Each interview transcript was reviewed line-by-line by TP, with all interview data being indexed to one or more codes. To address the aims of this article, analyses are confined to deductive codes relating to (i) specialist addiction services used by participants; (ii) participants’ views of specialist addiction services; (iii) participants’ reasons for not attending specialist addiction services; and (iv) types of treatment/support that participants said they wanted for their drinking.

Data indexed to these codes were systematically analyzed using Iterative Categorization (Neale, 2016) according to the principles of the Framework (Ritchie & Spencer, 1994). Themes were identified and differences and similarities between participants were explored. Since all the participants were asked the same broad questions and only 30 participants were interviewed, it has—somewhat unusually for qualitative research—been possible to use actual numbers in presenting the data. While this has enabled us to demonstrate the relative importance and frequency of our emerging findings (particularly in relation to gender differences), we do not seek to convey any empirical generalizability beyond our sample; indeed, we strongly caution against this (Neale, Miller, & West, 2014). Our goal is rather to identify themes and patterns that have potential transferability to other settings. In reporting, we use pseudonyms to protect participant’s anonymity, and quotations to illustrate key findings.

**Findings**

**Participant characteristics**

Participants included 18 men and 12 women, with a mean age of 47.9 years (range 20–68 years). Nineteen described themselves as White British; four as Asian British; three as Mixed Race British; three as German; and one as Somali. Nearly all participants reported many years of heavy
drinking and described symptoms of dependence. The types of drink they most often consumed were spirits, beer, and cider, although a few mostly drank wine and nearly all routinely consumed a range of drinks. Those who only drank beer or cider typically consumed 10–15 cans throughout the day (usually 7–9% alcohol by volume [ABV]). Other participants typically drank fewer cans of beer or cider (usually 5–8 cans) and between half and a bottle of spirits. A minority of participants only drank spirits. Twenty-two participants (12 men and 10 women) said that they were current smokers, and one man reported currently using heroin and other illicit drugs; a further nine (seven men and two women) stated that they had used illicit substances, such as cannabis, heroin, cocaine, and new psychoactive substances, in the past.

In the 12 months prior to the interview, 30 participants had attended an ED between 10 and 84 times (mean value = 24 times) and were admitted in the hospital from ED for 0 to 17 times (mean value = 5 times). Eighteen men had attended ED for 10 to 84 times (mean value = 25 times), and 12 women had attended ED for 10 to 56 times (mean value = 23 times). Participants’ self-reported living arrangements were diverse but often unstable. Nine lived in social housing; five lived in a hostel or sheltered housing; four were street homeless; four owned their own homes; three lived with family or friends on a permanent basis; two were staying temporarily with family or friends because they were homeless; two were in privately renting flats; and one lived in a nursing home. Nearly one-third of the participants (n = 9) had no formal educational qualifications and only two were in current paid work.

Use of specialist addiction services

At the time of interview, only eight participants (two men and six women) said that they were accessing support from a specialist addiction service (see Table 1). Of these, one man and one woman were using more than one service. One man and five women attended a community drug and alcohol team (CDAT); one woman had an alcohol liaison nurse; one man was a member of a peer-led user group (Self-Management and Recovery Training or SMART); one man received help for his drinking from his general practitioner; and one woman was currently a client in residential rehabilitation treatment.

Views of specialist addiction services

When eight participants, who were currently attending specialist addiction services, were asked what they liked about those services, they generally said very little, in spite of encouragement and prompting from the researcher. Indeed, even though some participants gave more than one response, their comments were invariably brief. Six participants (two men and four women) explained that what they liked about addiction services was the contact and relationships they had with staff and other clients and the support that those relationships offered them: “We’re responsible for all of us … setting up the group, helping with things … It’s all about supporting each other. So I’ve got friends here in the group” (Daniel, 44 years old).

Three participants (one man and two women) said that they liked particular types of treatment (e.g., going to groups or having one-to-one counseling) and two (one man and one woman) referred to enjoying specific activities that were on offer within addiction services (e.g., employment training or having free access to a gym). Two participants (both women) also said that they liked the fact that services monitored or regulated their alcohol intake by breathalyzing them and banning alcohol.

When the same eight participants were asked what they disliked about specialist addiction services, their responses were even briefer, and only five responded. Two participants (one man and one woman) complained that they were not getting the medication they felt they needed and two (one man and one woman) stated that they did not like being around other service clients who drank, did not take treatment seriously, or seemed to have more serious alcohol problems than themselves: “People will come here [community drug and alcohol team] and be drinking outside … They’re not serious about what we’re doing” (Jack, 53 years old).

The female participant who was living in a residential treatment setting also disliked the fact that she was living in an unfamiliar area and felt anxious about going out and crossing the local roads.

Reasons for not attending specialist addiction services

Twenty-two participants (16 men and 6 women) who were not attending any specialist addiction service at the time of their interview were asked why this was the case. Once again, participants struggled to articulate their reasons, but responses—when provided—were as follows.

### Table 1. Current use of specialist alcohol services* (n = 30).

<table>
<thead>
<tr>
<th>Type of service attended</th>
<th>Male</th>
<th>Female</th>
<th>All</th>
</tr>
</thead>
<tbody>
<tr>
<td>None</td>
<td>16</td>
<td>6</td>
<td>22</td>
</tr>
<tr>
<td>Community drug and alcohol team (CDAT)</td>
<td>1</td>
<td>5</td>
<td>6</td>
</tr>
<tr>
<td>Alcohol liaison nurse</td>
<td>0</td>
<td>1</td>
<td>1</td>
</tr>
<tr>
<td>Peer-led user groups</td>
<td>1</td>
<td>0</td>
<td>1</td>
</tr>
<tr>
<td>General practitioner (GP)</td>
<td>1</td>
<td>0</td>
<td>1</td>
</tr>
<tr>
<td>Residential rehabilitation</td>
<td>0</td>
<td>1</td>
<td>1</td>
</tr>
<tr>
<td>Total</td>
<td>19</td>
<td>13</td>
<td>32</td>
</tr>
</tbody>
</table>

*Two participants (one male and one female) attended multiple services.
Four participants (three men and one woman) explained that they did not need help from an addiction service— one participant said that he had stopped drinking, one participant said that he did not want to stop drinking, and two participants (one man and one woman) felt that they needed help with other health or social problems before they could address their drinking: “I need [a] mental health service. They need to listen to me, they need to help me out … If I’m happy and fine … I don’t drink” (Michelle, 25 years old).

In addition, four participants (all men) stated that they did not know what specialist addiction services were available or what types of support could be accessed at particular services. Four participants (two men and two women) explained that they did not go to addiction services as they had previously found the support offered unhelpful or felt that staff had treated them “badly.” Three participants (all men) also spoke of having health problems, particularly walking problems, which made it difficult for them to get to services. Further, two participants (again both men) stated that they were not currently ready for alcohol treatment but were planning to go to services in the future, and four participants (two men and two women) reported no reason at all for not attending services. Only one female participant said that she was currently on a waiting list for treatment—a place in a residential rehabilitation service.

Types of treatment and support wanted for drinking

All 30 participants were asked about any types of treatment or support they wanted for their drinking. In total, 27 participants (16 men and 11 women) were able to identify at least one type of treatment or support and 15 (10 men and five women) identified more than one type. Only three participants (two men and one woman) said that they did not want any help at all (one believed, he could stop drinking on his own, one reported memory problems that meant he could not remember what help he wanted, and one woman felt that she already had enough help in place through the probation service).

Of the 27 people who articulated a definite desire for support, 11 (five men and six women) spoke of wanting alcohol-specific treatment. The types of alcohol-specific treatment they described were diverse: four (one man and three women) wanted medication, specifically Librium; two (both women) wanted to go into residential rehabilitation treatment; two (one man and one woman) wanted drink-related advice; one man wanted professional detoxification; and one man wanted access to a community drug and alcohol team. In addition, one man said that he would like an alcohol worker to visit him in the community:

We [self and drug worker] could chat about how the week’s going. I’d offload some concerns … Because when it boils down to it, the main reason I was drinking was … loneliness … I’m killing two birds with one stone [if] I was meeting up with a [alcohol] worker. (Nick, 24 years old)

When participants were asked why they wanted alcohol treatment, two main reasons emerged. First, six participants (three men and three women) reported that alcohol treatment would help them to stop drinking and begin their “recovery.” Second, three participants (one man and two women) described psychosocial benefits, including greater confidence, reduced loneliness, and improved overall wellbeing: “I do feel that [residential] rehab would be good again … It would give [me] my confidence back” (Hannah, 68 years old).

Rather than prioritizing alcohol treatment, nine participants (six men and three women) explained that what they currently wanted was support for their mental health problems. In this regard, six participants (three men and three women) expressed a desire for individual counseling; two (both men) wanted medication; and one man wanted information and advice about his mental health diagnosis. These participants explained that they needed support with their mental health problems as a precursor to stopping drinking, to alleviate symptoms of depression and anxiety, and to maintain motivation for their recovery: “I need counseling … but no one’s offering me any counseling. It’s a long waiting list … Counseling is what will help me the most” (Gina, 31 years old).

In addition, six participants (five men and one woman) felt that having more social support would help their drinking. Of these, five (four men and one woman) expressed a desire for increased contact with friends (either drinkers or nondrinkers in recovery), and one man said he wanted to reconcile himself with estranged family members. Participants indicated that increased social contact could help to reduce boredom and loneliness and provide them with much needed support. Moreover, peers in recovery could inspire sobriety.

According to six participants (five men and one woman), securing employment or voluntary work would enable them to address their drinking. Participants noted that having something meaningful to do with their time, preferably paid, would reduce their boredom, offer them greater stability, boost their self-esteem, help them to feel better about themselves, and enable them to pay off their debts and “provide for” their family: “I just want to start working and try and help her [wife] at least to pay the child minder … I would like to start working and just paying my debts and trying to provide something for my family” (George, 37 years old).

In addition, six participants (two men and four women) explained that obtaining assistance in relation to
their housing and related practical issues would help their drinking. For example, two (one man and one woman) wanted to move house to escape their drinking environment and drinking associates, two (both women) felt they needed practical support around the home (one was struggling to manage domestic tasks because of ill health and the other was feeling stressed because she could not understand how to use home technology, such as the television or computer). In addition, two participants (one man and one woman) were street homeless and needed shelter as their health was deteriorating: “Because I breathe faster at times, breathe faster, not knowing why… And at times, it’s cold if I don’t dress properly… I can’t dress properly because I’m homeless… I just need not to sleep rough…” (Eric, 49 years old).

Lastly, two participants (both men) reported that they wanted to join a gym—one to reduce boredom and to occupy his time so that he did not drink, and another to improve his overall physical health: “I think if I can get myself sorted out to the gym and start getting myself fitter, I will start drinking less” (James, 64 years old).

Discussion

Emergency department usage for the last 12 months varied considerably between our participants (range 10–84 times) but was overall high (mean value = 24 attendances). Further, about one-fifth of their ED attendances converted into hospital admissions. Conversely, we found relatively low levels of contact with specialist addiction services: only 8/30 participants were receiving support from a specialist service at the time of interview. These findings seem consistent with the argument that there is a sub-group of alcohol-dependent people who may be using expensive hospital emergency (and in-patient) services when less costly specialist addiction services would be more appropriate for their needs (Hunt et al., 2006).

In contrast to the existing literature (Grant, 1997; Harris et al., 2013; Probst et al., 2015), our participants did not seem to be encountering structural barriers when they tried to access specialist addiction services. Relatively few participants reported that they did not know what help and services were available to them, spoke of previous negative treatment experiences that had deterred them from going to addiction services, or described problems getting to services because of health or mobility issues. In addition, only one was waiting for treatment. More commonly, participants did not appear to have or feel in need of help with their drinking. Furthermore, those who were attending specialist addiction services did not report any strong views on what they liked or disliked about those services, and those who were not going to specialist addiction services struggled to articulate reasons why they did not go. In short, they conveyed an underlying lack of interest in getting specialist help for their drinking.

When participants did articulate what they liked about the specialist addiction services they currently attended, they mostly referred to the social aspect of treatment, including the relationships they had with others in the service and the general activities the service offered. This seemed to indicate that those who attended addiction services were often looking for something more than just support with their alcohol dependence. This suggestive finding was reinforced when we explicitly asked all participants what help they wanted with their drinking. Individuals identified a wide range of support, including help with mental health problems; social support to reduce boredom and loneliness; paid or voluntary work to fill time and provide financial resources; help with housing-related issues; and access to a gym. Although about one-third of our participants reported that they wanted alcohol-specific treatment, some of these pointed to the psychosocial benefits of this (greater confidence, reduced loneliness, and improved overall wellbeing) rather than to the benefits of reduced drinking.

Our data, in addition, suggested some interesting gender differences in specialist addiction service use. While published literature mostly indicates that women encounter more barriers to accessing services than men (Allen, 1995; Brady & Ashley, 2005; Brady & Randall, 1999; Thom, 1987), we found that women were more likely to be attending, and receiving support from, a specialist service (cf. Drummond et al., 2005). Women also seemed, more likely than men, to report that they wanted alcohol-specific support, and were less likely to have social support, paid or voluntary work, or access to a gym. This finding is broadly consistent with previous research on the recovery trajectories of opiate users which has found that women have better family and social relationships and more access to informal support, including more material resources, than men (Neale, Nettleton, & Pickering, 2014). In terms of reasons for not going to a specialist addiction service, men seemed more likely than women to say that they did not want or need help, did not know what specialist services or support were available, or had mobility problems getting to services.

Together, our findings have a number of potential implications for policy and practice. They suggest that encouraging people (and particularly men) who frequently attend EDs for alcohol-related reasons to visit specialist addiction services instead is likely to be very difficult—however accessible and welcoming those specialist addiction services may be. This is because members of this sub-population of drinkers often do not appear to require, or perceive that they have a need for, alcohol-specific support. In contrast, they do seem to desire a
range of psychosocial support, including help with mental health problems; social support and companionship; meaningful ways of spending time; housing-related support; assistance with domestic activities; and financial resources. Accordingly, it may prove easier to motivate them to attend more generic health care and social care services, such as drop-in centers, peer support groups, day care services, or even employment and training services, than specialist addiction agencies. EDs may not be appropriate for their needs, but specialist addiction services will often not be suitable either, at least not in the short term.

In contrast, more innovative treatment approaches may be better at engaging and supporting people who frequently attend EDs for alcohol-related reasons (National Treatment Agency for Substance Misuse, 2006). ED screening, brief interventions, and referrals to specialist alcohol services may work for some but are unlikely to be sufficient for many others (Baker & Lloyd, 2015). Involving family members in care planning as recommended by the National Institute for Health and Care Excellence (2011) will also probably have limited impact on a population that tends to have poor social support. In contrast, case management and assertive outreach approaches that focus on both health and social care needs; prioritize patient goals even if these do not directly relate to drinking; provide regular contacts outside of service settings; and offer support over an extended period of time are likely to be more appreciated by this population, and particularly by the men (Gilbert et al., 2012; Hilton et al., 2001; Stout, Rubin, Zwick, Zywiak, & Bellino, 1999).

Some important limitations of our analyses should, of course, be noted. Most obviously, our data were derived from a small qualitative study conducted in just one city. As such, our findings cannot be generalized to other locations, either within the United Kingdom or beyond. The extent to which individuals (and particular sub-groups, such as women or men) are willing to utilize either specialist addiction services or EDs will inevitably depend on many factors. These relate to the actual and perceived characteristics of both types of services (nature of the treatment and support available, accessibility, cost, staff attitudes, etc.) in any locality as well as in the wider health and social care system. For example, the nature, accessibility, and perceived attractiveness of both specialist addiction services and emergency care in a large city, such as London, will almost inevitably differ from that available in a small rural area elsewhere in the United Kingdom or in a country where health care is primarily private or insurance-based. Furthermore, all of our participants were recruited via hospitals with specialist alcohol teams. Our findings may have been different had we recruited from EDs that did not have access to specialist alcohol workers.

Interpretation of our data is further compromised by the lack of comparable studies in other countries. Even though we address an international problem, we have, to our knowledge, undertaken the first qualitative study of people who frequently attend EDs for alcohol-related reasons and the first ever study (qualitative or quantitative) to explore their use of specialist addiction services. We successfully recruited 30 vulnerable people who had entrenched drinking problems and were very diverse in terms of their age, gender, ethnicity, and other socio-demographic characteristics. Our participants had a similar socio-demographic profile (gender, age, and related health and social problems) of participants in other international surveys and epidemiological studies; thus suggesting that our sample was not unreflective of the population more generally (Curran et al., 2003; Dent et al., 2010; Fleming et al., 2007; Hansagi et al., 2001; Moore et al., 2007; Whiteman et al., 2000; Williams et al., 2001). Nonetheless, the themes and patterns that we identified, and the implications for policy and practice that we suggest, do now need to be studied further via more in-depth qualitative research and new quantitative research using larger sample sizes conducted in different countries, regions, and health care systems.

Acknowledgments

We would like to thank the 30 individuals who participated in the research for sharing their experiences, and numerous hospital staff for facilitating access to patients and hospital data. We would especially like to acknowledge Paul du Buf and Beverley Harniman for their support.

Declaration of interest

The authors declare that they have no conflicts of interest. The authors alone are responsible for the content and writing of the article.

Funding

We would like to thank Alcohol Research UK (ARUK) for funding this project. Dr. Joanne Neale and Professor Colin Drummond were part-funded by the National Institute for Health Research (NIHR) Biomedical Research Centre for Mental Health at South London and Maudsley NHS Foundation Trust and King's College London; Colin Drummond was also part-funded by the NIHR Collaborations for Leadership in Applied Health Research and Care South London at King's College Hospital NHS Foundation Trust. The views expressed are those of the authors and not necessarily those of ARUK, the NHS, the NIHR, or the Department of Health.
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