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'When you are homeless, you are not thinking about your medication but your food, shelter or heat for the night': behavioural determinants of the homeless population adherence to prescribed medicines

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1 'When you are homeless, you are not thinking about your medication, but your 2 food, shelter or heat for the night': behavioural determinants of homeless 3 patients' adherence to prescribed medicines 4 5 **Abstract** Objectives: This study aimed to explore behavioural determinants of homeless 6 7 patients' adherence to prescribed medicines using Theoretical Domains Framework 8 (TDF). 9 Study design: A qualitative study using semi-structured, face-to-face interviews. 10 11 12 Methods: Participants were recruited from a homelessness primary healthcare centre 13 in Aberdeen, United Kingdom (UK). Face-to-face interviews were audio-recorded 14 and transcribed verbatim. Thematic analysis of the interview data was conducted 15 using the Framework Approach based on the Theoretical Domains Framework (TDF). National Health Service (NHS) ethical and Research and Development (R&D) 16 17 approval was obtained. 18 19 Results: Twenty-five patients were interviewed, at which point data saturation was 20 achieved. A total of 13 out of 14 TDF domains were identified that explained the 21 determinants of adherence or non-adherence to prescribed medicines. These included: 22 'beliefs about consequences (e.g. non-adherence leading to poor health); 'goals' of 23 therapy (e.g. being a 'normal' person with particular reference to methadone 24 adherence); and 'environmental context and resources' (e.g. stolen medicines and the

25 lack of secure storage). Obtaining food and shelter were higher priority than access 26 and adherence to prescribed medicines while being homeless. 27 28 Conclusions: Behavioural determinants of non-adherence identified in this study were 29 mostly related to participants' homelessness and associated lifestyle. Results are relevant to developing behaviour change interventions targeting non-adherent 30 31 homeless patients and to the education of healthcare professionals serving this 32 vulnerable population. 33 34 Keywords: Adherence, behaviours, homeless, prescription medicines, theoretical 35 domains framework (TDF), vulnerable patients 36

'When you are homeless, you are not thinking about your medication, but your food, shelter or heat for the night': behavioural determinants of homeless patients' adherence to prescribed medicines Introduction Homelessness takes many forms including sleeping rough, living in derelict buildings, residing in temporary shelters offered by local authorities as well as living in squats or sofa surfing. In the United Kingdom (UK), individuals are considered homeless if they no longer have a legal right to occupy their accommodation or if it would no longer be reasonable (e.g. due to safety concerns) to continue to live there.² Homelessness is a widespread problem across the globe. In Scotland over 35,000 individuals made applications to Scottish local authorities in 2014-15 requesting accommodation on the basis of homelessness.³ Reducing health inequalities remains a key health policy priority in the UK. 4-6 Healthcare policies emphasise that addressing health inequality requires specific focus on disadvantaged populations at highest risks of health problems, at the level of both healthcare services delivery and research. Evidence suggests that the health status of people who are homeless is lower than the rest of the population, with higher mortality rates, mainly arising from opioid overdose, psychoactive substance use and heart failure.⁷ Prevalence of tuberculosis, HIV, hepatitis C are also higher^{8,9} with street dwellers often vulnerable to injuries, assault, exposure and skin problems. Poor health status is associated with a longer length of time registered as homeless. 10

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Given the higher morbidity and mortality rates amongst the homeless population, adherence to prescribed medicines is imperative in achieving optimum health benefits. Limited evidence suggests that homeless patients are less adherent to their prescribed regimen and demonstrate poorer therapy outcomes than the rest of the population. 11-12 A systematic review of the international literature suggested that socio-economic status of patients may impact patient adherence to their medicines.¹³ Further evidence from this specific vulnerable population and clinical groups has been recommended. There is also a dearth of theoretically informed investigation around medicines adherence research with the homeless population. This is despite growing emphasis on the use of theory in research designed to inform behaviour change interventions.14 This study aimed to explore behavioural determinants of homeless patients' adherence to prescribed medicines using Theoretical Domains Framework (TDF). Method Semi-structured, face-to-face interviews were conducted with patients registered at Marywell Healthcare Centre for the homeless in Aberdeen, North East of Scotland, UK. This centre provides services to a patient population of approximately 380, of whom approximately 50% are on methadone therapy (source: personal communication with lead clinician). Patients aged 18 years and over, prescribed at least one medicine; and assessed by their general practitioners (GP) as having a good relationship with practice staff were included. This was important to ensure that interviews were conducted in a conducive

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and safe environment for both participants and researchers. Those without the capacity to provide informed consent or unable to communicate in English language were excluded. GPs and practice nurses followed a screening procedure to identify suitable participants during routine clinical consultations. Those patients who expressed an interest were referred to the researchers on site. Further information about the research was provided before informed consent was obtained. Participants were offered soft drinks and biscuits for refreshment. No other incentives were provided.

An interview schedule (Box 1) was developed based on the limited available literature. The interview schedule was reviewed for credibility by an expert panel including a GP, a nurse practitioner (involved in the healthcare of homeless people), a GP practice support pharmacist, a community pharmacist and three academic health services researchers. The schedule was then piloted amongst four participants who met the inclusion criteria. Based on the pilot results, no changes in the interview schedule were needed hence the pilot transcripts were analysed together with the main study interview transcripts. Interviews were planned to take no more than 30 minutes, were audio-recorded with participant permission, and transcribed verbatim. Interviews were conducted until data saturation was achieved as deemed by the researchers when no additional themes were emerging. Duplicate, independent checking of the transcripts against audio-recordings and subsequent analysis was undertaken. Quantitative, demographic information was collected from participants prior to each interview as part of the consent process.

Researchers (VP, KM and DS) met to discuss initial coding after analysing the first four transcripts. Thematic analysis was undertaken using the framework technique¹⁵ based on the Theoretical Domains Framework (TDF) adapted to behavioural determinants of adherence to prescribed medicines. 16 TDF is a theoretical framework of determinants of behaviour which combines 33 theories of behaviour into 14 domains (including knowledge, skills, capabilities, beliefs, emotions, roles and social influences). 16 The TDF has been used by researchers to investigate determinants of behaviours or to explore issues around implementation of behaviour change interventions. In exploratory research, the framework can be applied to either all or part of a research study including formulation of a research instrument, such as a survey or topic guide or interview schedule for a qualitative study; as a basis for a framework for undertaking qualitative data analysis; or to interpret the results. This research was reviewed and approved by West of Scotland NHS Ethics Service (14/WS/1094) and NHS Grampian Research and Development Committee (2014RG003).

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Results

Demographic characteristics

Twenty-five patients were interviewed, the majority of whom were male (n=15) (Table 1) with a mean (SD) age of 40.7 (6.7) years (range: 28-54 years). Most participants rated their health as either fair (n=10) or bad/very bad (n=10) and were unemployed but not currently looking for work (n=19). Participants had been homeless for periods of less than six months (n=4) to over five years (n=3). Several manifestations of homelessness were noted during the interviews that shed further

light into participants' demographic characteristics and their lifestyle. Incidence of rough sleeping, consumption of a poor diet, drug misuse, violence and imprisonment were all noted. Drug or alcohol misuse were the most common reasons cited as leading to homelessness. Participants reported being prescribed medicines for the management of wide range of conditions including mental health issues, asthma, epilepsy, pain and dental issues including co-morbidities.

Table 1 to appear here

Key themes

A total of 13 (out of 14) TDF domains that reflected behavioural determinants of adherence were identified from the data of which goals, environmental context and resources, beliefs about consequences, knowledge, social influence and behavioural regulation were the six most frequently cited domains. These are described in this section with quotes corresponding to each of the 13 identified domains presented in Table 2. The final TDF domain not identified in the data was 'professional/social role and identity.

Goals

Several participants emphasised the benefits of their prescribed medicines, especially methadone. They believed that methadone was helping them to lead a 'normal' life, enabling them to feel 'stable', 'confident' and keeping them away from illicit drug use and its consequences including crime.

159	'Now I'm on methadone script, and I'm stable and that, and I've not been back to jail and that it's kept
160	me stable, and it's managed to keep me and my girlfriend together. If it wasn't for that then we wouldn't
161	be together.' 31 years old, male
162	
163	Some participants demonstrated clear 'goals' with regards to their therapy outcomes
164	in contextualising the importance of adherence. One participant described the goal as
165	to 'fight the devil' referring to her addiction with illicit substances.
166	
167	"it's like fighting the devil. So you've got the good one and the bad one [gestures to each
168	shoulder] so you're trying to eradicate -the bad one to keep the good one. So aye they do work,
169	they work really quite well.'47 year old, female
170	
171	Environmental contexts and resources
172	The importance of 'environmental contexts and resources' was noted as a key
173	determinant in all stages of the medicines taking process, namely access to medicines,
174	retention of medicines and following prescribed regimens. Barriers of access to
175	medicines often related to visiting a community pharmacy for timely collection of
176	dispensed prescriptions. Lack of means to commute to the community pharmacy, or
177	ill health, often prevented timely collection.
178	
179	'Sometimes it was a lot of (problems) getting there (to a chemist), like sometimes people would say I'll
180	give you a lift and then they wouldn't turn up. Never had money for bus fares and sometimes I wasn't
181	actually fit to walk up to my chemist.' 38 years old, male
182	
183	Lack of stable accommodation and chaotic lifestyle meant that adherence to
184	prescribed medicines was not always the participants' main priority.
185	
186	'When you are homeless, you are not thinking about your medication; but your food, shelter or heat for
187	the night' 28 years old, female

188	
189	One participant described sleeping rough in the area where the pharmacy was located
190	so as to enable convenient access to prescribed medicines. This demonstrates a strong
191	sense of 'motivation' and 'behavioural regulation' with regards to the importance of
192	timely access to prescribed medicines.
193	
194	'Just getting to the chemist was a problem with me being homeless because I didn't know which end of
195	the town I was going to be in every night. I didn't knowI could have nowhere to go. I was just walking
196	about the streets normally. I used to walk up to the general area where my chemist is and just end up
197	lying and sleeping there or somewhere.' 38 years old, male
198	
199	Lack of secure space to store prescribed medicines was a common issue for
200	participants. Some participants made reference to medicines with special storage
201	requirements.
202	
203	'Methadone is supposed to be stored in the fridge as well so if you don't have a home you haven't got a
204	fridge' 35 years old, female
205	
206	Belief about consequences
207	'Beliefs about consequences' of non-adherence was a key determinant of adherence to
208	prescribed medicines. For example, with particular reference to methadone, the
209	prospect of reverting back to past habits of drug misuse was perceived as one such
210	consequence. References were also made to other prescribed medicines.
211	
212 213	'I would be a high risk again with blood clots (if I don't take my warfarin)if you come off the
214	trazodone it can kind of make you paranoid. And I know by getting an endoscopy I know that if I don't
215	take the omeprazole I can suffer.' 47 years old, female
216	

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218	'Knowledge' of prescribed medicines
219	Most participants identified themselves as being aware to the importance of adherent
220	behaviour. Participants demonstrated their knowledge with regards to why specific
221	medicines had been prescribed to them by their GPs.
222	
223	'I'm on methadone, salbutamol, Seretide, something for my chest, Epilim for my epilepsy. Only got
224	diagnosed with epilepsy last year and I've been asthmatic all my life. Probably got made a lot worse
225	when I was homeless.'40 years old, male
226	
227	Some reported having conversations with their prescribers demonstrating involvement
228	in shared decision-making in prescribing of medicines.
229	"I say what's wrong, they [the prescriber] say what's maybe good and then we sort of like, try and work
230	it that way." 40 year old, female
231	
232	Social influence
233	Some participants gave accounts of willingly sharing their medicines in their social
234	circle. Theft was often a barrier to retention of medicines as indicated by participants
235	sleeping rough as well as in temporary accommodation such as hostels.
236	'You are keeping (medicines) in your socks, down your trousers, bra even. Because if you fall asleep and
237	it's in your socks it could be quite easily stolen.' 28 years old, female
238	
239	Participants mentioned their apprehension of encountering individuals in pharmacy
240	premises with whom they had strained or violent relationships in the past. Such
241	apprehension was also related to potentially encountering strangers asking
242	participants to illegally sell their prescribed methadone.

243	T've came out of pharmacies heaps of times and folk have been like of you on meth, have you got meth
244	for sale? And I'm like nah sorry Some of them persist and try and get you and I'm not selling any.'
245	38 years old, male
246	
247	Behavioural regulation
248	Examples of adherent practices related to setting up phone reminders to take their
249	medicines as well as prioritising the collection of prescriptions as their first activity in
250	the morning.
251	
252	"even now when I'm not daily dispense it's quite easy [to take medicines as prescribed]. I take it every
253	morning at the same time so I don't forgetI take it at the same time every day for the simple reason it's
254	routine. A lot easier.' 41 years old, male
255	
256	Examples of non-adherent practices were also cited by participants. Forgetfulness was
257	often a key issue. Accounts of doubling up the dosage to make up for the missed
258	doses and finding their own way of adjusting the dosage and medicines regimen were
259	some examples of non-adherent practices.
260	
261	Discussion and conclusion
262	Discussion of key findings
263	Results from this study have provided a unique perspective on this vulnerable and
264	under-researched population with regards to the behavioural determinants in relation
265	to their adherence to prescribed medicines.
266	
267	While adherent practices were noted amongst some participants, both intentional and
268	unintentional non-adherence were apparent in the data. Participants' beliefs about
269	consequences, perceived goals of therapy and environmental contexts and resources

were amongst the behavioural determinants associated with adherence to prescribed medicines. Socio-economic factors such as unstable housing, family conflict, being alone have been shown to negatively impact on adherence to prescribed medicines in research studies undertaken with the general population. Participants in this study have demonstrated the importance of these factors in adhering to prescribed medicines in the context of their homelessness. Interventions to improve adherence of medicines amongst the homeless population can benefit from focusing on the behavioural determinants identified in this study. Use of behaviour change technique taxonomy (BCTT version 1)¹⁷ provides a methodology for identifying content of any complex behaviour change interventions that are to be designed, implemented and evaluated. A recent systematic review of the international literature around interventions to improve adherent behaviour has shown that even the most effective interventions did not lead to large improvements in adherence or clinical outcomes. Novel use of theoretical frameworks are essential in designing complex interventions of behaviour changes more likely to succeed.

Lack of secure storage was one of the key barriers faced in retaining the prescribed medicines. Some local authorities in the UK have developed medicines management policies for homeless individuals living in temporary accommodation, such as hostels, where locked facilities to store prescribed medicines have been made available. Results of this study suggests that while such provisions are likely to benefit the occupants, there is a potential need for such services to be extended to the wider homeless population, for example to those sleeping rough. Delivery of prescribed medicines to the temporary accommodation or a nominated social care professional collecting prescriptions on behalf of the homeless individual are also amongst the

recommended options.¹⁹ With hindsight, such an approach could also mean missed opportunities for community pharmacy in providing opportunistic advice to this vulnerable population. Previous prospective evaluation conducted with homeless individuals has shown that access to temporary homeless shelters can lead to improvements in the health status and access to care during their time in such accomodation.²⁰ Similar improvement in outcomes has been shown across diverse areas, such as substance abstinence and reduction in risk taking behaviours, especially when supportive services are offered on site, for example for counselling or provision of regular meals.²¹

Study strengths and limitations

This study has some limitations. Not every participant in this study was currently homeless as some participants had recently moved to temporary or more permanent housing but were still registered with the homeless healthcare practice. With such participants, the researchers enquired about their experiences while they were facing homelessness. In this research only the patients with a good relationship with the healthcare professionals were included. This approach was used to ensure the safety of both research participants and the researchers. In addition, participants were recruited through their primary healthcare centre, an environment where they were known to be comfortable. It is likely that the results may not be representative of all homeless populations nevertheless this exploratory research gives valuable insight into an under-researched population.

Duplicate checking of transcripts against audio-recordings and independent framework analysis of the confirmed transcripts maximised the trustworthiness of the

findings. Use of the TDF allowed key determinants of adherent and non-adherent behaviours with prescribed medicines to be explored.

Practice and research implications

The results of this study suggest that homeless patients face many unique barriers around adherence to prescribed medicines, mostly associated with homelessness and associated lifestyle. While health professionals based in specialist homelessness healthcare facilities might be more aware of the barriers, homeless patients who are using mainstream healthcare services such as community pharmacy will benefit from the wider healthcare professional sectors' greater awareness and understanding of these barriers. Patient counselling should be tailored to address the unmet needs of these patients.

There is scope for greater integration between health and social care services to enable homeless patients to retain, manage and derive optimal benefit from their medicines. Future research needs to consider wider aspects of self care including homeless individual's diet, injury prevention and management, sleep, health literacy, physical activity and hygiene. Scope of the current study should also be extended to the wider population using survey methodology to reach those who do not access healthcare centres. Exploration of the perspectives of the wider health and social care profession are also warranted. Such research will provide foundations to the development and implementation of theoretically based interventions for homeless individuals to optimally manage their medicines including provision of safe storage facilities and its impact on adherence and health outcomes.

345 Conclusion 346 Participants associated the behavioural determinants of non-adherence identified with homelessness and related lifestyle. Results are relevant to developing targeted 347 348 behaviour change interventions for non-adherent homeless patients. 349 Results suggest that there is scope for greater integration between health and social 350 care services to enable homeless patients to retain, manage and derive most benefit 351 from their prescribed medicines. While housing homeless individuals remains a 352 government policy priority, in future policies should also address healthcare issues 353 faced by homeless individuals as identified in this study. Homeless patients could 354 benefit from healthcare professionals' understanding and recognition of the barriers 355 associated with adherence to medicines. 356 357 References 358 359 1. Homeless link, About homelessness, Available: http://homeless.org.uk/abouthomelessness#.UjxuEj mDBY. Accessed 05 March 2016. 360 361 362 2. Department of communities and Local Government. Statutory Homelessness in England. Available: 363 https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/437273 364 /201503_Statutory_Homelessness.pdf. Accessed 20 March 2016.

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