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Helping to identify homeless people with a learning disability – a pilot study

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Key points

- People with a learning disability who are homeless face increased health risks
- Identifying those who have a learning disability is difficult, meaning they may miss out on support
- We explored if the Learning Disability Screening Questionnaire (LDSQ) could be used in homeless services
- The pilot study found the LDSQ had good reliability between raters and could identify people with a learning disability in this setting

Abstract

Background: People who are homeless are at risk of experiencing a number of problems with their physical and mental health. This risk increases if the person also has a learning disability (LD). New legislation requires health services in England to work collaboratively to reduce homelessness and to help identify and support those who are homeless. Many people who are homeless do not have their LD recognised, meaning they may miss out on the support they need.

Aim: This pilot study aimed to evaluate the use of the Learning Disability Screening Questionnaire (LDSQ) in a homeless service.

Method: Nine people who used the homeless service completed the LDSQ with researchers. Staff members also completed the LDSQ in relation to the participants to give a measure of inter-rater reliability.

Results: Three people were indicated by LDSQ scores as likely to have LD. Two subsequently had this status confirmed, but the third did not attend for further assessment. All but two items on the LDSQ

showed complete agreement. High and significant agreement was found between raters for LDSQ total and percentage scores.

Discussion: The results indicate that it is feasible to use the LDSQ in homeless services and that it shows good inter-rater reliability. Some suggested ways of adapting its use for these settings and the role of nurses are provided. Further research with larger sample sizes is needed to confirm the results.

Introduction

Being homeless has a significant negative affect on the physical and psychological health on those who do not have a secure place to live. These health problems are made worse because people who are homeless also experience a number of barriers to accessing health care. These include poor experiences of care, associated costs e.g. for travel to services, and the demands of meeting other needs first, such as work and shelter (see Roche et al, 2018). A recent review of health care provision for people who are homeless indicated that the best performing primary care services were more likely to be matched to the needs of the homeless population, to provide a wider range of services on the premises, for example that addressed social care as well as health needs, and to include a nurse as part of the staff team (Jego et al, 2018).

There has also been attempts to improve service provision to homeless people through the introduction of recent legislation in England. The Homelessness Reduction Act (HRA) 2017, requires local authorities and health services to work together to support homeless people and to prevent homelessness occurring in the first place (Paudyal and Saunders, 2018). A basic barrier to achieving these aims is identifying those who are homeless in the first place. This may be a particular problem for health services, as the point of contact with people who are homeless is often emergency services (see Roche et al, 2018) where limited patient contact time may mean that the person’s homelessness is not identified.

The difficulties in identifying the needs of homeless people are even greater when the person also has a learning disability (LD). People with LD already experience significant risks to their health (Emerson et al, 2012), which increase for those who are also homeless. This group are also at higher risk of exploitation, bullying and abuse (Lougheed and Farrell, 2013). The exact prevalence of people with LD who are homeless is unknown, as their LD is frequently unrecognised, not recorded by services (Emerson et al, 2016) or not disclosed by the person because of embarrassment, fear of stigma, abuse or exploitation (Lougheed and Farrell, 2013). Research in this area does, however, suggest that there are a higher number of people with LD in the homeless population than would be expected based on the 2.2% prevalence rate of LD and that they have ongoing support needs for a longer period than those without LD (Beer et al, 2012; Oakes and Davies, 2008; Van Straaten et al, 2017).

Having an unrecognised LD places the person at a significant disadvantage, meaning they may not receive the support they need to help meet their health and other needs. This may include difficulty understanding the complex processes required to apply for financial and other support, due to problems with literacy, processing, understanding and remembering relevant information. They will not experience reasonable adjustments in relation to their health and will have difficulty accessing specialist LD services if these are required (Beer et al, 2012).

Some attempts have been made to address these issues by using screening questionnaires to help identify people who may be likely to have LD. Van Straaten and colleagues (2017) used a screening tool to identify those with suspected LD in homeless services in the Netherlands, but there has been no equivalent research in the UK. One screening tool which is being increasingly used in a range of community and specialist service settings in the UK and abroad is the Learning Disability Screening Questionnaire (LDSQ). The LDSQ has been found to be easy to use and to perform well in a number of settings (e.g. McKenzie et al, 2012; 2015) and its use has been highlighted and recommended by a number of organisations (e.g. Royal College of Nursing, 2015). It was designed to be used by staff

who are not LD specialists and to be completed either with the person suspected of having LD or by someone who knew him/her well, taking minimal time to complete. These characteristics suggest that it may be suitable for use in homeless services, where staff are often busy, have limited time to conduct lengthy questionnaires and do not always have specialist knowledge about LD (Beer et al, 2012). The present pilot study aimed to assess if it was feasible to use the LDSQ in homeless services and if it had good reliability in this setting.

Method

Participants

Participants were nine people who were homeless who used a drop-in homeless service in a large urban area in South East Scotland. Participant were aged 28-52 years (mean = 42.7, SD = 11) and eight were male and one was female. Three were non-British and had English as a second language. Five had attended mainstream school and four had attended specialist schooling (two for behavioural difficulties, two for difficulties with learning). Six participants had one or more difficulties, including mental health problems (4); substance misuse (3); previous offending (4); physical health difficulties (2) and challenging behaviour (1). Participants were self-selecting, but were excluded if they were under the influence of drugs or alcohol, aggressive or experiencing extreme mental health problems at the time of completing the LDSQ. Staff members at the service, all of whom had worked there for at least 6 months, also completed the LDSQ about an individual to give a measure of inter-rater reliability.

Procedure

Ethical approval for the project was obtained from the first author's university ethics board. Permission was obtained from the homeless service to conduct the research on their premises. Two of the researchers visited the drop-in service and provided information about the study to staff and those using the service. This was in an accessible format and the researchers were available to

explain further and answer any questions. All service users visiting the service at the times the researchers were present were invited to participate by the researchers or in conjunction with a staff member, unless they were under the influence of drugs/alcohol at the time, displaying aggression or staff indicated that participation may be detrimental, for example, if someone was experiencing an acute mental health problem at that time. Service users who wished to participate were asked to complete and sign a consent form. Staff who knew the participant were also asked to complete the LDSQ about him/her. Those who were indicated by the LDSQ as likely to have LD were offered further assessment (assessment of intellectual and adaptive functioning) to see if they met the diagnostic criteria for LD. If they did, with their permission, their GP was advised of the results of the assessment.

Measure

The Learning Disability Screening Questionnaire (LDSQ) was used to provide an indication of whether the person was likely to have LD or not. This was chosen as it has been found to identify individuals with and without LD with high levels of accuracy (e.g. McKenzie et al, 2012, 2015) and has been used settings that have similar characteristics to homeless services. These include being non-specialist settings, such as criminal justice services (e.g. see Health Care Improvement Scotland, 2014), where individuals may not have English as a first language and may be vulnerable to stigma and exploitation. The LDSQ comprises seven items that are scored as ‘Yes’ or ‘No’ and converted to a percentage score. Those with a score falling below the cut-off are indicated as likely to have LD.

Results

LDSQ percentage scores ranged from 14 to 100 (mean = 69.7, SD = 36.9). Three participants were indicated as likely to have LD by their LDSQ scores. Of these three, one was not previously known to LD services and was subsequently assessed and found to meet the diagnostic criteria for LD, one was already known to LD services and the third did not attend for the diagnostic assessment that was offered.

Inter-rater reliability

Kappa was used to assess the extent to which staff and service users agreed on the responses to the seven LDSQ items. All items had significant agreement with p values < 0.05. Five of the seven individual items had complete agreement, with kappa values of 1.00. The item relating to time had a kappa value of .61 and the write item had a value of .71. There was also complete agreement, about those who were indicated as likely to have LD, based on classification by LDSQ percentage score (kappa = 1.00, p= 003).

Pearson's correlations were used to assess agreement between staff and service users on LDSQ total and percentage scores. Significant and high correlations were found between LDSQ total scores ($r=.918$, $p<.001$) and percentage scores ($r=.956$, $p<.001$).

Discussion

The aims of this small pilot study were to explore whether it was feasible to use the LDSQ in a homeless service to help identify those who were likely to have LD and whether the results were comparable when the LDSQ was completed by staff or the service users themselves. The results of the study have to be considered in the context of the limitations of the small sample size and that the research involved a single homeless service in one location in the UK.

The study identified three of the nine participants as likely to have LD (33%). This figure is consistent is with that found by Van Straaten and colleagues (2017), who reported that 29.5% of their Dutch homeless sample had probable LD, but is higher than the 12% (6 out of 50 participants) found by Oakes and Davies (2008) in their UK study. The difference may be because the participants in the research by Oakes and Davies (2008) were recruited via a primary care practice, whereas our own study recruited from a homeless service. Our result may reflect that the participants were self-selecting and those who had concerns about having LD may have been more willing to participate.

The LD status of two of those indicated as likely to have LD was subsequently confirmed, however the third individual did not attend for the further assessment that was offered. This highlights one of the challenges of providing good health care to people with LD who are homeless and the need to provide integrated, flexible and responsive services when the person is on-site.

The study also found complete agreement between staff and service user responses on the majority of the LDSQ items, the exceptions being items relating to telling the time and reading. Closer inspection of these responses indicated degrees of, rather than absolute, difficulty with a skill. For example, a service user noted that he could write but would need help with spelling, whereas the staff member reported the person as being able to write. Similarly, one service user could only tell the time on a digital clock, which led to differences in scoring. It may be that some participants try to hide or minimise their difficulties through embarrassment or fear of being stigmatised (McKenzie et al, 2019) and those completing the LDSQ may need to take this into consideration. The LDSQ provides specific instructions on scoring that addresses many such degrees of difficulty. While the LDSQ was designed to be used without the need for training, the results of the study suggest that some additional input into scoring may further improve the reliability.

Overall, there was a high level of agreement on the total and percentage LDSQ scores and, importantly, on who was indicated as having LD. This suggests that the LDSQ may offer a quick and easy way to help identify those who may be particularly vulnerable within homeless services.

Conclusion

The pilot project suggests that the LDSQ may offer a suitable and reliable means of helping to identify people in the homeless population who have LD. Further research with a larger sample size across a range of homeless services is, however, needed to confirm this. Nurses are likely to be well-placed to help develop and implement screening for LD in collaboration with homeless services, to help ensure that the support needs of people with LD are identified and met. This is for a number of reasons. First, research suggests that nurses are key professionals in higher performing primary care

services for homeless people (Jego et al, 2018). Second, nurses can administer the LDSQ as part of a basic health needs assessment and interpret the results in the context of their wider knowledge of the particular health needs of homeless people. Third, they are well placed to liaise with specialist health and other services if the individual is identified as likely to have LD and requires further assessment and support. Finally, nurses are skilled in discussing sensitive topics and, as such, are more likely to get an honest report of any difficulties that people experience that are relevant to scoring the LDSQ.

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