Perspectives in Public Health

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Editorial

Welcome to this unthemed issue of *Perspectives in Public Health* – bringing a diverse range of peer review and front matter material.

Camacho et al. have provided an important paper, highlighting increasing sexually transmitted infection (STI) rates in England and particularly among population above 45 years, something that Local Authority and National Health Service (NHS) commissioners need to be aware of. In my experience, most sexual health improvement campaigns are focussed on younger adults, therefore the tone of campaigns and methods of reach into the more mature adult population will require consideration.

Reddy and Mahmood's paper on No Recourse to Public Funds (NRPF) status describes research undertaken in partnership with local statutory, voluntary and community organisations in Wolverhampton. NRPF status applies to individuals and families who are subject to immigration control and limits their access to state-funded benefits in England. The findings highlight the risks and vulnerabilities experienced by people with NRPF, and led to development of online resources, training and protocols to support and safeguard people with NRPF.

The use of incentives to achieve behaviour change is a bit of a dilemma for public health commissioners. The pressures on public health budgets and the political and public perceptions of the use of incentives mean that research on such initiatives is limited. Relton et al.'s *Effect of Financial Incentives on Breastfeeding: A Cluster Randomized Clinical Trial* | Breastfeeding | *JAMA Pediatrics* | JAMA Network found a modest but statistically significant increase in breastfeeding prevalence as a result of offering a financial incentive to women in areas of low breastfeeding prevalence. In this issue, McCormack et al. describe the experience of pregnant women enrolled in a scheme to incentivise smoking cessation during pregnancy. Their findings and discussion point to the importance of the relationship between women and service advisors, and the challenges experienced by the women and their sense of achievement in quitting smoking. In the current economic climate, a small incentive may be very much appreciated by participants in behaviour change services, but who's going to pay for it?

In our final peer-review paper, Hei Wan Mak et al. consider the mental health and wellbeing of people with informal caring responsibilities during different phases of the pandemic, highlighting the importance of recognising and supporting the mental health needs of this group as part of healthcare planning and delivery.

I hope you enjoy this issue. Do consider us when submitting your work for publication – RSPH's membership is diverse and our reach is wide!

cpd ARTICLE

The July 2023 CPD paper was 'Corporate social and community-oriented support by UK food retailers: a documentary review and typology of actions towards community wellbeing' by C Lee et al.

Answers: 1d, 2b, 3d, 4c

Nepal health financing in light of federalism and pandemic

KC Saugat Pratap
Knowledge Management Officer, Masters of Public Health, HERD International, Bhaisepati, Lalitpur 44600, Kathmandu, Nepal.
Email: spk266@gmail.com

S Sharma
HERD International, Bhaisepati, Nepal

AR Pandey
HERD International, Bhaisepati, Nepal

SC Baral
HERD International, Bhaisepati, Nepal

Corresponding author:
KC Saugat Pratap, as above

INTRODUCTION

Nepal is now a Federal Democratic Republic state after the promulgation of the Constitution of Nepal in 2015.[1] The country has three tires of government – one federal, seven provincial and 753 local governments.[2] Each level of government is authorised to execute its powers by enacting laws, policies, programs, and annual budgets within its respective jurisdiction, as defined by the Constitution. In subjects under their authority, all three levels can write and issue laws governing their financial authorities, charge taxes, collect income, create a yearly budget, establish plans and programs, and put them into action. The early stages of Federalism also met with the global spread of COVID-19 which brought unprecedented difficulties in financing health. Along with the political changes, there has been some fresh data on health outcomes. For instance, life expectancy increased to 70 years in 2017, up from about 38 years in 1960. The infant mortality rate has also declined from 216 per 1000 live births in 1960 to 27 per 1000 live births in 2019. The maternal mortality ratio also declined from 553 to 186 per 100,000 live births between 2000 and 2017 in Nepal. Against this backdrop, this viewpoint offers an understanding of the various dynamics that need to be considered in developing a health budget and the challenges that Nepalese policymakers face in the current light of federalism, pandemic and long-term health goals.

HEALTH SECTOR BUDGET

The budget for health grew almost three fold from Nepalese Rupees (NPR) 40.6 billion in FY 2016/17 to NPR 123.3 billion in FY 2022/23. These increases may be attributable to the COVID-19 prevention and control programs. In the newly declared budget of FY 2022/23, the health budget has fallen in comparison to the previous FY (Figure 1).

BROADER TRENDS IN HEALTH FINANCING AND UHC

Nepal's per capita gross domestic product (GDP) increased by 61% from 2000 to 2017 and per capita public spending on health doubled during the same period. The rise in per capita, continuous government spending on health between 2000 and 2017 was mostly attributable to increasing total government expenditures as a percentage of GDP, followed by economic growth. Reprioritisation of the health sector's proportion of overall government expenditure (or its absence) hampered growth in per capita public spending on health. For instance, reprioritisation of health fell from nine percent of total government spending in 2000 to five percent in 2017.[3]

While economic development may recover, government spending on health remains low in comparison to other countries in the region and worldwide.[4] As a result, ensuring that public spending on health does not fall further as a percentage of total government spending is an important policy. Despite the aforementioned health-financing issues, Nepal has steadily improved its Universal Health Coverage (UHC) coverage index from 2000 to 2017, surpassing the low-income country average in recent years.[5] Over time, key health outcomes have improved. As a result, it is critical for Nepal to maintain and build on its gains, as well as to continue to prioritise its health sector.

As per the constitution, budget allocation is split among all three tiers of government, but largely remains within the remit of the federal government. Even though in FY 2022/23, the share of the federal government has declined to 67.2% from 74% of the previous FY, and there has been increase both at the province and the local level in FY 2022/23.[6] It is crucial to enforce allocative efficiency to ensure that the funds are utilised effectively at all levels. Also, federalism has opened up the capacity of the subnational governments to collect taxes and manage their own finances. By tapping into their fiscal space, subnational governments can prioritise resource allocation to address the specific needs and priorities of their communities. It is important for subnational governments to balance their spending with their revenue-raising capacity and to ensure that their fiscal policies are sustainable in the long term.

CHALLENGES IN THE RECENT YEARS

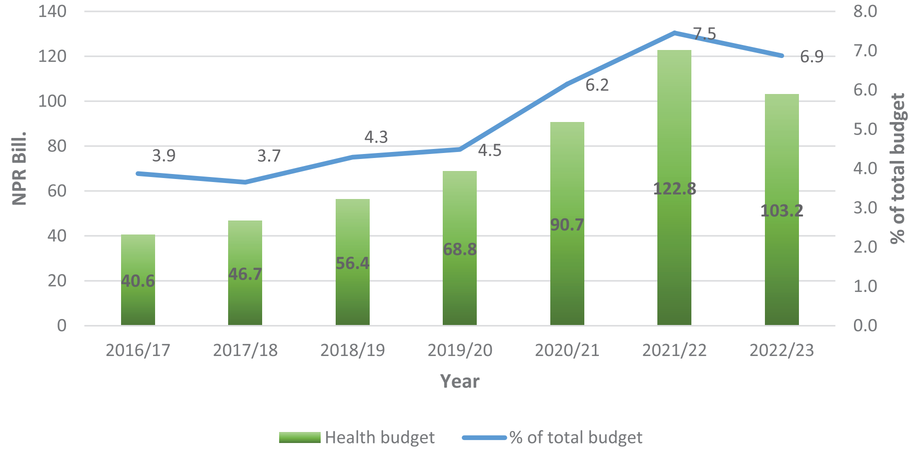
Impact of COVID-19 Pandemic

Nepal cannot continue to rely on favorable macroeconomic conditions to increase fiscal space for health in the wake of the COVID-19 outbreak, as it has

SAGE Publications
ISSN 1757-9139 DOI: 10.1177/17579139231180750

Figure 1

Health budget (left axis) and its rate of growth (right axis)



done for the past two decades. The increase in per capita government spending on health between 2000 and 2017 was mostly attributable to both higher government spending and economic growth (as measured by GDP per capita). In the short-to-medium term, the COVID-19 outbreak has resulted in negative economic growth estimates, underlining the significance of at least maintaining the share of the public budget dedicated to health (ref). Furthermore, between March and April 2020,[7] COVID-19-imposed lockdowns reduced coverage of important services, such as reproductive, maternity, newborn, and child health with institutional births, by 52%.[7] The federal Ministry of Health and Populations (MoHP) budget has tripled in five years of federalism, from NPR 33.3 billion in FY 2017/18 to NPR 101 billion in FY 2020/21. COVID-19 is attributed to this increase. However, while there has been an increase in the overall budget, the same cannot be said for the allocation of budget at the subnational level. In other words, the amount of money allocated for COVID-19-related activities by local government, has not increased at the same rate as the national government's budget for COVID-19.

Additional budget needs for UHC

If the Government evaluates health spending in the spirit of SDG, Nepal can make progress toward achieving UHC. The commitments made by Nepal to achieve the SDGs and UHC by 2030 are heavily reliant on public funding. Effective planning and budgeting processes are crucial for the efficient use of resources in the health sector. Without proper planning and budgeting, even if more resources are allocated to the health sector, they may not be utilised optimally, and the desired outcomes may not be achieved. Also, another challenge is that to reach a conservative goal of 90% coverage of Maternal and Child Health (MCH) services, the government must spend more than five percent of GDP on health.[8] Thus, compared to what would be required to attain UHC, Nepal has been investing significantly less in health as a percentage of GDP.

Limited fiscal space for local governments

Local governments have multi-sectoral deliverables including health services. They are recipients of budget from provincial governments with thematic allocation. Local governments also have their annual budget and work plan. Limited flexibility for local governments to decide when and for what their budget should be spent is hindering the possibility of budget adjustment for investment in health.

High out-of-pocket payment

Out-of-pocket payments (OOP) account for 57.7% of all health expenditures in Nepal despite a variety of treatment subsidies, for instance incentives programs such as Free Health Care and Safe Motherhood Program and insurance schemes.[9] This high level of OOP is a result of the financial cap on service utilisation, lack of awareness and administrative difficulties to access service, and financial inability to finance the enrollment of the vast majority of the population (more than 80%) that still requires coverage.

Absorptive capacity of local governments

Subnational governments have had trouble absorbing their allocation, primarily because of the COVID-19 pandemic disruptions and lack of capacity.[10] They have made great strides in developing budget procedures, but they have not been able to properly utilise their resources.

Fragmented social security schemes

The management of numerous social health protection programs, including the free health care program, free delivery, health insurance, and so forth, inside the MoHP and elsewhere, continues to be challenging due to a fragmented approach.

WAY FORWARD

Health federalism and the COVID-19 pandemic have brought to light some important issues that, if promptly resolved, could enable effective implementation of public health policies and strategies. The country needs to complete and approve the national health finance strategy, then move forward with its implementation. There needs to be strict consideration of the obstacles to budget absorption with corresponding responses. Federal government needs to encourage subnational governments to spend more money on the health sector. A mechanism should be created for tracking and combining health-related budget allocation and spending across all governmental levels. For example, in Australia, the National Health Expenditure Database (NHE) collects information on health expenditures from all levels of government, as well as private insurers and individuals.[11] The mechanism has generally been effective in tracking and combining health-related budget allocation and spending across all levels of governments and have been used to inform policy decisions and improve the efficiency and effectiveness of health systems. More study is needed on enrollment patterns, service usage, referral management, contribution collecting, and spending management with a long-term sustainability perspective in light of the national health insurance program's six years of operation. Situation analysis, need assessment, and health impact assessment should be done on a regular basis to determine which priorities should be set to support the growth of the health sector and proper resource allocation at all levels of the government. Regardless of their responsibilities, there is a dire need for collaboration across horizontal and vertical levels of government. It is helpful to have systems in place for them to coordinate their efforts and create consensus to advance their interests. It is advantageous for these units to band together in representative bodies for additional tasks including capacity building and research as well as to offer a common voice. The coming days shall present an opportunity for the country to face the depleted economy and march toward inclusive development and more resilient growth of the health system, guaranteeing that no one is left behind. The economic scars from the pandemic and transition run deep.

CONFLICT OF INTEREST

The author(s) declared no potential conflicts of interest with respect to the research, authorship, and/or publication of this article.

FUNDING

The author(s) received no financial support for the research, authorship, and/or publication of this article.

ORCID ID

Saugat Pratap KC https://orcid.org/0000-0002-3032-6672

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CURRENT TOPICS & OPINIONS

The climate crisis – can a community-led approach work?

Climate change is the biggest threat to human health: in this article, O'Connor et al. explore the question around whether a community approach could be beneficial to tackling climate change. It uncovers an unexplored area, namely sustainable community-level responses which deliver behaviour change for the climate emergency.

BC O'Connor
University of Salford, Allerton Building, Salford, M5 4WT, UK
Email: b.c.oconnor@edu.salford.ac.uk

M Hardman
University of Salford, Salford, UK

LM Donkin
Bolton Council, Bolton, UK

PA Cook
University of Salford, Salford, UK

Corresponding author:
Bryony C O'Connor, as above

CLIMATE CHANGE AS A THREAT TO HUMAN HEALTH

Climate change is the biggest threat to human health.[1] Over 300 Local authorities across the United Kingdom have declared climate emergencies,[2] and there have been over 1500 declared by equivalent local authorities across the globe.[3] Local authorities recognise the scale of the challenge and have set targets to reach 'net zero'. Net zero, that is, not releasing more carbon dioxide than is captured, necessitates significantly reducing the amount of carbon dioxide emitted.[4] Local authorities and the communities they serve are well placed to address this challenge both in terms of carbon emissions, as they "have powers or influence over roughly a third of emissions in their local areas" (p.3).[5] and also through their connection and knowledge of their communities. This article asks the question: how can communities come together to make sustained change and accelerate progress towards net-zero?

JUSTIFICATION FOR THE APPROACH

The concept of communities coming together around a collective cause such as climate change is not new. As outlined in the Big Lottery Fund Report, communities working on climate change projects can lead to change. The challenge, as highlighted by the authors, is both the sustainability of the change and the impact towards reducing carbon emissions.[6]

The Local Government Association has several case studies highlighting community responses to the climate agenda.[7] Such studies demonstrate meaningful engagement with the community around the climate; reach into groups not already engaged with the environmental agenda; and commitment to this approach. In Wiltshire, for example, two-thirds of the residents engaged in developing the priorities for the climate strategy were not already from environmental groups. However, the evidence of impact of this engagement is unclear, leading to the question: could the response have been strengthened by the community being involved in the delivery of the strategy? Other areas, such as Warwickshire, are investing in skills to support and build capacity in engagement, ensuring the voice of local people is woven into the development of the climate strategy.

Community-led action can be effective because of its ability to respond and mobilise quickly, adapt to climate impacts, and be an authentic approach because decisions are made locally

A report from New Local around Climate Change and Community Action strongly advocates for a local response to the climate crisis.[8] This puts the case forward that community-led action can be effective because of its ability to respond and mobilise quickly, adapt to climate impacts, and be an authentic approach because decisions are made locally. This power of community action has been demonstrated during the recent COVID-19 pandemic: in Bolton, the community was a key partner in helping to shape the response by providing assurance, delivering messages as a 'trusted voice', and developing community solutions.[9] Climate change, like COVID-19, is an emergency but is arguably a greater challenge.[10]

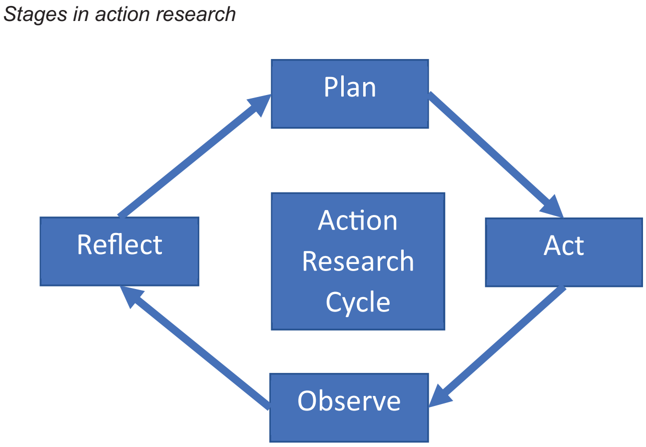
The New Local report outlines examples where a community-led approach has galvanised action and led to changes that support low-carbon choices. The examples include: 'Ambition Lawrence Wilson', a community-driven project that has led to a community-owned solar farm; and the

SAGE Publications
ISSN 1757-9139 DOI: 10.1177/17579139231180802

Figure 1

Stages in action research

Source: Adapted from Costello,[12] p. 7 © Costello, 2003, Action Research, Continuum, an imprint of Bloomsbury Publishing Plc.



Cambridgeshire model, networking community groups and supporting residents to be ‘climate leaders’ through training and resources. Interestingly, this latter example has an element that is an evaluation of the carbon footprint of local organisations and businesses.

The above examples are promising; however, their effectiveness has not been evaluated. Further questions remain around whether a community approach can meaningfully contribute to a reduction in carbon emissions, whether this can be sustainable and whether it can build collective action and accelerate progress towards net zero. Moreover, it is not clear the extent of the reach and diversity of the communities they work with. Are they going beyond the ‘usual suspects’ and delivering sustainable change that would not have happened without the invention of council support or funding?

Examples include: ‘Ambition Lawrence Wilson’, a community-driven project that has led to a community-owned solar farm; and the Cambridgeshire model, networking community groups and supporting residents to be ‘climate leaders’ through training and resources

Working ‘with’ and ‘for’ the community in the above examples has been a key ingredient to support community-led action. The gap in knowledge remains: how do we create that sustainable change, build momentum at a community-level, and evaluate whether and how it works? Action research might be a useful approach to explore how to bring diverse communities together to tackle climate change. This is because action research is collaborative and participatory following a continuous cycle of plan, act, observe, and reflect (see Figure 1). Action research creates ‘action’ and adds new knowledge ‘research’, addressing the question around which approach works or if it works. Moreover, the ethos of action research is that it is ‘with’ and ‘for’ the community rather than ‘at’ and ‘about’ the community.[11]

What evidence is there that an action research approach might work? In the realms of climate change, action research has mostly focused on climate adaptation and there is limited literature on using an action research approach for climate mitigation. Two studies from Australia and United States have used action research to design and implement policy change at a national and state level, respectively, in the field of climate mitigation.[13,14] There remains an opportunity therefore to build on the methodology but with a focus on community-led action as a vehicle for delivering sustainable community behaviour change. We are currently trialling such an approach in Bolton, with co-researchers recruited from the community, using an action research approach.

CONCLUSION

Community engagement and participatory approaches can support a community response. In some examples, these are a shared response between the council and the community and in others, they are truly community-led. However, many such projects have not been evaluated and the success factors are unclear. There is a gap in understanding what a sustainable response is; in other words, does it deliver behaviour change at a community-level? Finally, there remains the question, how do we build the momentum and collective community action seen for other emergencies, most notably COVID-19, for the climate emergency?

FUNDING

The author(s) disclosed receipt of the following financial support for the research, authorship, and/or publication of this article: The first author is a PhD student at the University of Salford, and an employee at Bolton Council. This study/project was funded by the NIHR (NIHR Local Authority Academic Fellowship Programme (NIHR302206)/Doctoral Local Authority Fellowship). The views expressed are those of the author(s) and not necessarily those of the NIHR or the Department of Health and Social Care.

CONFLICT OF INTEREST

The author(s) declared no potential conflicts of interest with respect to the research, authorship, and/or publication of this article.

ORCID ID

Bryony C O’Connor https://orcid.org/0000-0002-6596-4711

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Studentification: Shining a Light on Students' Experiences of Living Amongst the Private Rented Sector: Impacts on Wellbeing and Study

With the expansion of higher education in the UK in 1992, the demand for student term-time accommodation increased. Universities could not accommodate all students within their halls of residence, and many students turned to the Private Rented Sector for term-time accommodation, leading to 'studentification' in some areas which is a process of student domination of residential neighbourhoods, largely driven by rent and locality to campus (1). The process has propelled a niche private sector rental market, characterised by a high demand for Houses in Multiple Occupation; intensive numbers occupying designated student areas and short-term tenancies between September and July driving annual tenant turnover (2).

Clearly, a significant number of students live amongst the Private Rented Sector. However, the student perspective is largely absent from the literature, despite students contributing to their local economies and cultural life. Instead, existing research tends to identify students as a 'causal' factor for degradation of the area and concentrates on the local residents' experience of studentification, including an increase in disruption, poorly kept properties, noise nuisance and crime (3). Local residents appear aggrieved by studentification; however, students are likely facing the same experiences. This is concerning as housing is a social determinant of health; poor housing is linked with poor health and wellbeing (2). Students are at a transition stage in their lives and action to support them can be seen as an important public health objective (in terms of their ability to reach their potential) as part of the life course approach endorsed by Marmot (4).

For many students, university is the first time away from home. They may face homesickness, difficult financial decisions and the pressures of living alone, alongside juggling academic demands. International students are often presented with further difficulties including language barriers and acculturative stress. These challenges can contribute to poor health and wellbeing, to which younger students are particularly vulnerable, due to undergoing a crucial period of psychological and biological change between the ages of 15-24 (5,6). However, the pressures from housing have not been considered as influential over a student's health and wellbeing. This is likely because many students are young and inexperienced, particularly when it comes to the housing market. Their naivety to housing standards, coupled with the social acceptance that student housing is of poor condition, has encouraged students to tolerate unsatisfactory accommodation and to avoid speaking out about their experiences (1,2,7).

The literature has begun to address the housing issues some students face. Morris and Genovese (2) remarked properties rented by students were typically older, with low levels of insulation, giving rise to damp and mould issues. Other problems including overcrowding, insecurity and poor maintenance were mentioned, however their exploration was limited due to the study's primary focus on fuel poverty. Nonetheless, Johnson, Cole and Merrill (8) had a broader focus and found students renting privately experienced a wide range of environmental health risks including inadequate security locks, missing smoke alarms, pest infestation, and damp and mould, compromising physical health. The study was quantitative, and therefore did not address students' emotions relating to the hazards, yet an older qualitative study by Christie, Munro and Rettig[7] noted similar hazards, and found students became stressed over poor housing, limiting academic focus.

New research led by Lynch motivated by the observation that there was a gap in the literature regarding the students' own perspectives on their living environments, has found challenges for students living in a densely populated studentified area, as well as benefits. In particular, issues such as the length of tenure, feelings of security, wellbeing and connectivity were considered extremely important alongside physical housing conditions. The study clearly indicates that the short-term nature of living tends towards a less extended interest in the area. There was also a disparity between the University area being seen as ‘home’ and a ‘home’ away from university.

Lynch study findings relate to Maslow’s Hierarchy of Needs (9) in terms of physiological, safety and belonging needs, including respect of self and others and all of this relates to students’ ability to reach their potential. Some have hypothesised that the concept of a ‘home’ is intrinsic to supplying psychological security and our identity (10). This would relate to the theory of ontological security, defined as the sense of reliability, trust and confidence of persons and things, extending to the home. As the link between housing, health and wellbeing is multidimensional and often described as complex, Rolfe (11) developed an empirically informed framework using the experiences of low-income tenants in the PRS to elucidate the relationship and found positive housing experiences created feelings of relaxation, comfort, a sense of self, socialisation opportunities, and reduces stress to improve health and wellbeing. All aspects important for experiencing ontological security (12). For example, with Christie, Munro and Rettig (7) finding poor housing increased student stress, it suggests ontological security was not achieved, likely due to students not feeling in control or at ease in their private property.

New research is emerging; however, further research is important to continue to shed light on studentification, with particular focus on the impact on a student’s wellbeing and studies. New studies will be able us to understand in greater depth the theories behind achieving good wellbeing for students, taking not just their academic but their lived experience, whether it be Maslow’s Hierarchy of Needs (9)ontological security or an alternative theory.

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Trends and projections in sexually transmitted infections in people aged 45 years and older in England: analysis of national surveillance data

Authors

C Camacho
Division of Population Health, Health Services Research & Primary Care, The University of Manchester, Manchester M13 9PL, UK
Email: c.camacho@nhs.net

EM Camacho
Division of Population Health, Health Services Research & Primary Care, The University of Manchester, Manchester, UK

DM Lee
Faculty of Health, Psychology and Social Care, Manchester Metropolitan University, Manchester, UK

Corresponding author:
Christine Camacho, as above

Keywords

sexually transmitted infections; older people; epidemiology

Abstract

Aims: We describe the epidemiology of sexually transmitted infections (STIs) and HIV in people aged ⩾45 years in England and provide future projections about the burden of STIs in this age group.

Methods: Analysis of national surveillance data in England from 2014 to 2019 for chlamydia, gonorrhoea, herpes, syphilis, anogenital warts and HIV was carried out. Time trends were assessed by the Poisson regression and reported using incidence rate ratios (IRRs). Two scenarios were modelled to predict the number of new STI diagnoses and associated costs in 2040.

Results: In 2019, there were 37,692 new STI diagnoses in people ⩾45 years in England. Between 2014 and 2019, there was a significant increase in the rate of new STI diagnoses in men (IRR = 1.05, $p = .05$) and those aged 45–64 years (IRR = 1.04, $p = .05$). Absolute numbers of new STI diagnoses in men who have sex with men increased by 76% between 2014 and 2019 (IRR = 1.15, $p < .001$). In adults aged ⩾50 years, the number of episodes of care for HIV increased over time (age = 50–64 years, IRR = 1.10; age = 65+ years, IRR = 1.13; $p < .001$). The modelled scenarios predicted an increase in STI diagnoses and costs in older people by 2040.

Conclusion: STI rates in England are increasing in people aged ⩾45 years. The population is ageing and older people will contribute an increasing burden to STI costs if this trend continues. The reasons for this trend are not fully understood and further longitudinal epidemiological research is needed. Sexual health promotion campaigns and healthcare interventions targeted at older people should be prioritised.

INTRODUCTION

There is a broad consensus that the incidence of sexual health infections in older people (aged ⩾45 years) has increased over the last two decades.[1–3] In 2015, the Annual Report of the Chief Medical Officer for England focused on the health of the 'Baby Boomer' generation, then aged 50–70 years. This reported that sexually transmitted infections (STIs) had increased by a third in this age group, with a notable increase in new HIV diagnoses and the proportion of older people living with HIV.[1] Similarly, a recent international review found evidence of increasing STI rates in older people (typically ⩾50 years) in the US, Canada and Australia.[2] A study using data from genitourinary medicine (GUM) clinics in one region of England showed that new STI diagnoses in people aged 45 years and over more than doubled between 1996 and 2003.[3] The emerging recognition that the burden of STIs is increasing in older people is reflected in current health policy in England, with the National Institute

ISSN 1757-9139 DOI: 10.1177/17579139221106348

for Health and Care Excellence (NICE) recently introducing the recommendation that healthcare professionals should ask older people about their sexual history and identify their risk of STIs.[4]

In stark contrast to this, the WHO's 2021 report on global progress on STIs did not even report prevalence rates of STIs for people aged over 49 years.[5] Recent evidence suggests that older people are hidden or marginalised in the area of sexual health and that they face significant barriers in seeking advice and treatment including stigma and embarrassment both on the part of older people and healthcare professionals.[6–8] Contrary to popular assumptions, many older people remain sexually active and those having condomless sex with a new partner or multiple partners are potentially at risk of STIs.[2,9–11] However, it remains unclear what factors are driving the increasing STI rates in older people, with physiological, behavioural and social theories being proposed.[11]

Like many high-income countries, England has an ageing population, with those aged over 45 years forecast to grow by 4.4 million people between 2018 and 2038.[12] There is a growing body of data on sexual activity in older people, including those who remain sexually active into their 70s and 80s, with regular sexual expression associated with various positive health outcomes.[9,13] Therefore, it is increasingly important to understand the evolving epidemiology of STIs in older adults so that behavioural factors, service delivery, and clinical and public health interventions can be ready to respond.

This article has the following two key aims:

1. To describe the epidemiology of STIs and HIV in people aged ⩾45 years in England between 2014 and 2019.
2. To estimate the future burden of STIs in this age group in England.

METHODS

This is a cross-sectional analysis of national surveillance STI data in England from 2014 to 2019.

Data sources

The National Institute for Health Protection (NIHP) – formerly Public Health England (PHE) – has compiled data on STIs in England using information submitted by specialist and non-specialist[i] sexual health services to the Genitourinary Medicine Clinic Activity Dataset Version 2 (GUMCADv2) Surveillance System. Data on chlamydia diagnosis are collated through the Chlamydia Testing Activity Dataset (CTAD) Surveillance System, also managed by PHE. Aggregate anonymised data from GUMCADv2 and CTAD were used for the STI analysis.[14,15] HIV data collated by PHE from the HIV & AIDS New Diagnoses & Deaths Database and the HIV and AIDS Reporting System (HARS) were used at an aggregated level for the HIV analysis.[16] Office of National Statistics (ONS) population estimates for 2014–2019 and projections for 2038 were used to calculate rates per 100,000 population.[17]

Inclusion criteria

'Older people' is used to refer to people aged 45 years and over for STI analysis and 50 years and over for the HIV analysis (due to how the source data were aggregated by age). New STI diagnoses for named infections were available for chlamydia, gonorrhoea, herpes, syphilis, anogenital warts and HIV. A total new STI diagnosis count was available which also included *Mycoplasma genitalium* and *Shigella* infections from 2015 onwards. Analysis of trends over time for all total new STIs excluded data from 2014 due to the change in definition for this measure. Information on age at HIV diagnosis, the number of people receiving HIV care and HIV late presentations by age were included. HIV late presentations are defined at people with a CD4 count below 350 cells/μL at diagnosis.[18] HIV was excluded from modelling as this is an established discipline with recommended methodologies which were outside the scope of this article.[19]

Data analysis

The unit of analysis is a new episode of infection so individuals may be duplicated in the data set if they have been diagnosed with more than one STI. The rates of new infections per 100,000 population were calculated using the ONS population estimates.[17] Time trends were assessed by the Poisson regression and are reported using incidence rate ratios (IRRs) and their 95% confidence intervals (CIs). Data were analysed using Stata v17 (Stata Corp, College Station, TX, USA). Two scenarios which predict the number of new diagnoses of chlamydia, gonorrhoea, herpes, syphilis and warts in older people in 2040 were modelled. The first model (demographic change model) assumes that the rate of new STI diagnoses in people aged over 45 years will remain the same as it is in 2019; changes in the number of STI diagnoses are due to changes in population structure (i.e. the projected number of people aged over 45 years in England in 2040). The second model (continuing trend model) assumes that the rate of STI diagnoses in people aged over 45 years will continue to change at the rate observed between 2014 and 2019.

Economic modelling

Current National Health Service (NHS) recommendations for the treatment of STIs (excluding HIV) were used to estimate the associated costs (from an NHS perspective) using a bottom-up approach.[20] As HIV is a lifelong condition, rather than modelling costs for new cases, the number of episodes of secondary care was used as a measure of resource use. NHS unit costs were derived from the most recent versions of the NHS reference costs database,[21] Personal Social Services Research Unit (PSSRU) unit costs of health and social care,[22] and the NHS drug tariff.[23] Unit costs included in the analysis are reported in Supplemental Appendix 1. The unit cost (per case/episode) was multiplied by the predicted number of cases/episodes for each model scenario.

Ethics and patient and public involvement

No ethical approval was required for this secondary analysis of PHE data. There was no direct patient or public involvement in this analysis.

RESULTS

In 2019, there were 468,342 new STI diagnoses in England, of which 37,692 (8.0%; 95% CI = 8.0%–8.1%) occurred in people aged 45 years and over. In people aged ⩾45 years, chlamydia was the most common diagnosis comprising 26.1% of the total ($n = 9849$), followed by gonorrhoea with 19.3% ($n = 7263$). The majority of new diagnoses were in males (73.7%, $n = 27{,}786$) and people aged 45–64 years (92.6%, $n = 34{,}921$). The most common route of transmission was between men who have sex with men (MSM), who accounted for 36.7% ($n = 13{,}834$) of new diagnoses in 2019 (Table 1).

Analysis of all new STI diagnoses (including HIV) at the local authority level showed an uneven geographical distribution of STIs in adults aged ⩾45 years. Out of 150 English local authorities, 38 had an STI rate higher than 160 per 100,000 population over 45 years. This included 26 out of the 33 London boroughs, with Brighton and Hove, Manchester and Southampton having the highest rates outside of London (Supplemental Appendix 2).

Trends over time

Between 2014 and 2019, there were 198,144 new STI diagnoses in people aged 45 years and over (Table 2). Over this time period, there was a significant increase in the rate of new gonorrhoea diagnoses (IRR = 1.16, $p = .01$) and chlamydia diagnoses (IRR = 1.10, $p = .03$). The majority of new STI diagnoses were in men ($n = 143{,}465$, 73.7%). People in the 45–64 years age group accounted for 92.6% of STI diagnoses in those aged over 45 years ($n = 184{,}120$). The most common route of transmission in 2014 was in heterosexual men, who accounted for 40.4% of new STI diagnoses ($n = 12{,}481$). Over time, this has changed, and the dominant route of transmission in 2019 was among MSM ($n = 13{,}843$, 36.7%), which increased by 76% between 2014 and 2019 (IRR = 1.15, $p < .001$).

Trends over age and time

Younger people continue to bear the highest burden of STIs; between 2014 and 2019, people aged under 45 years accounted for 92.5% of new STI diagnoses ($n = 2{,}456{,}033$). However, in the youngest age groups, there is a significant downwards trend in the rate of new STI diagnoses while in the older age groups, including those aged 45–64 years, the rates of STI are increasing (Table 2).

HIV

In 2019, there were 850 new HIV diagnoses in people aged 50 years and over in England (Table 1). This decreased from 1051 new diagnoses in 2014, although the trend failed to reach significance (IRR = 0.94, $p = .61$). Between 2014 and 2019, the over 50s population increased by 1.7 million people, from 19.4 to 21.0 million. In this period, there were 5336 new HIV diagnoses in older people, 72% ($n = 3834$) of which were in men (vs women). The ratio of male-to-female diagnoses remained stable at 2.5:1. There were no significant trends over time for new HIV diagnoses in adults aged ⩾50 years.

In 2019, there were 38,260 episodes of HIV care for older people in England, which represents 42.4% of all HIV care episodes (Table 3). This is an increase of 13.1 percentage points in the proportion of adults aged ⩾50 years receiving HIV care from 2014. Episodes of HIV care increased significantly in both the 50–64 years (IRR = 1.10, $p < .001$) and the over 65 years age groups (IRR = 1.13, $p < .001$). Less than 2000 older adults received a late HIV diagnosis between 2014 and 2019. There was a significant decreasing trend for late diagnosis in adults aged 50–64 years (IRR = 0.95, $p = .001$) and those aged over 65 years (IRR = 0.92, $p = .01$).

HIV episodes of care – trends and costs over age and time

There has been a downwards trend over time in HIV episodes of care (EoC) for those in younger age groups, while in adults aged 50 years and over, the number of EoC has increased over time (age = 50+ years, IRR = 1.11, $p < .001$), which partly reflects the changing demographic of people living with HIV over time.In terms of NHS costs for HIV care, there was a net increase of £3.4m between 2014 and 2019. This was driven by the over 50 years age group whose costs increased by £4.3m, whereas in younger age groups, costs decreased by £0.88m in this period (Table 3).

Activity and cost projections

The total number of diagnoses for chlamydia, gonorrhoea, herpes, syphilis and warts in 2019 among older people in England was 28,660. The cost of treating these STIs in 2019 was estimated to be £2.97m. Both scenarios projected an increase in STI diagnoses in people aged over 45 years by 2040 (Table 4). By 2040, annual NHS treatment costs for STIs in people aged 45 years and over are estimated to be between £3.1m (assuming STI rates remain the same but reflecting demographic population change) and £40.5m (assuming the changes in STI rates observed between 2014 and 2019 continue).

DISCUSSION

Between 2014 and 2019, there was a significant increase in the rate of new STI diagnoses in people aged 45–64 years, with new gonorrhoea and chlamydia diagnoses roughly doubling over the 6-year period. Specifically, 2019 saw 37,692 new STI diagnoses in England in people aged 45 years and over, which was 8% of the total STI diagnoses. MSM and the 45–64 years age group have seen the highest increases in new STI diagnoses. Episodes of HIV care have also significantly increased in people aged 50 years and over. The modelled scenarios predicted an increase in STI diagnoses and costs in older people by 2040.

Strengths and limitations

This study used a large administrative data set which included all STI and HIV diagnoses in England in both specialist and non-specialist settings, thereby minimising bias. As far as we are aware, this is the first national analysis of the epidemiology of STIs in people aged over 45 years in England. We describe significant increases in STI rates in older people in England, consistent with global data from both high- and low-/middle-

Table 1

New STI diagnoses for people aged 45 years and over; new HIV diagnoses, episodes of care and late diagnoses for people aged 50 years and over in England by diagnosis, gender and age group.

	2014	2015	2016	2017	2018	2019	IRR (95% CI)	*p*-value
Diagnosis								
Chlamydia	5870	6042	6343	6890	8534	9849	1.10 (1.01–1.20)	0.03
Gonorrhoea	3317	3894	3602	4461	6061	7263	1.16 (1.05–1.30)	0.01
Herpes	4134	4119	4095	4027	4197	4185	0.99 (0.88–1.11)	0.87
Syphilis	1062	1279	1573	1896	1995	2169	1.14 (0.95–1.36)	0.17
Warts	5441	5374	5163	5129	5412	5317	0.98 (0.89–1.09)	0.76
All new STIs[a]	30,902[b]	31,233	30,878	31,895	35,544	37,692	1.04 (0.99–1.10)	0.13
Gender								
M	22,028[b]	22,489	22,079	23,032	26,051	27,786	1.05 (1.00–1.09)	0.03
F	8855[b]	8709	8724	8788	9309	9750	1.02 (0.95–1.10)	0.63
Age group								
45–64	28,803[b]	29,096	28,776	29,602	32,922	34,921	1.04 (1.00–1.09)	0.05
65+	2099[b]	2137	2102	2293	2622	2771	1.06 (0.93–1.21)	0.36
Route of transmission (excludes HIV)								
Male (heterosexual)	12,481[b]	12,275	12,057	11,532	11,511	11,190	0.98 (0.97–0.98)	<0.001
Male MSM	7880[b]	8448	8338	9691	11,868	13,834	1.15 (1.14–1.16)	<0.001
Female (heterosexual)	7414[b]	7449	7413	7398	7663	7982	1.02 (1.01–1.02)	<0.001
Female WSW	32[b]	26	20	33	43	70	1.35 (1.21–1.50)	<0.001
HIV								
New HIV diagnoses	1051	903	885	802	845	850	0.94 (0.75–1.18)	0.61
New diagnoses by gender								
M	758	664	642	574	613	583	0.93 (0.78–1.12)	0.47
F	293	239	243	227	232	267	0.96 (0.71–1.31)	0.82
New diagnoses by age group								
50–64	847	758	738	684	711	714	0.95 (0.80–1.13)	0.57
65+	204	145	147	118	134	136	0.91 (0.62–1.34)	0.63
HIV episodes of care								
50–64	19,700	22,181	24,784	27,223	29,509	32,275	1.10 (1.10–1.10)	<0.001
65+	3180	3613	4100	4639	5252	5985	1.13 (1.13–1.14)	<0.001
HIV late diagnoses								
50–64	342	292	279	229	272	258	0.95 (0.92–0.97)	<0.001
65+	67	58	64	47	47	44	0.92 (0.86–0.98)	0.01

STI: sexually transmitted infection; HIV: human immunodeficiency virus; IRR: incidence rate ratio; CI: confidence interval; MSM: men who have sex with men; WSW: women who have sex with women; M: male; F: female.

[a] Includes other STIs so total different.

[b] Not included in regression model.

Table 2

Trends over age, gender and time for new STI diagnoses.

Age (years)	2014	2015	2016	2017	2018	2019	IRR (95% CI)	*p*-value
Males								
13–14	120	108	96	101	88	90	0.93 (0.80–1.09)	0.38
15–19	25,495	23,466	21,323	20,970	21,350	21,702	0.99 (0.98–1.01)	0.53
20–24	73,133	69,556	65,228	64,536	66,808	67,444	1.00 (0.99–1.01)	0.77
25–34	82,192	83,245	79,548	80,233	87,091	94,029	1.03 (1.02–1.04)	<0.001
35–44	31,271	31,698	29,808	30,532	34,126	38,353	1.05 (1.03–1.08)	<0.001
45–64	20,314	20,771	20,367	21,176	23,943	25,584	1.05 (1.02–1.09)	<0.001
65+	1714	1718	1712	1856	2108	2202	1.05 (0.96–1.16)	0.28
Females								
13–14	1070	806	615	605	610	586	0.91 (0.86–0.97)	<0.001
15–19	62,207	55,796	52,312	50,893	50,063	49,389	0.98 (0.97–0.99)	<0.001
20–24	79,061	74,543	73,198	73,747	76,702	79,843	1.03 (1.02–1.04)	<0.001
25–34	52,691	52,479	52,503	53,507	56,575	59,213	1.03 (1.01–1.05)	<0.001
35–44	15,125	14,736	14,962	15,069	15,905	16,891	1.03 (1.00–1.06)	0.04
45–64	8471	8307	8351	8354	8837	9208	1.02 (0.96–1.08)	0.55
65+	384	402	373	434	472	542	1.07 (0.86–1.34)	0.52
Persons								
13–14	1202	921	723	710	708	678	0.91 (0.84–0.99)	0.02
15–19	88,259	79,824	74,316	72,358	71,951	71,649	0.99 (0.97–1.00)	0.02
20–24	152,745	144,698	139,357	138,947	144,175	148,107	1.02 (1.01–1.03)	<0.001
25–34	135,042	136,020	132,560	134,131	144,102	153,750	1.03 (1.02–1.05)	<0.001
35–44	46,431	46,478	44,902	45,719	50,170	55,400	1.05 (1.02–1.07)	<0.001
45–64	28,803	29,096	28,776	29,602	32,922	34,921	1.04 (1.00–1.09)	0.05
65+	2099	2137	2102	2293	2622	2771	1.06 (0.93–1.21)	0.36

STI: sexually transmitted infection; IRR: incidence rate ratio; CI: confidence interval.

income countries showing increasing STI rates in older people.[24] This study used data from England, but the trends and projections may be generalisable to other countries with similar demographic trajectories. A key limitation of this study relates to the source data being only available in aggregate form. This meant that individual level regression analysis could not be used to explore associations between socio-demographic factors and STI diagnoses. Data were aggregated either by diagnosis and age or diagnosis and ethnicity, so we were unable to include

Table 3

Trends and costs over age, gender and time for HIV episodes of care (EoC).

Age (years)	2014		2019		Trend from 2014 to 2019		
	EoC	Cost[a]	EoC	Cost[a]	IRR (95% CI)	*p*-value	Cost change
Male							
<15	221	£61,438	110	£30,580	0.87 (0.84–0.91)	<0.001	–£30,858
15–24	1606	£446,468	1345	£373,910	0.95 (0.94–0.97)	<0.001	–£72,558
25–34	8224	£2,286,272	8426	£2,342,428	1.00 (1.00–1.01)	0.64	£56,156
35–49	25,140	£6,988,920	23,989	£6,668,942	0.99 (0.99–0.99)	<0.001	–£319,978
50–64	14,827	£4,121,906	23,283	£6,472,674	1.09 (1.09–1.10)	<0.001	£2,350,768
65+	2613	£726,414	4740	£1,317,720	1.12 (1.12–1.13)	<0.001	£591,306
Total	52,631	£14,631,418	61,893	£17,206,254	1.03 (1.03–1.03)	<0.001	£2,574,836
50+	17,440	£4,848,320	28,023	£7,790,394	1.10 (1.09–1.10)	<0.001	£2,942,074
Female							
<15	259	£72,002	153	£42,534	0.91 (0.88–0.94)	<0.001	–£29,468
15–24	907	£252,146	788	£219,064	0.97 (0.96–0.99)	<0.001	–£33,082
25–34	4347	£1,208,466	2817	£783,126	0.91 (0.91–0.92)	<0.001	–£425,340
35–49	14,355	£3,990,690	14,284	£3,970,952	1.00 (0.99–1.00)	0.25	–£19,738
50–64	4872	£1,354,416	8992	£2,499,776	1.13 (1.12–1.14)	<0.001	£1,145,360
65+	567	£157,626	1245	£346,110	1.17 (1.15–1.19)	<0.001	£188,484
Total	25,307	£7,035,346	28,279	£7,861,562	1.02 (1.02–1.02)	<0.001	£826,216
50+	5439	£1,512,042	10,237	£2,845,886	1.13 (1.13–1.14)	<0.001	£1,333,844
Persons[b]							
<15	482	£133,996	263	£73,114	0.89 (0.87–0.92)	<0.001	–£60,882
15–24	2516	£699,448	2133	£592,974	0.96 (0.95–0.97)	<0.001	–£106,474
25–34	12,572	£3,495,016	11,243	£3,125,554	0.98 (0.97–0.98)	<0.001	–£369,462
35–49	39,499	£10,980,722	38,273	£10,639,894	0.99 (0.99–0.99)	<0.001	–£340,828
50–64	19,700	£5,476,600	32,275	£8,972,450	1.10 (1.10–1.10)	<0.001	£3,495,850
65+	3180	£884,040	5985	£1,663,830	1.13 (1.13–1.14)	<0.001	£779,790
Total	77,949	£21,669,822	90,172	£25,067,816	1.03 (1.03–1.03)	<0.001	£3,397,994
50+	22,880	£6,360,640	38,260	£10,636,280	1.11 (1.10–1.11)	<0.001	£4,275,640

HIV: human immunodeficiency virus; EoC: episode of care; IRR: incidence rate ratio; CI: confidence interval.
[a] Based on 2019 NHS reference cost – outpatient HIV (stable patients) £278 per episode.
[b] Including where gender is ‘unknown’ or ‘other’.

Table 4

Cases of STIs and estimated treatment costs for 2019, with projections for 2040.

	2019	Model 1 – 2040 (95% CI)	Model 2 – 2040 (95% CI)
Actual and projected new STI diagnoses			
Chlamydia	9788	10,156 (9,958–10,353)	95,169 (94,565–95,774)
Gonorrhoea	7241	7521 (7351–7691)	192,609 (191,749–193,469)
Herpes	4174	4376 (4246–4506)	4283 (4155–4412)
Syphilis	2163	2259 (2165–2352)	36,085 (35,713–36,458)
Warts	5294	5577 (5431–5723)	4483 (4352–4614)
Total	28,660	29,888 (29,151–30,624)	332,630 (330,534–334,727)
Estimated and projected costs (£)			
Chlamydia	1,163,402	1,207,090 (1,183,612–1,230,567)	11,311,841 (11,239,973–11,383,710)
Gonorrhoea	909,325	944,442 (923,097–965,788)	24,187,850 (24,079,826–24,295,872)
Herpes	150,014	157,268 (152,608–161,928)	153,947 (149,337–158,558)
Syphilis	263,929	275,595 (264,229–286,961)	4,403,146 (4,357,715–4,448,577)
Warts[a]	484,941	510,857 (497,449–524,264)	410,640 (398,619–422,661)
Total	2,971,610	3,095,252 (3,020,995–3,169,508)	40,467,424 (40,225,470–40,709,378)

STI: sexually transmitted infection; CI: confidence interval; Model 1: demographic change model; Model 2: continuing trend model.
Data for 2019 include only cases where both age and gender were known.
[a] 30% of cases resolve without treatment.

ethnicity in this analysis. There was also a change in the way STI data were collected in 2015 which meant that 2014 data could not be used when analysing trends for all new STIs. Finally, we did not use transmission dynamic modelling which is more accurate than epidemiological models in predicting future trends in new STI diagnoses.[25] This was due to a lack of data on additional factors which may be associated with changing STI rates in older people, for example, behavioural data and social networks.[26]

Context

Only one comparable study was identified, from the West Midlands STI Surveillance Project.[3] The West Midlands is a region in England with a population of 5.9 million people. The rates of chlamydia, genital herpes, gonorrhoea and syphilis in people aged 45 years and over attending GUM clinical were analysed over an 8-year period from 1996 to 2003. The analysis included 4445 STI episodes in older people and found an overall doubling in STI rates over the study period.

Our analysis is broader in scope, in terms of geography, diagnoses and settings. Data cover the whole of England, with over 155,000 new STI diagnoses in older people, HIV is included, and activity data come from both specialist and non-specialist settings. Older people are less likely to attend a sexual health clinic after having condomless first sex with a new partner and/or $\geqslant 2$ partners and no condom use,[10] so this analysis may be more representative including older people presenting, for example, to primary care. The West Midlands analysis used rate ratios, comparing their first and last data points on the number of episodes to assess temporal trends. We used incident rate ratios from the Poisson regression to assess trend, which uses data from all available years and takes into account the population at risk in each year. Our method found more modest changes in STI rates, but we believe it is more robust, and would allow comparison with future analyses looking at changes over different periods of time. The West Midland analysis did collect disaggregated data allowing a more in-depth data analysis describing activity in four narrower age bands, whereas we were limited to two broader groups. However, despite having ethnicity data, they reported they were unable to use this in their analysis due to small numbers.

The results of this study are consistent with the emerging global literature of STIs in older people. Surveillance data from the US, Canada and Australia all show increases in diagnosis rates of STIs in older people and older people living with HIV/AIDS.[24,27,28] Older people are often excluded from epidemiological analysis of STI trends so there is a dearth of comparable studies.[5,29]

STI risk factors for older adults

A range of physiological, socio-behavioural and structural factors have been proposed as explanations for the increasing STI incidence among older adults.[30] Ageing is associated with reductions in immune response which could increase susceptibility to infection.[31] Older women may be at an increased risk of acquired STIs due to reduced vaginal lubrication and thinning of the vaginal mucosa.[27] Decreasing testosterone levels in men can lead to erectile problems which make condom use more difficult, contributing to increased STI risk.[27] The widespread use of Sildenafil (Viagra) has allowed men to engage in penetrative sex later in life.[32] Consistent with research in younger men, older MSM who report Viagra use are more likely to engage in unprotected sex.[33]

Social changes in recent decades, such as higher divorce rates, changing social attitudes and increasing foreign travel, have led to people taking new partners in later life, intergenerational relationships and engagement with sex workers.[11] Older people are less likely to have had sex education at school, and are typically excluded from sexual health promotion programmes more often targeted at young people.[34] These factors may lead to people being less able to negotiate safe sex in later life.[35]

Older people are less likely to seek help for STIs, have decreased condom use, lower rates of STI testing and delayed presentation for treatment.[10,36] In a US sample of people aged 40–80 years, over 75% of those who experienced a sexual health problem did not seek help from a health professional.[37] Healthcare professionals are less likely to initiate sexual health conversations with older people; the mutual reluctance from older people and healthcare professionals to raise sexual health concerns in a clinical setting present significant barriers to treatment.[38]

Implications

The estimated annual treatment costs for cases of STIs in people aged over 45 years in 2019 were around £3m. The modelled scenarios for 2040 suggest that costs could increase modestly due to demographic changes (if STI rates remain as they are in 2019) or increase by more than 10-fold (if STI rates in this age group continue to change at the same rate as between 2014 and 2019). These estimates may be considered conservative and worst-case scenarios, respectively, but provide reasonable bounds of future healthcare spending in this area upon which commissioners can draw when planning sexual health services to meet the changing demands of the future as our population ages.

Policy-makers should continue to promote older people being asked about their sexual history in primary care settings[4] and also consider the sexual health of this age group in future public health campaigns. A key area for further research is longitudinal studies of sexual behaviour and evaluation of health delivery and prevention interventions targeted at older people. Also, there are very limited data on the relationship between ethnicity and STIs in older adults. We have made assumptions about trends in STI rates using population-based projections, future analyses could use transmission dynamic modelling using behavioural parameters specific to older people.

CONCLUSION

STI rates in England are increasing in people aged over 45 years. Although the numbers are small relative to younger people, this population demographic is increasing and people aged 45 years and over will contribute an increasing burden to STI costs if this trend continues. A combination of changing societal norms, structural barriers in accessing health care and knowledge about STIs and increased biological susceptibility are all likely contributors to these increasing STI rates. Further epidemiological research is needed to assess trends and causal associations. This article highlights a clear need for sexual health promotion campaigns and healthcare interventions targeted at people aged over 45 years.

ACKNOWLEDGEMENTS

The authors thank PHE for providing access to the GUMCAD data.

AUTHOR CONTRIBUTIONS

C.C. designed the study and carried out the analysis. E.M.C. designed and carried out the economic analysis. D.M.L. carried out the analysis and interpretation of data. All authors contributed to drafting the manuscript and approved/revised the final version of the manuscript for intellectual content.

CONFLICT OF INTEREST

The author(s) declared no potential conflicts of interest with respect to the research, authorship and/or publication of this article.

ETHICAL APPROVAL

No ethical approval was required for this secondary analysis of PHE data.

FUNDING

The author(s) received no financial support for the research, authorship and/or publication of this article.

ORCID ID

Christine Camacho https://orcid.org/0000-0002-5013-3093

DATA AVAILABILITY

Data on STI diagnoses in England by demographic characteristics and geographical region are publicly available from PHE at https://www.gov.uk/government/statistics/sexually-transmitted-infections-stis-annual-data-tables. Additional data were requested from the PHE HIV and STI department to allow analysis at the local authority level. Data were managed in line with the HIV and STI data sharing policy (https://www.gov.uk/government/publications/hiv-and-sti-data-sharing-policy).

SUPPLEMENTAL MATERIAL

Supplemental material for this article is available online.

NOTES

i. Specialist (Level 3) services: genitourinary medicine (GUM) services and integrated GUM/SRH services. Non-specialist (Level 1 and Level 2) services: SRH services, young people's services, online sexual health services, termination of pregnancy services, pharmacies, outreach and general practice, and other community-based settings.

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Mental health and wellbeing among people with informal caring responsibilities across different time points during the COVID-19 pandemic: a population-based propensity score matching analysis

Authors

Hei Wan Mak
Department of Behavioural Science and Health, University College London, London, UK

Feifei Bu
Department of Behavioural Science and Health, University College London, London, UK

Daisy Fancourt
Department of Behavioural Science and Health, University College London, 1–19 Torrington Place, London WC1E 7HB, UK.
Email: d.fancourt@ucl.ac.uk

Corresponding author:
Daisy Fancourt, as above

Keywords

informal carers; COVID-19; mental health; mental wellbeing

Abstract

Aims: Due to a prolonged period of national and regional lockdown measures during the coronavirus (COVID-19) pandemic, there has been an increase reliance on informal care for informal carers. In light of this, the current study compared the experiences of carers and non-carers on various mental health and wellbeing measures across six key time points during the pandemic.

Methods: Data analysed were from the University College London (UCL) COVID -19 Social Study. Our study focused on six time points in England: (1) the first national lockdown (March–April 2020); (2) the beginning of first lockdown rules easing (May 2020); (3) the second national lockdown (November 2020); (4) the third national lockdown (January 2021); (5) the easing of the third lockdown (March 2021); and (6) the end of restrictions (July–August 2021). We considered five mental health and wellbeing measures: depressive symptoms, anxiety symptoms, loneliness, life satisfaction, and sense of being worthwhile. Propensity score matching was applied for the analyses.

Results: We found that informal carers experienced higher levels of depressive and anxiety symptoms than non-carers across much of the pandemic. During the first national lockdown, carers also experienced a higher sense of life being worthwhile. No association was found between informal caring responsibilities and levels of loneliness and life satisfaction.

Conclusion: Given that carers are an essential national healthcare support, especially during a pandemic, it is crucial to integrate carers' needs into healthcare planning and delivery. These results highlight that there is a pressing need to provide adequate and targeted mental health support for carers during and following this pandemic.

INTRODUCTION

Prior to the COVID-19 pandemic, there were around one in eight adults (approximately 6.5 million people) providing some form of informal care in the UK, estimated to have a replacement value of £132 billion a year.[1] Informal care is defined as unpaid care and support for others (typically family, relatives, friends, or neighbours) who may have a disability, chronic illness, mental health problem, or other care needs. This can include providing supervision, practical or instrumental care (e.g. shopping, household chores) and personal care (e.g. dressing, bathing, eating, using the bathroom, emotional support).[2,3]

ISSN 1757-9139 DOI: 10.1177/17579139221104973

With population ageing where the life expectancy for people with long-term health conditions has improved, the demand for informal care has increased to meet the needs and to support the sustainability of health and social care system.[3] As such, informal care is becoming increasingly important within society.

However, informal care, especially personal care, can be physically and mentally demanding. According to Carers UK,[1,4] nearly one in seven of informal carers juggle their caring responsibilities with work, 15% provide over 50 h of care per week, and 17% care for more than one person. In addition, 3% of the UK general population (more than 1.3 million people) are ‘sandwich’ carers – people with the dual responsibility of caring for elderly or disabled/sick family members and young children. Often, carers are faced with challenging tasks and stressful situations and are required to maintain high levels of vigilance; this can create chronic stress.[5] This can have a profound impact on carers’ personal and social life, and physical and mental health and wellbeing. A substantial wealth of literature shows that caring responsibilities have an adverse effect on physical and mental health and health-related behaviours. For instance, it has been shown that people who provide informal care experience higher levels of depression and anxiety, inadequate sleep, higher levels of loneliness, and a higher risk of stroke.[1–3,6–8] However, there are also some reported benefits of caregiving, such as self-esteem and sense of meaning.[9–11]

During the coronavirus (COVID-19) pandemic, members of the public faced prolonged periods of social distancing, reduced access to local services and community facilities, and restricted face-to-face contacts. Particularly, people considered clinically vulnerable (e.g. older adults aged 70 or above and people with specific medical conditions) faced greatest social restrictions as they were advised to follow stricter advice, often not leaving their homes (‘shielding’). For many, this led to an increased reliance on informal care and a consequent increase in care intensity for informal carers.[12] Indeed, a report from Carers UK has shown that there were an additional 4.5 million informal carers during 2020 while the outbreak of COVID-19 was ongoing.[13] Also, limited access to health services means that many carers faced more stressful situations related to care recipients’ medical conditions.[14,15] Moreover, to protect those they were caring for, carers themselves had to shield, facing the same tougher restrictions on their social lives and disrupting usual social support networks. There are, consequently, concerns that the mental health of carers was adversely affected during the pandemic. However, while there has been wide-spread concern for the negative impact of COVID-19 pandemic on mental health of the public[16–19] and formal carers and other healthcare professionals,[20,21] with results suggesting worsening mental health during the pandemic compared with before, less attention has been paid to the mental health and wellbeing of informal carers during the pandemic.[12–15,22–24]

Among the studies that have been conducted, it has been shown that, since the start of the pandemic, people who provided informal care were likely to be women, younger adults, have children under the age of 18, and have paid work.[13] These individuals often experienced a double burden of working or childcare and providing informal care. Some preliminary research has already shown the negative impacts of the pandemic on informal carers. These include increased levels of depression (especially for those who spend 20 h or more per week on caring),[14] increased mental strain (e.g. the concerns of risk of COVID-19 infection in family),[23] increased alcohol consumption and use of illegal drugs,[22] increased feelings of frustration,[24] and feelings of loss of control and uncertainty.[12] However, to date these studies have generally relied on relatively small sample sizes and focused on one time point rather than looking at the evolution of experiences across the pandemic. Furthermore, there has been little research on the impact of informal caring on positive wellbeing during the pandemic.

In light of this, the present study compared the experiences of carers and non-carers on a number of mental health and wellbeing measures, namely depressive symptoms, anxiety symptoms, loneliness, life satisfaction, and a sense that life is worthwhile across various time points during the COVID-19 pandemic. As caring responsibilities are socially patterned, with the demographics of carers (e.g. females)[1] already linked to less favourable mental health and wellbeing outcomes, this study aimed specifically to disentangle whether the negative impacts of informal caring responsibilities on carers’ mental health and wellbeing were attributable to individual demographics or the role of being an informal carer itself. While direct experimental studies in this context were not feasible or practical, we sought to mimic experimental conditions and to effectively account for the effects of observed confounding factors by using the statistical technique of propensity score matching (PSM).

METHODS

Participants

This study analysed data from the UK COVID-19 Social Study run by University College London (UCL), a longitudinal study that focuses on the psychological and social experiences of adults living in the UK during the COVID-19 pandemic. The study commenced on 21 March 2020 and involves regular online data collection from participants for the duration of the pandemic. The study is not random and therefore is not representative of the UK population. However, it does contain a heterogeneous sample that was recruited using three primary approaches. First, convenience sampling was used, including promoting the study through existing networks and mailing lists (including large databases of adults who had previously consented to be involved in health research across the UK), print and digital media coverage, and social media. Second, more targeted recruitment was undertaken focusing on (1) individuals from a low-income background, (2) individuals with no or few educational qualifications, and (3) individuals who were unemployed. Third, the study was promoted via partnerships with third sector organisations to vulnerable groups, including adults with pre-existing mental health conditions, older adults, carers, and people experiencing domestic violence or abuse. The study was approved by the UCL Research Ethics Committee [12467/005] and all participants gave informed consent. A full protocol for the study is available online at https://github.com/UCL-BSH/CSSUserGuide.

This study focused on mental health and wellbeing among respondents with caring responsibilities across sic key time points during the pandemic. Given that there were variations in rules and restrictions and the time points that changes to these rules came in across different nations in the UK, we only considered participants who lived in England. We also restricted our sample to participants who completed the survey within 7 days of each time point to correspond to changes in the study design. (At the early stage of the study, participants were followed-up weekly. In August 2020, the study was converted to monthly follow-up and participants were randomly assigned into 4 groups receiving the survey link at different weeks). We further restricted our sample to those who provided responses to all measures. Participants who opted not to provide details on their demographic background (e.g. gender and household income) were additionally excluded from the analysis. Specifically, our six time points were the 5–7 days following the introduction of each of these measures: (1) the first national lockdown (data captured 28 March – 3 April 2020; $N=10{,}414$); (2) the beginning of first lockdown rules easing (data captured 16–22 May 2020; $N=19{,}259$); (3) the second national lockdown (data captured 14–20 November 2020; $N=3{,}712$); (4) the third national lockdown (data captured 16–22 January 2021; $N=3{,}408$); (5) the easing of the third lockdown (data captured 20–26 March 2021; $N=4{,}068$); and (6) the end of restrictions (data captured 31 July – 6 August 2021; $N=3{,}128$).

Measures

Caring responsibilities

Participants were asked whether they had caring responsibilities for elderly relatives or friends, people with long-term conditions or disabilities, or grandchildren. A binary variable was created to indicate if they had any of the responsibilities.

Outcome variables

Five mental health and wellbeing variables were considered. *Depressive symptoms* was measured using the Patient Health Questionnaire (PHQ-9), a standard instrument for diagnosing depression in primary care which consists of nine items with 4-point responses ranging from ‘not at all’ to ‘nearly every day’.[25] Higher overall scores indicate more depressive symptoms. *Anxiety symptoms* was measured using the Generalised Anxiety Disorder assessment (GAD-7), a well-validated tool used to screen and diagnose generalised anxiety disorder in clinical practice and research.[26] The assessment includes seven items with 4-point responses ranging from ‘not at all’ to ‘nearly every day’, with higher overall scores indicating more symptoms of anxiety. *Loneliness* was measured using the three-item UCLA-3 loneliness, a short form of the Revised UCLA Loneliness Scale (UCLA-R).[27] Each item is rated with a 4-point rating scale, ranging from ‘never’ to ‘always’, with higher scores indicating greater loneliness. *Life satisfaction* was measured using the Office for National Statistics (ONS) personal wellbeing question ‘overall, how satisfied are you with your life nowadays?’, a 10-point scale. *Sense of that life is worthwhile was* measured using the ONS personal wellbeing question ‘overall, to what extent do you feel the things you do in your life are worthwhile?’, a 10-point scale.[28] For both ONS scales, higher scores indicate higher levels of life satisfaction or sense of being worthwhile.

Covariates

This study considered a set of covariates that could be associated with both caring responsibilities and/or mental health/wellbeing outcomes based on previous empirical research.[29,30] These included age groups (age 18–29, 30–59, 60+), gender (male versus female), ethnicity (white versus ethnic minorities), living arrangement (living alone, not living alone and not living with children, not living alone and living with children), marital status (married/in a relationship versus not married/not in a relationship), education (degree or above versus without a degree), employment status (employed versus not employed), household income (<£30,000 versus ⩾£30,000 per annum), keyworker status (yes versus no), living area (city/town versus remote area, e.g. village/hamlet/isolated dwelling), long-term mental/physical health condition (yes versus no), having minor/major stress about COVID-19 (yes versus no), and confirmed/suspected of contracting the COVID-19 virus (yes versus no).

We also considered perceived social support and empathy. For perceived social support, it was measured using an adapted version of the six-item short form of Perceived Social Support Questionnaire (F-SozU K-6). Each item is rated on a 5-point scale from ‘not true at all’ to ‘very true’. Minor adaptations were made to the language in the scale to make it relevant to experiences during COVID-19 (Supplementary Table 1). Higher scores indicate greater perceived social support.[31,32] For empathy, it was measured using the Interpersonal Reactivity Index (IRI). Two scales were the focus in the COVID-19 Social Study: empathetic concern/‘emotional empathy’ and perspective-taking/‘cognitive empathy’. Both scales consist of seven items with a 5-point measure ranging from ‘does not describe me well’ to ‘describe me very well’, and were averaged. Higher scores indicate greater levels of empathetic concern or perspective-taking.

Statistics

Our analysis used PSM, a technique that stimulates an experimental setting in an observational dataset and creates a treatment group and a control group from the sample.[33] One advantage of using PSM over regression approaches is that it controls more effectively for the effects of observed confounders, and hence while results remain observational, bias attributable to confounding can be minimalised significantly. We used PSM to estimate the average treatment effect for the treated (ATT), which is the difference between the average mental health/wellbeing outcomes of participants who had caring responsibilities (carers) and the average outcomes for the same group under the hypothetical scenario that they did not have any caring responsibilities (non-carers).

In the analysis, we used weighted PSM models and applied the kernel matching method with cross-validation bandwidth.[34] Kernel matching uses weighted averages of all individuals in the control group to create the counterfactual outcome, and matches participants in the treatment group to those in the control groups based on the distance of their propensity score. Higher weight is given to the matches whose propensity scores are closer to each other and lower weight to those whose propensity scores are distal from each other.[35] A common support condition was imposed to ensure the quality of the matches;[30] only less than 2% of the data were dropped (mostly from the control units). Regression adjustment was also applied on the matched sample to reduce bias due to residual differences after matching and to obtain an unbiased estimate of the treatment effect.[34,36,37] Missing values were handled with list-wise deletion. High quality of matching was achieved. As shown in Supplementary Figures 1–6, the density distributions of the treatment and control groups overlapped across two study samples across the six time points, indicating good balances of the observed variables between the groups after matching. This suggests that the confounding bias relating to observed covariates should have been reduced significantly.

In addition to the main analysis, three sets of sensitivity analysis were performed. First, we compared mental health and wellbeing between carers and non-carers by restricting the sample to those who reported that their mental health had got worse during the first lockdown in April/May versus before the pandemic. Analysing this would shed light into whether carers continued to suffer more mentally compared to those who were not carers at a time when the mental health of the whole UK population had declined.[19] Second, we tested whether caring intensity may play a role in affecting informal carers' mental health and wellbeing. Two binary variables were generated, with one using 3 h or above as the threshold (3 h or above versus less than 3 h) and a higher intensity threshold (6 h or above versus less than 6 h). Due to data availability, we were only able to test the intensity in the first two time points: the first national lockdown and the easing of the first lockdown.

To account for the non-random nature of the sample, all analyses were weighted to the proportions of gender, age, ethnicity, and education obtained from the Office for National Statistics.[38] All analyses were carried out using Stata/MP 17.0.

RESULTS

Descriptive statistics

In our analytical samples across six time points, around one in four self-identified as informal carers (in line with the Carers Week 2020 report).[13] While the samples shared very similar backgrounds, there was some heterogeneity especially between the first and final time points. For instance, there were fewer younger adults and slightly more older adults aged 60+ in the final time point. Also, there was a decline in stress about COVID-19 and in confirmed or suspected COVID-19 cases as the pandemic continued. Respondents' mental health and wellbeing, on the other hand, were fairly stable (Supplementary Table 2).

Among respondents who provided informal care, when asked to report on the last weekday, 54% reported of not caring for a friend or a relative (suggesting that caring duties were not full-time for half of the sample), more than one in four reported spending 2 h or less on caring, and one in five reported spending 3 or more hours (Figure 1).

Depressive symptoms

Our results show that carers had more depressive symptoms than non-carers during the first national lockdown, easing of the first lockdown, the second national lockdown, and the end of restrictions. The estimated average treatment effect of being carers on the levels of depression appeared to be the strongest when all the restrictions were lifted in July 2021 (ATT = 1.01, 95% CI = 0.44,1.59) (Figure 2 and Supplementary Table 3). No differences were seen during third lockdown or its easing.

Anxiety symptoms

There were no meaningful differences between carers and non-carers during the first lockdown in anxiety (ATT = 0.27, 95%CI = 0.03,0.57). However, similar to depressive symptoms, we found that caring responsibilities were associated with higher levels of anxiety during the easing of the first lockdown, the second and third national lockdowns, and the end of restrictions. The estimated treatment effect of being carers on the anxiety levels were the strongest during the second lockdown in November 2020 (ATT = 0.84, 95%CI = 0.33,1.35), and were the modest when the first national lockdown began to ease (ATT = 0.42, 95%CI = 0.17,0.67) (Figure 3 and Supplementary Table 3). There were no differences during the easing of third lockdown.

Loneliness

No association was found between caring responsibilities and the levels of loneliness at any of the time points (Figure 4 and Supplementary Table 3).

Life satisfaction

No association was found between caring responsibilities and the levels of life satisfaction at any of the time points (Figure 5 and Supplementary Table 3).

Sense of being worthwhile

Our analysis shows that respondents with caring responsibilities were more likely to have a higher sense of life being worthwhile, but only during the first national lockdown in March 2020 (ATT = 0.29, 95%CI = 0.14,0.44) (Figure 6 and Supplementary Table 3).

Figure 1

Time spent on caring for a friend or a relative in a day among informal carers

Source: UCL Covid-19 Social Study.

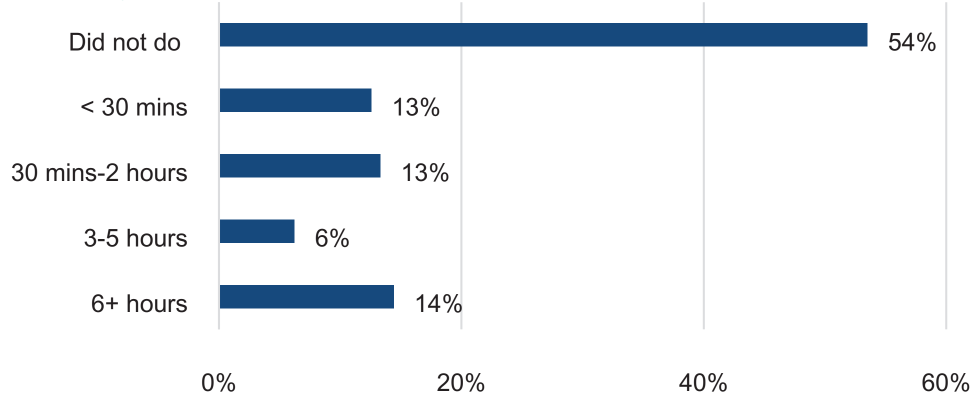
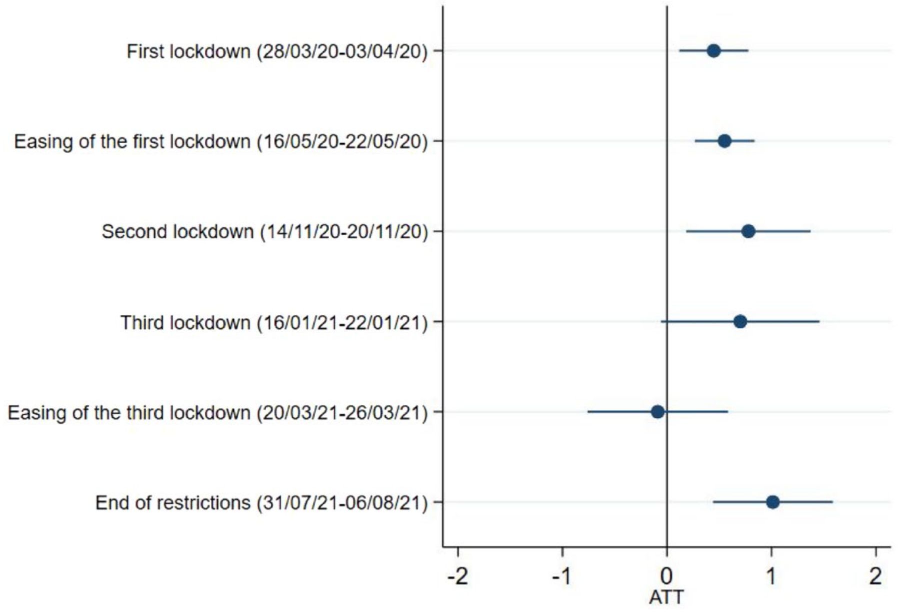


Figure 2

Depressive symptoms



Sensitivity analysis

When restricting our analyses just to respondents who experienced a decline in their mental health during the first lockdown compared to prepandemic periods, informal carers were more likely to experience higher levels of depressive symptoms when all restrictions were lifted in July/August 2021 (ATT = 1.93, 95%CI = 0.51,3.35). No associations were found for other outcomes, nor for other time points (Supplementary Table 4). When comparing various levels of intensity, we found that informal carers who cared for 3 or more hours a day experienced greater levels of anxiety during the easing of the first lockdown compared to those who cared for less than 3 h (ATT = 0.69, 95%CI = 0.10,1.28) (Supplementary Table 5a). Results were consistent when comparing those who cared for 6 or more hours a day versus those who cared for less than 6 h (ATT = 0.72, 95%CI = 0.05,1.38) (Supplementary Table 5b).

DISCUSSION

This study examined the differences in mental health and wellbeing between carers and non-carers across different time points (from March 2020 to July/August 2021) during the COVID-19

Figure 3

Anxiety symptoms

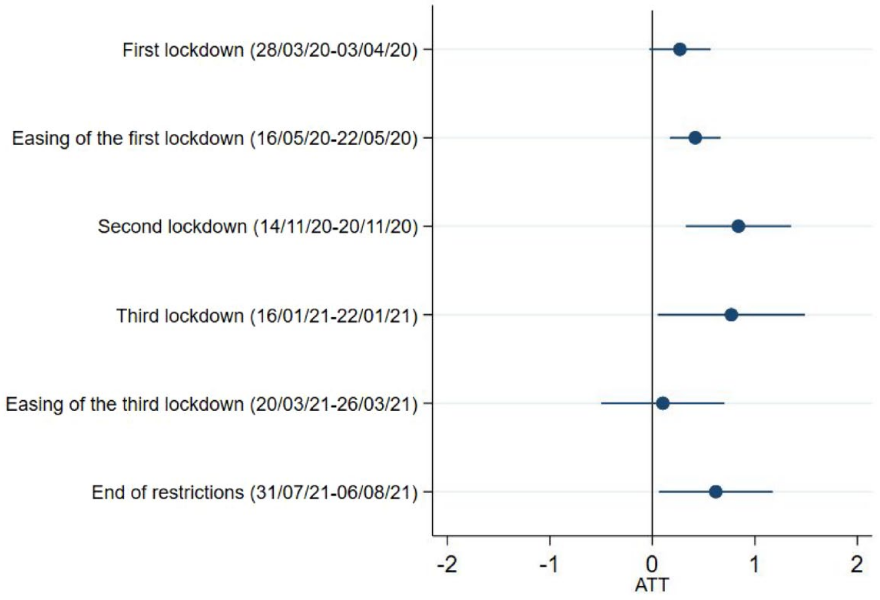
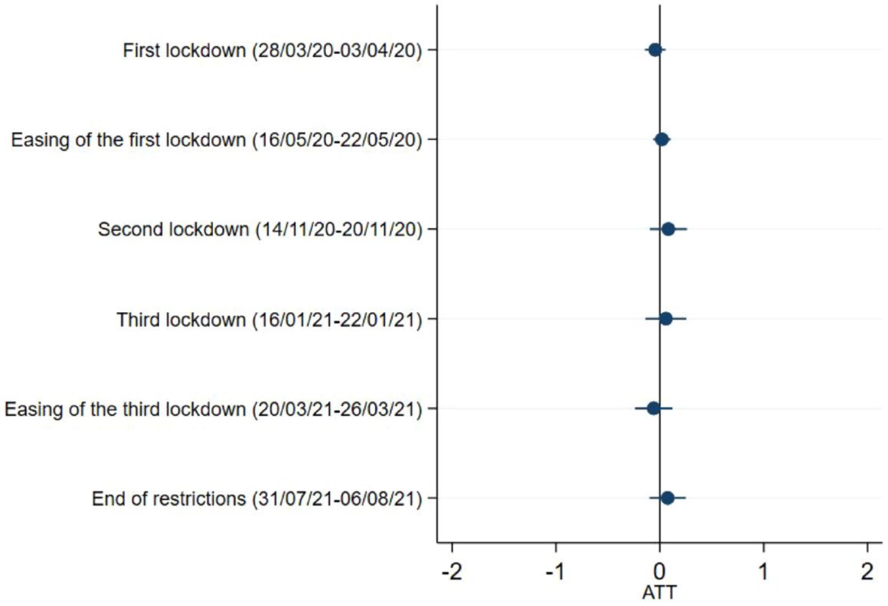


Figure 4

Loneliness



pandemic using data from England. Results showed that informal carers experienced higher levels of depressive and anxiety symptoms than people without caring responsibilities across much of the pandemic. The relationship between being a carer and poorer mental health (particularly for depressive symptoms) was strongest during first and second lockdown and when all restrictions eased in summer 2021. Results were consistent when the sample was restricted to those who reported their mental health being adversely affected by the pandemic. Such differences were independent of socio-demographic backgrounds and personal characteristics, long-term health conditions, and stress about the virus or virus diagnosis. There was no evidence that carers differed from non-carers in loneliness and life satisfaction. However, we found that carers experienced a greater sense of their lives being worthwhile at the beginning of the first lockdown in England, but no difference was found at later time points when the lockdown measures were eased or when new restrictions were introduced. Among people with informal caring responsibilities, those who worked for 3 or more hours a day experienced greater anxiety symptoms when the first lockdown began to ease in comparison to carers who worked for less hours. No difference was found for other outcomes.

Our findings that carers had generally higher levels of depressive and anxiety symptoms during the COVID-19 pandemic are consistent with existing literature before the pandemic highlighting the mental health burden of informal caring[5,7] and with qualitative and small-scale cross-sectional studies during the COVID-19 pandemic.[12–14,23] The negative effect of caregiving can be explained by the chronic stress model. Care provision creates physical and psychological strain over extended periods of time, which is accompanied by high levels of unpredictability and uncontrollability, frequently requires high levels of vigilance, and creates secondary stress due to competing demands in other roles.[5] Chronic stress can lead to psychosocial distress and worsening mental health. The negative experiences associated with caregiving were likely to intensify during the COVID-19 pandemic as a result of cuts to formal care, reduced paid working hours, reduced informal support from other relatives or friends, restricted access to healthcare services, and fear of virus infection.[12,14,15,24] These experiences could be further exacerbated as the intensity for informal caring increased, as demonstrated in our sensitivity analysis that carers who worked for longer hours were more likely to feel anxious.

Figure 5

Life satisfaction

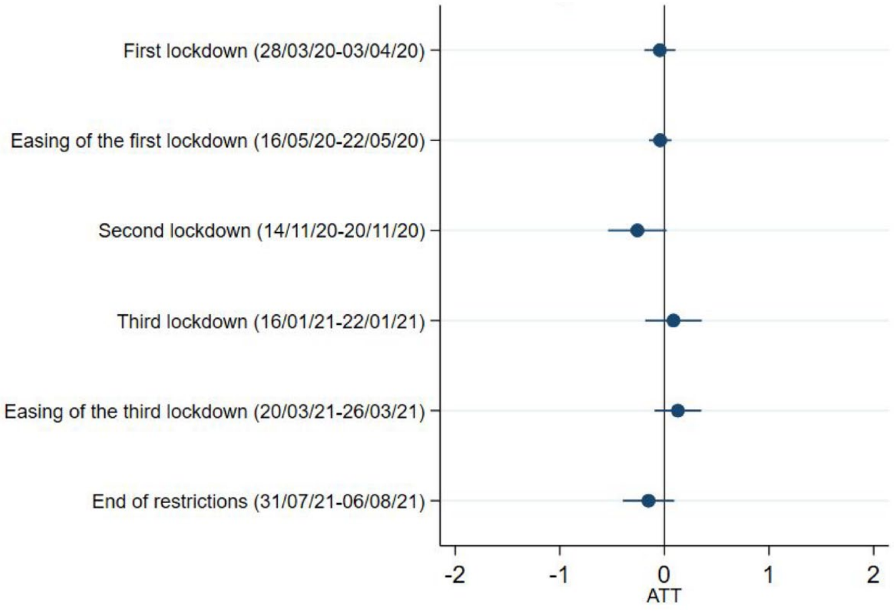
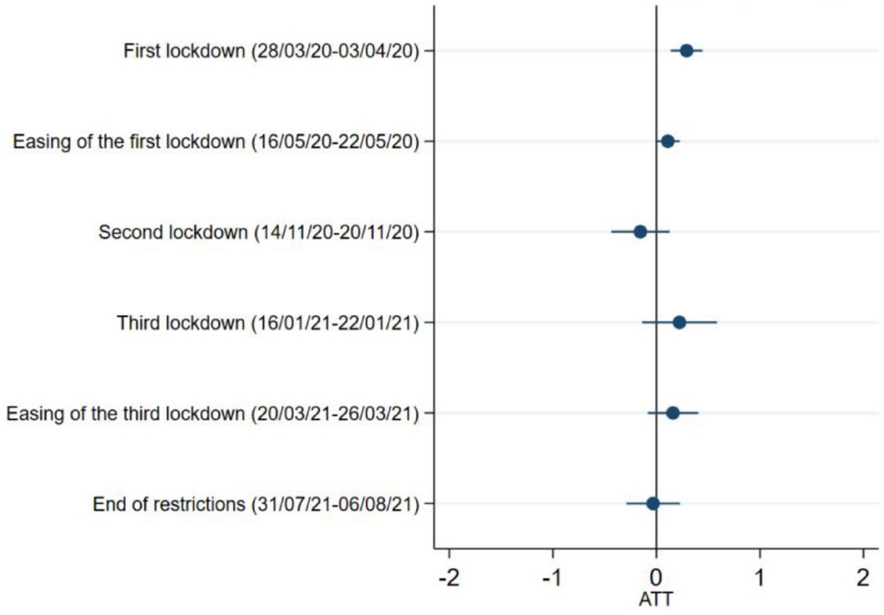


Figure 6

Sense of being worthwhile



In addition to this, our study goes beyond previous finding by showing that the differences in depressive and anxiety symptoms between carers versus non-carers were fairly stable across the different stages and intensities of the lockdown restrictions. Levels of depressive symptoms continued to be higher among carers even when all COVID-19 related restrictions were lifted. There are a number of potential explanations for this. First, it could be explained by a feeling of exhaustion from the ongoing responsibilities lasting over a year. It is also possible that informal carers may have had greater concerns about the relaxation of restrictions, perhaps due to concerns about them or the person they cared for being more at risk again of coming into contact with the virus. It is further possible that with the relaxations, any additional support carers were receiving from friends or other relatives may have decreased as people had more opportunities to engage in usual leisure pursuits. While these results are not especially surprising,[39,40] they are still of particular concern in the context of the pandemic as they suggest that, unlike for the general public,[41] carers' poorer mental health may be less likely to improve even when the lockdown measures were relaxed. Many vulnerable individuals have been more reliant than ever before on their informal carers. So if poor mental health leads to carer burnout, either affecting care during the pandemic or the willingness and capacity to provide care in the aftermath of the pandemic, this could have substantial implications for those individuals but also for the wider health and social care sector, leaving more work to be carried out by formal carers. In light of this, it is critical that informal carers are provided with adequate targeted mental health support.

Our results also provide some greater nuance in our understanding of specific aspects of carer mental health. First, it is notable that anxiety symptoms were only slightly (and not significantly) higher among carers than non-carers during first lockdown. This resonates with research showing a general increase in anxiety among the population as a whole when the pandemic first started, which may have led to a diminishing of the usually reported difference in anxiety among carers versus non-carers.[42] At the same time, our study has shown that carers may also have experienced a greater sense of life being worthwhile compared to non-carers in the early part of the pandemic. This is in line with previous studies that show the positive experience of caregiving, such as gratification, companionship, meaning, sense of purpose, personal growth, and so forth.[9–11] Our findings on worthwhileness provide empirical support for the view that both negative and positive experiences may emerge as independent dimensions as a result of caregiving.[43] However, it is important to note that the difference in worthwhileness between carers and non-carers was only significant at the beginning of the lockdown. A potential explanation is that as the difficult situation unfolded, the initial greater sense of being worthwhile and appreciation by those they were caring for and others within communities may have been gradually eroded by the stresses of providing that care but also by the decreasing social recognition of the role carers were playing during the COVID-19 pandemic. Similar patterns have been noted for formal carers, who experienced greater societal appreciation in the early part of the pandemic (including with the national 'clap for carers') but who simultaneously reported decreasing appreciation from the government as the pandemic continued contributing to poorer morale.[44] Furthermore, it is notable that carers still had higher depressive symptoms at the start of the pandemic, suggesting that this period still took a psychological toll.

It is also notable that we found no evidence that carers differ from non-carers in loneliness and life satisfaction, which seems to contradict to previous studies that show the correlation between being an informal carer and higher levels of loneliness and lower levels of life satisfaction (although results on life satisfaction are less conclusive as it varies across the types of care, the health conditions of the care recipients, the length of care, etc.).[15,43,45,46] Previous studies have suggested that the reasons for these higher levels of loneliness and lower levels of wellbeing are that care provision is a time and energy consuming task that can restrict carers' personal and social life. Indeed, a report from Carers UK showed that nearly half of the carers reported not having time to spend on social activities and difficulties being able to leave the house.[46] However, such feelings may have changed in the context of the COVID-19 pandemic, although reports suggest loneliness and social isolation remained a challenge for many carers.[15] Due to the lockdown and social distancing measures, face-to-face social activities were greatly restricted for the whole population. As a consequence, caring responsibilities may have reduced feelings of isolation among carers as others experienced some of the same social restrictions that they faced before the pandemic, and carers may have felt less of a sense of missing out. As carers had some exemptions from the 'stay at home' orders to visit the people they cared for, they might also have been able to maintain companionship during these difficult times. This is supported by a report showing that two in five young carers and one in five young adult carers built a stronger relationship with the person they were caring for during the pandemic[22] and nearly three in five carers reported being able to keep in touch with family and friends despite the lockdown measures.[15] It is also possible that the gap in the levels of loneliness and life satisfaction between carers and non-carers was reduced as a study has shown that mental health has worsened for the general population in the UK.[19]

This study had several limitations. First of all, the UCL COVID-19 Social Study did not use a random sample, therefore our sample is not representative of the population. However, the study does have a large sample size with wide heterogeneity, including good stratification across all major socio-demographic groups, and analyses were weighted based on population estimates of core demographics, with the weighted data showing good alignment with national population statistics and another large-scale nationally representative social survey.[47] But we cannot rule out the possibility that the study inadvertently attracted individuals experiencing more extreme psychological experiences, with subsequent weighting for demographic factors failing to fully compensate for these differences. Moreover, like many other longitudinal studies, attrition remains an issue in our study and hence there was heterogeneity in our samples across the six time points. Second, the UCL COVID-19 Social Study did not collect any information before the pandemic. Therefore, we were not able to compare the average treatment effect of being a carer before and during the pandemic. Further work is needed to understand if the pandemic has heightened the mental health risk for carers compared with usual times. Third, this study treated carer status as a binary variable, without further exploring the intensity of caregiving (although a sensitivity analysis was run for the first few months of the pandemic), which has important implications for carers' mental health and wellbeing. It is unknown whether individuals took on new informal caring responsibilities during the pandemic or withdrew from usual informal caring roles. Therefore, future work is needed to examine the role of care intensity and how fluctuating patterns of care affected mental health.[14] Relatedly, while PSM can effectively control for observed confounding factors and can stimulate an experimental study on an observational dataset where an experimental setting is not feasible, it is unable to capture unobserved confounding factors. Therefore, future studies are needed to ascertain how experiences of carers versus non-carers varied depending on the type of care provided, the quality of the relationship between carers and the care recipients, and the health conditions of the care recipients. Finally, our analysis focused on comparisons between carers and non-carers at different time points in the pandemic, using PSM to control for confounding variables. However, this analysis did not show how the trajectories of mental health and wellbeing changed for carers versus non-carers, and this topic could be the focus of future research.

CONCLUSION

The severe lockdown and social distancing measures implemented to control the spread of Covid-19 led to increasing burden for informal carers. The results of this study support some previous literature suggesting that carers were more likely to experience higher levels of depressive and anxiety symptoms during the pandemic, as in non-pandemic circumstances. But they build on these findings by quantifying this difference and showing how the mental health experiences changed in line with changing social restrictions during COVID-19. Carers were also more likely to feel a higher sense of life being worthwhile compared to non-carers, but this effect was attenuated after the first lockdown. In contrast to the existing studies, we found no differences in loneliness and life satisfaction between carers and non-carers, suggesting either that the companionship provided through caring during lockdown and social solidarity in experiencing social restrictions may have offered some emotional benefits to carers, or that worsening levels of personal and social wellbeing among non-carers (as documented in previous studies) closed the gap between the experiences of carers and non-carers. As carers are an important support to the national healthcare support, it is therefore crucial to integrate their needs into healthcare planning and delivery, especially when the health service is stretched as during this pandemic. While there is some existing support available to carers, the results presented here highlight the importance of ensuring adequate and targeted mental health provision to support carers during and following this pandemic so that they are able to continue their vital work.

ACKNOWLEDGEMENTS

We are very grateful to all participants in the COVID-19 Social Study.

AUTHOR CONTRIBUTIONS

FB conceived the study. HWM conducted the data analyses. HWM, FB, and DF wrote the first draft. All authors provided critical revisions. All authors read and approved the submitted manuscript.

CONFLICT OF INTEREST

The author(s) declared no potential conflicts of interest with respect to the research, authorship, and/or publication of this article.

ETHICAL APPROVAL AND CONSENT TO PARTICIPATE

Ethical approval for the COVID-19 Social Study was granted by the UCL Ethics Committee. All participants provided fully informed consent. The study is GDPR compliant.

FUNDING

The author(s) disclosed receipt of the following financial support for the research, authorship, and/or publication of this article: This COVID-19 Social Study was funded by the Nuffield Foundation [WEL/FR-000022583], but the views expressed are those of the authors and not necessarily the Foundation. The study was also supported by the MARCH Mental Health Network funded by the Cross-Disciplinary Mental Health Network Plus initiative supported by UK Research and Innovation [ES/S002588/1], and by the Wellcome Trust [221400/Z/20/Z]. DF was funded by the Wellcome Trust [205407/Z/16/Z]. The researchers are grateful for the support of a number of organisations with their recruitment efforts including: the UKRI Mental Health Networks, Find Out Now, UCL BioResource, SEO Works, FieldworkHub, and Optimal Workshop. The study was also supported by HealthWise Wales, the Health and Care Research Wales initiative, which is led by Cardiff University in collaboration with SAIL, Swansea University. The funders had no final role in the study design; in the collection, analysis, and interpretation of data; in the writing of the report; or in the decision to submit the paper for publication. All researchers listed as authors are independent from the funders and all final decisions about the research were taken by the investigators and were unrestricted.

PPI

The research questions in the UCL COVID-19 Social Study built on patient and public involvement as part of the UKRI MARCH Mental Health Research Network, which focuses on social, cultural, and community engagement and mental health. This highlighted priority research questions and measures for this study. Patients and the public were additionally involved in the recruitment of participants to the study and are actively involved in plans for the dissemination of findings from the study.

ORCID IDS

Hei Wan Mak https://orcid.org/0000-0002-2013-1644
Feifei Bu https://orcid.org/0000-0003-2060-3768

AVAILABILITY OF DATA AND MATERIALS

Anonymous data will be made available following the end of the pandemic.

SUPPLEMENTAL MATERIAL

Supplemental material for this article is available online.

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Exploring pregnant women’s experiences of stopping smoking with an incentive scheme with ‘enhanced’ support: a qualitative study

Abstract

Aim

This study aims to understand pregnant women’s experiences of smoking cessation with an incentive scheme in a deprived UK city. This is important because smoking cessation with pregnant women is one of the most important public health initiatives to promote, and is particularly challenging in deprived areas. Whilst financial incentive schemes are controversial, there is a need to better understand pregnant women’s experiences. The scheme combined quasi-financial incentives (shopping vouchers) for validated quits (carbon monoxide validated at <10ppm), enhanced support from smoking cessation advisors, the opportunity to identify a ‘Significant Other Supporter’ and Nicotine Replacement Therapy.

Methods

With the focus on understanding pregnant women’s experiences, a qualitative design was adopted. Semi-structured interviews were completed with 12 pregnant women from the scheme, and the three advisors. All interviews were transcribed, and thematic analysis conducted.

Results

Pregnant women reported various challenges to quitting, including long-established routines, and stress. Participants were aware of stigma around incentives but were all very positive about the scheme. The relationship with advisors was described as fundamental. The women valued their advice and support, whilst uptake of the ‘Significant Other Supporter’ appeared low. Participants viewed the carbon monoxide monitoring as ‘an incentive’, whilst the vouchers were framed as a ‘bonus’. Advisors perceived the vouchers as helping engage pregnant women and maintain quit status, and women appreciated the vouchers both as financial assistance and recognition of their accomplishments.

Conclusion

This study highlights the great value women placed on the support, advice and monitoring from specialist advisors. The distinction between vouchers as a welcomed bonus, rather than ‘the incentive’ to engage, is important. How smoking cessation and schemes to promote this are communicated to pregnant women and health professionals is important, particularly given the stigma and controversy involved.

Key words – smoking cessation; pregnant women; health inequalities; health promotion; incentive scheme; qualitative research

Introduction

Smoking cessation in pregnancy is an important and beneficial public health initiative [1]. As well as the detrimental health effect on the woman [2], there is significant risk to the foetus, including placental abnormalities, low birth-weight and sudden unexpected death in infancy [3-4]. Smoking in pregnancy is complex and poses a challenge for health promotion initiatives designed to facilitate change [5-7]. Research suggests complexity is heightened for disadvantaged pregnant women [5, 8-9]. For example, stopping smoking affects relationships and social networks where smoking is the norm [8]. This is important to recognise, given that smoking is a major contributor to health inequalities in England, with those who live in the most deprived areas more likely to smoke and less likely to quit [10-11]. The Public Health England Profile (2019) for the region in which this study was conducted (in the West Midlands) is characterised by high levels of deprivation, smoking in pregnancy, and infant mortality [12].

Financial incentive schemes have been subject to controversy but there is growing evidence from the United States (US), the United Kingdom (UK) and France, that they are effective in supporting pregnant women to stop smoking [e.g., 5, 13-18]. Challenges around the large variability of settings, differing intervention designs and lack of conclusive, seminal studies have been linked to the slow implementation of incentives in clinical practice with pregnant women who smoke [18].

Incentive interventions are often multifaceted, with additional components to support smoking cessation, such as counselling and social support [19]. For example, a ‘Significant Other Supporter’ (SOS) scheme found the combination of ‘bolstered’ social support and financial incentives increased quit rates [5]. With the multifaceted designs, few studies are directly comparable; context may have a moderating effect on such interventions [19].

Whilst psychosocial interventions are known to be effective, it is unclear precisely ‘how’ and ‘for whom’, with questions remaining around implementation and dissemination [13]. Caution is urged in attributing the apparent success of financial incentive schemes to the use of incentives per se, rather than more intricate details about how the schemes operate [20].

In the UK, more research is needed to examine whether financial incentives are a beneficial and cost-effective way to help pregnant women stop smoking [6]. Schemes have been piloted with promising results [21-24]. Changes in policy and practice are needed to reflect the ‘compelling evidence of benefit’ of financial incentives for pregnant women [25]. Incentive schemes appear to encourage pregnant women from socially deprived communities to stop smoking [15, 18, 24].

Nevertheless, pregnant women in the UK, their significant others and hospital professionals all had mixed views about the use of financial incentives, highlighting moral arguments and questioning the extent to which the quit would be maintained [7]. More research is required to enhance understanding of potential new initiatives, including financial incentives [7]. Qualitative research has an important role to play in understanding such views and experiences.

This qualitative study formed part of a service evaluation of the incentive scheme (detailed below), focussing on pregnant women’s experiences of stopping smoking with the scheme, and the perceived impact of ‘incentives’.

The scheme

The scheme combined quasi-financial incentives (vouchers) with ‘enhanced support’ ((i.e., regular (at least 4-weekly) support from stop smoking advisors, throughout pregnancy and for 12 weeks after)).

All pregnant women who smoked were invited to participate in the incentive scheme by their midwife. They could be referred into the scheme at any point during pregnancy. The maximum amount they could receive was £260 worth of gift vouchers – if recruited early in pregnancy and remained quit until 12 weeks postpartum (all quits had to be carbon monoxide (CO) validated (<10ppm)). They received: £20 voucher at two weeks quit, four weeks quit, and at every subsequent (continuous) four week quit point until delivery, and £60 at 12 weeks post-partum.

Women were also invited to identify a 'Significant Other Supporter' who was a non-smoker or would quit alongside her and provide support in the social setting. The SOS was entitled to receive £40 worth of gift vouchers if the pregnant woman remained quit at 12 weeks postpartum and they themselves were smoke free (CO validated as <10ppm). A range of Nicotine Replacement Therapy (NRT) products were also provided to the pregnant woman at no-cost.

The scheme commenced in May 2016 and had 57 clients at the time of evaluation (client characteristics at baseline were: mean (SD) age 27.3 (6.2) years; 17.6 (7.9) weeks gestation, 58% living with children and 72% living with a partner who smokes). The qualitative data collection took place between May 2017 and December 2017.

Method

This was a qualitative descriptive study [26-28], which reflected the study's position within a wider service evaluation of the scheme. Qualitative data was generated from semi-structured interviews with a purposive sample of 12 pregnant women on the scheme, and all advisors involved in delivery (n=3).

Recruitment of pregnant women

To align with the scheme measuring quit rates at four weeks, 12 weeks and 12 weeks post-partum, we aimed to recruit pregnant women at each of these time points for interview. Thus, purposive sampling was used to select information rich cases [29]. Advisors facilitated recruitment and invited all women they met at one of the timepoints to participate in an interview (regardless of quit status). Advisors talked about the evaluation during routine appointments and went through the participant information sheet. If the client consented to their information being passed to the researchers, the advisor called the researcher to discuss further and arrange an interview if the client was happy to proceed. Participants were assured that this was voluntary. They were reminded that they could change their mind and cancel the interview at any time. This process continued until the quota of women had been reached for each time point; we intended to interview five at each timepoint but at the time of data collection, only two at the postpartum stage were willing to take part.

Data collection with pregnant women

Interviews were conducted at participants' homes or community venues and explored perceptions of the scheme and impact, including specific elements (i.e. the support from the advisors, the incentives, and the SOS element). Interviews were conducted by the second author and two research assistants, all non-smokers, and experienced in qualitative research. Participants were made aware that the researchers were separate to the scheme and were interested in their experiences.

Recruitment and data collection with advisors

All advisors involved in the scheme's delivery participated in a one-to-one interview (n = 3) at their workplace. Interviews focused on perceived challenges, benefits and impact of the scheme, and recommendations for future delivery.

Participants

Table 1 shows the sample and pseudonyms used.

Table 1: Participant sample and pseudonyms (n=15)

4-week quit mark	12-week quit mark	12-week post-partum quit mark	Advisors
Debbie Lucy Beverley Megan Catherine	Olivia Sophie Donna Maggie Felicity	Jane Nicky	Alex Lisa Mary
n=5	n=5	n=2	n=3

No further demographic data were collected from participants.

Ethics

Ethical approval was gained from the University's Ethics Committee. The interviewer gained informed signed consent from all participants. All participant documents were shared with a project advisory group (consisting of the service provider and local authority) and representatives of the target audience to ensure they were appropriate. Participants were also given a list of relevant support services, including, bereavement, miscarriage, and relationships.

The researchers did not disclose the names of any women who completed an interview to advisors. It was made clear that advisors would not be told what they personally had said and that their names would not be shared. All identifying information has been removed.

Data analysis

Interviews were audio-recorded and transcribed verbatim. Thematic analysis focused on identifying, analysing and reporting patterns within the data [30-31], guided by the aims and objectives of the study. The emphasis was on generating a descriptive summary of the information, organised in a manner that best fits the data [26]. Generating the themes was a creative and active process [31] undertaken by two researchers (not involved in data collection). Thematic maps were created to assist this process [27]. The two researchers discussed the thematic maps and any differences in how the data had been interpreted and organised, to cross-check interpretation and reduce/acknowledge potential bias. However, as the interpretation required was 'low inference' [26-28] there was much consensus between the researchers' interpretations. All researchers refined and agreed the final themes.

Results

Three main themes were identified: (1) Challenges to quitting: "Not smoking has been really hard", (2) Importance of the support from advisors: "I just couldn't stop on my own", and (3) Vouchers as 'a bonus', not the incentive.

1) Challenges to quitting: "Not smoking has been really hard"

For most participants, smoking had been an entrenched part of their daily routines. They regularly talked about smoking 10-20 a day, often since school and/or for more than 10 years. A need to '*break the cycle'* (Jane) was frequently reported and that giving up, despite them wanting to do so, was not easy:

> *"Literally since I have left school I have smoked every single day. My morning was get up, have a cup of tea and have a fag [cigarette]. That was my life, so not smoking has been really hard" Sophie*

Participants identified stress as having played a large part in their smoking, linked to relationships breaking down, tensions with wider family, parenting, and work. For some, stress was talked about as the reason why they originally started or as a routine response to stress and/or to help them cope with anxiety.

There were concerns among participants about stress impacting negatively on the baby:

> *"It got to a point (with work) where it was like, I am that stressed, would it be better for the baby for me to smoke so I am not stressed or should I just risk the stress...what do I do?" Sophie*

The women often described smoking as the norm within their social circles, including partners, friends and other family members. After being asked what the hardest part about quitting was, Maggie responded:

> *"Obviously, my partner smoking and everything, and it's like a lot of my family will smoke, so it's like … yeah, so everyone smokes …" Maggie*

This theme was consistent across advisor and pregnant women interviews. Advisors, whilst acknowledging the support of someone in the women's social setting was helpful, felt that most potential SOSs did not want to engage officially in the scheme as it required them to quit alongside her. However, it is worth acknowledging that the SOS did not have to be their 'partner'. Indeed, one of the advisors highlighted that one woman (not interviewed) had selected a female friend as her SOS and they supported each other to quit smoking.

A broader challenge related to the controversy surrounding incentives for smokers, alluded to by advisors and clients. They seemed acutely aware of stigma and negative public opinion, including social media and local press coverage of the scheme:

> *"I know there has been a lot of stigma over these vouchers. Why should women get paid for giving up smoking when they are pregnant when there are women who can't have babies and they don't smoke and all that. So I know… I have read all that on Facebook" Beverley*

Advisors also referred to negative attitudes of health professionals, including some midwives:

> *"A few of the pregnant ladies say that the midwives can be quite sharp with them, because they are smoking during pregnancy and it puts them off coming" Mary*

With such controversy, there had been limited communications about the scheme. This is important because client engagement can be hindered by a lack of (accurate) information about the scheme. Both staff and clients highlighted that there seemed to have been some misunderstanding/miscommunication (often at the time of referral) about aspects of the scheme, such as eligibility, the requirements for vouchers, weighting of vouchers and the SOS.

2) Importance of the support from advisors - "I just couldn't stop on my own"

Most of the women interviewed had tried to cut down when trying to conceive or upon learning they were pregnant. Three women explained experiences of health problems for themselves or their children as strengthening their motivation. Participants talked about their mindset as being fundamental to quit smoking; if they personally felt they wanted to or needed to quit, they were determined to achieve and maintain this. However, they perceived the scheme as integral to their success because they felt they needed that extra support to stop completely. This was captured by Megan's explanation that "*I just couldn't stop on my own*". Overall, participants placed great value on the regular, one-to-one support and specialist advice from the stop smoking advisors, and the CO monitoring.

Consistent across the client and staff interviews was the importance of the relationship with advisors and the regular support they provided. All clients expressed strong gratitude to the advisors, and described feeling that the advisors were rooting for them and that it was "*more personal*" (Nicky) than other smoking cessation services:

> *"It was nice to have the support. It was nice, like I say, to have someone. It felt like someone was doing it with me ... I just didn't feel like I was doing it on my own" Felicity*

Some clients did not want to let the advisors down. Personal qualities of the advisors were often mentioned as important, including their friendliness, accessibility, motivational skills and non-judgemental attitudes:

> *"She will even ask about your home life and that can affect you smoking/not smoking, the day to day stresses of life. So I think the support is absolutely brilliant. I have been lucky with my support worker. She genuinely cares" Olivia*

Linked to the perceived challenge of stress, stress-management advice and support to replace long-established smoking routines appeared to be a key part of discussions with advisors:

> *"It helps being able to talk to someone about it, she helps me with advice like how I can divert from wanting a cigarette, go and do something" Lucy*

Advisors also regarded building rapport with clients as an important part of their role, and to help the clients better understand their habits to provide the best opportunity possible to quit:

> *“I think a lot of people get in a bit of a mess and they have tried different things, but it is not what you use, it is how you use it and it is how you would put the behavioural changes as well… I am helping them to understand their smoking a bit more and piece everything together” Lisa*

The range of NRT products available (such as the patches, gum, mints, inhaler) were framed as positive, particularly within the early stages. Whilst several of the participants had tried NRT in the past, the wide choice at no cost was valued – as was the option to keep trying until finding the ‘*right one for you*’:

> *“Nicotine replacements are very expensive and for people that can’t afford… it is good that they do provide that for you and you haven’t got to pay anything too… even though smoking is expensive, also quitting smoking is expensive” Olivia*

3) Vouchers as ‘a bonus’, not the incentive

The women interviewed framed the vouchers as more of an added ‘*bonus*’ or reward rather than an ‘*incentive*’ per se. They often stressed that they would have quit with or without the vouchers, because of the health of their baby and the support of the advisor:

> *“… even if they didn’t have like the incentive of the actual vouchers, it is still the support, having that person to talk to and that person that will give you advice and everything…” Lucy*

Nevertheless, participants appreciated receiving the vouchers both in terms of the financial value and in recognition of the hard work involved in maintaining a quit:

> *“… even if the vouchers didn’t exist, I would have still done how I have done now… it is nice to get a little reward for doing your hard work” Debbie*

Throughout the advisor interviews, the vouchers were regarded as a key motivator for sustained engagement and quit status. Advisors talked about the voucher incentive as helping to attract pregnant women and ‘*get them in the door*’, particularly in the context of a deprived city:

> *“…people are living off the breadline and these vouchers do help… it is quite a carrot for a lot of people, especially as a lot of people (here) haven’t got much money” Alex*

They also believed that once engaged, the vouchers encouraged clients to maintain their quits:

> *“It (receiving vouchers) actually motivated people, definitely I have had a few clients come on and said that they don’t actually have a lot of money and they struggle and the vouchers have definitely given them a push and the motivation to quit smoking” Mary*

Indeed, clients talked about saving vouchers up so they could look forward to a ‘*big shop,*’ most frequently for items for the baby or towards the expense of Christmas:

> *“I’ve saved them up (the vouchers). I bought the baby one or two things and the rest are going towards Christmas” Nicky*

During the appointments, clients were required to provide a CO reading to confirm quit status before vouchers could be given. This monitoring and feedback element appeared an important and valuable part of the scheme. It was often talked about as ‘*an incentive’* (e.g., Jane, Olivia and Debbie) that ‘*makes you think an awful lot*’ (Olivia). The objective measure confirming their quit status reinforced their sense of achievement and pride in their accomplishments:

> *"Even with the CO reading you feel like you have achieved something… It was less than half… it was there to see. I had done so well" Olivia*

Moreover, there was often a sense that the women felt healthier after they had quit:

> *"I am a lot healthier. I can feel the difference in my health. I am not as out of breath as quick, I am a lot more energetic…considering I am pregnant as well" Donna*

Discussion

The study identified various challenges for pregnant women living in a deprived area, to quit smoking. Clients were generally heavy smokers for whom smoking was an entrenched part of their daily routine. Previous research has shown that women emphasise the benefit of supportive relationships when making lifestyle changes [32], yet partners, family members and the women's wider social circle often continued to smoke, which is a known barrier to smoking cessation [33]. This may explain the low uptake of the SOS element of the scheme and further consideration is warranted.

Smoking was common (and socially acceptable) among clients' family and friends. Previous research has found that stopping smoking can affect relationships and social networks where smoking is the norm [8]. A family approach to support and education around these potential risks may increase uptake of the SOS scheme to facilitate maternal smoking cessation. Additionally, SOSs within this scheme would have been entitled to a relatively small amount (£40) if they and the pregnant woman were verified as quit at 12 weeks postpartum. This contrasts a previous SOS programme in the US where the SOS received monthly vouchers if the pregnant woman remained quit [5].

Echoing previous qualitative research, current and future stress appeared to play a large part in their smoking and was identified as a key challenge [8]. Managing stress and techniques to help with this postpartum would be worth exploring further with pregnant women [34].

Exploring with clients any other benefits since quitting may also help to support a quit longer term. A longer-term follow up to understand the impact on their smoking status in the first year postpartum and beyond is needed.

Clients expressed their gratitude to the stop smoking advisors. The multi-faceted nature of this scheme appears to facilitate the capability, opportunity and motivation of the women to quit smoking [35]. Clients valued the support of the advisor first and foremost, and the NRT products available to them free-of-charge. In deprived communities, for whom purchasing such products may not seem an affordable option, this may be beneficial, particularly when trying to ascertain which product works best for them.

This study identified motivating factors other than monetary. The CO monitoring was often framed as '*an incentive'* – to see an objective measurement confirming their quit status appeared to provide extrinsic motivation and reinforce their sense of pride and achievement. This echoes a larger, mixed methods evaluation of a smoking cessation scheme that combined financial incentives (and CO testing), behavioural support and pharmacotherapy [16]. In wider research there seems to be no difference in success rates based on the monetary value of the incentive [17], which further echoes the vouchers viewed as a bonus alongside existing cessation strategies.

The women interviewed described '*wanting to quit'* because of pregnancy or having *'tried to cut down'*, supporting the need for women to be at the contemplation or preparation stages identified within the Transtheoretical model (TTM) of health behaviour change to successfully quit smoking and maintain this status [36]. This may be why clients who were already preparing to quit, saw monetary vouchers as more of a '*bonus*' or '*reward*' rather than an '*incentive*' to stop smoking. Social influence and perceived social judgement could have affected this; participants were acutely aware of the controversy around pregnant women receiving vouchers for quitting. This may have shaped their responses in interviews, and indeed to advisors, to avoid potential negative judgement. Findings support previous research around the mixed views of pregnant women about the use of financial incentives to support smoking cessation [7].

The cautionary note remains, about attributing the apparent success of incentive schemes to the incentives alone, rather than more intricate details about how the scheme is delivered (e.g., around CO monitoring and receiving feedback) [20]. Clients valued the advice, support (including NRTs), and monitoring (of CO readings) that came with the advisor as part of the enhanced support package. Therefore, it is hard to disentangle what is driving the reported success of the scheme. It may not be appropriate to isolate the different aspects of the scheme however, as they appear inextricably linked [16].

Arguably, there is a need for more openness and transparency around such incentive schemes and evaluations, to recognise the role they play in building the evidence-base. The language of ‘incentive scheme’ may do little to limit the controversy and stigma that surrounds such schemes.

Our study resonates with previous research that (pregnant) smokers from deprived areas benefit from more intensive, flexible and personalised support [9]. A ‘less prescriptive approach’ to providing smoking cessation services may improve cessation rates in such areas [9]. However, we would highlight that such flexibility can present a challenge for evaluating, building the wider evidence base and demonstrating the impact of such schemes. Further qualitative data collection with all groups could help better understand the more intricate details about how schemes operate [20].

Strengths and Limitations

Drawing on qualitative research can help better understand how to support women when developing public health promotions and cessation schemes [37]. In this study, the combination of interviews with both advisors and clients helped to triangulate results and provide more contextual information about elements of the scheme.

Further research is needed to explore the transferability of these findings and their application to other incentive schemes and other geographical areas. As noted, no demographic data were collected from clients, which would have allowed more detailed exploration of their responses and any differences within the sample. Ultimately, the purpose of this study was to provide a descriptive summary of the patterns across the dataset [26]. The potential of selection bias in the client interviews is acknowledged; we did not manage to include pregnant women who had been unsuccessful in quitting or had disengaged, and clients were recruited through the scheme's advisors.

Conclusion

Pregnant women in deprived areas face various challenges to quitting smoking. This study found that a multi-faceted approach was valued by pregnant women, attaching great importance to the support, advice and monitoring from specialist advisors. The women's distinction between vouchers as a (welcomed) bonus rather than 'the incentive' should be recognised. This study underlines the importance of how information about smoking cessation and associated schemes are communicated to pregnant women, and health professionals, particularly given the stigma and controversy involved.

Acknowledgements

NB. Acknowledgements removed to facilitate anonymous peer review; uploaded separately

Ethical approval was gained from *(*name omitted for anonymous peer review)* University's Ethics Committee. No funding was received for this study.

Conflict of interest

The authors declare no conflict of interest.

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