

Deaths from COVID19 reviewed as part of the LeDeR programme

Pauline Heslop, programme lead at the University of Bristol

Introduction

This short paper describes key information relating to 50 people with learning disabilities whose death has been attributed to COVID19. Each of the people have had their death reviewed as part of the Learning Disabilities Mortality Review (LeDeR) programme.

The aim of the paper is to highlight those aspects of the condition itself, or the care provided to those who have died, that can inform a better understanding of COVID19 as relevant to people with learning disabilities. The objectives are to:

- Describe the symptoms and presentation of COVID19 in a sample of 50 people with learning disabilities.
- Describe the circumstances of their death.
- Extract any learning for future service provision in relation to COVID19 in people with learning disabilities.

Key findings

Numbers are small so care needs to be taken when interpreting these findings or communicating our analyses, but from the 50 completed reviews of deaths related to COVID19 there are six broad conclusions:

1. Mobility impairments and/or mental health needs may be proxy indicators of people at risk of catching the virus, or may underpin prejudicial attitudes towards care, treatment and judgements about ceilings of care.
2. It would seem appropriate to consider people with learning disabilities and epilepsy as being at increased risk of death from the virus and pay attention to protecting them.
3. The key symptoms of COVID19 in the general population (fever, new continuous cough, loss of sense of smell or taste) may not be as apparent in people with learning disabilities.
4. The use of DNACPR decisions and the initiation of palliative/end of life care should be monitored to ensure that this population is not being disadvantaged.
5. Close attention needs to be paid to safe and appropriate hospital discharge planning. One in five of the completed reviews indicated that the person had previously been discharged from hospital, only to be readmitted again soon afterwards.
6. Additional resourcing for specialist learning disabilities staffing and expertise in primary and secondary care appears to be indicated from the findings of this small study.

The 50 people who have died

The sample of 50 people have been purposively selected – they are the first 50 completed reviews that have been received by the University of Bristol for analysis. This is not therefore a representative sample of those who have died from COVID19 in England. The outbreak of the virus was initially concentrated in London before spreading in an uneven pattern across the rest of England. The completion of the LeDeR programme reviews of death was also dependent upon staff availability to do so, when many reviewers were redeployed to clinical work at a time of great pressure in health and care services. This should be borne in mind when considering the analyses.

Over half (56%) of the 50 reviews were of people from the Midlands, 38% from London and a small proportion from the North West.

All of the deaths occurred between 19th March and 19th May 2020.

Of the 50 deaths in question, 60% were of males and 40% of females. This is similar to the overall deaths reported to LeDeR in 2019 (58% males, 42% females). Office for National Statistics (ONS) data for the general population of England and Wales reports mortality from COVID19 of 55% males and 45% females¹.

The majority of the people with learning disabilities (70%, n=35) were aged 50-74 years (the comparative figure for deaths reported to LeDeR in 2019 was 61%). Fewer than ten² of those included in the 50 reviews of deaths related to COVID19 were aged under 50; fewer than 10 were aged 75 or over. By contrast, (ONS) data for the general population of England and Wales reports that 47% of deaths were in people aged 85 years and over³.

People from Black, Asian or Minority Ethnic Groups (BAME) are disproportionately represented in the sample of people with learning disabilities: 60% are white British and 40% from BAME groups. The overall proportion of deaths notified to LeDeR in 2019 was 90% white British and 10% from BAME groups. This is a similar trend to that found in general population data⁴.

A small number (10%) of the completed reviews did not report the level of a person's disabilities. 36% had mild learning disabilities; 28% had moderate learning disabilities; and 26% severe disabilities. There are no deaths of people with profound/multiple learning disabilities included in the 50 completed reviews although these accounted for 10% of deaths notified to the LeDeR programme overall in 2019.

The usual residence of the 50 people in this sample is fairly evenly spread: 30% lived in their own or their family home; 26% had supported living arrangements; and 20% lived in a residential home. Fewer than 10 people lived in a nursing home, and fewer than 10 in any other form of usual residence.

Of the 50 people in the sample of 50 deaths, 15 had Down's syndrome.

¹<https://www.ons.gov.uk/peoplepopulationandcommunity/healthandsocialcare/conditionsanddiseases/articles/coronaviruscovid19roundup/2020-03-26#coviddeaths>

² Numbers fewer than 10 have been suppressed to protect confidentiality.

³ As above.

⁴ As above.

Multimorbidity (the presence of two or more long-term health conditions) is common in people with learning disabilities⁵ and almost all of the sample of 50 completed reviews had two or more long-term conditions; all had at least one long-term condition. Table 1 shows the most commonly reported long-term conditions in the sample of 50 deaths.

Many of these mirror the known long-term health conditions that place people at risk of developing COVID19⁶, but others (e.g. mobility impairment, mental health needs) are not. It may be that people with mobility impairment and mental health needs are more vulnerable because they require regular and sustained contact with other people for support, but we must also alert to, and guard against, decisions to treat based on existing impairments.

Table 1: The most commonly reported long-term health conditions		
Condition	Number	%
Mobility impairment	32	64%
Cardiovascular problems (most commonly hypertension)	27	54%
Epilepsy	18	36%
Mental health needs	17	34%
Obesity	15	30%
Dementia	14	28%
Respiratory conditions	12	24%
Diabetes (Type I or Type II)	10	20%

The deaths of the 50 people with learning disabilities

Symptoms of COVID19

A wide range of symptoms that the person was unwell with COVID19 were reported in the sample of 50 reviews. These are summarised in Table 2 below. The most frequently reported symptoms were difficulty breathing, cough or fever. Almost all (86%, n=43) had one or more of these three most commonly reported symptoms; just over half (54%, n=27) had two or more of these three symptoms; fewer than 10 people had all three symptoms.

Of note is that none of the reviews noted that the person had lost their sense of smell or taste, although this is signal symptom in the general population. It may be that this is difficult to determine in some people with learning disabilities, particularly those who are unable to report this verbally. Perhaps a better indicator is loss of appetite in this respect, but this was reported in fewer than 10 of the 50 deaths.

⁵ <http://www.bristol.ac.uk/sps/leder/resources/annual-reports/>

⁶ https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/892085/disparities_review.pdf

Table 2: The most commonly reported symptoms of COVID19

Symptom	Number	%
Difficulty breathing	27	54%
Cough	26	52%
Fever	25	50%
Generally unwell	<10	*
Loss of appetite	<10	*
Lethargy/tiredness	<10	*
Recent urine or chest infection	<10	*
Diarrhoea or vomiting	<10	*
Other symptoms	<10	*
No symptoms	<10	*

A small number of the 50 reviews noted that the person had exhibited no symptoms of COVID19 prior to their death. It may of course be that the person did have symptoms but that these had not been recognised. Of note is that a small number had been treated for urine or chest infections in the preceding fortnight or so.

Likely source of infection

Clearly it is difficult to be sure about the likely source of COVID19 infection of a person, so these are tentative findings. Of the 50 completed reviews, it appears that the majority of infection sources were in the community (42%, n=21) or the person's usual place of residence (40%, n=20). Fewer than 10 people were thought to have been infected in hospital.

Treatment for COVID19

Information about the treatment a person received once their symptoms had been recognised is patchy in these 50 reviews, with 12 reviews not describing this at all. We would therefore urge caution in interpreting this data as it may be the case that reviewers were not aware of all the treatments received.

Of the 38 reviews that do describe the treatment received, the majority note that the person received antibiotics (63%, n=24) or oxygen (60%, n=22). Fewer than 10 people received mechanical support with their breathing (full or non-invasive ventilation) and a very small number (fewer than 10) received full treatment in an Intensive Care Unit.

Of interest and possible concern is that more than three quarters of people (78%, n=39) had a 'Do Not Attempt Cardiopulmonary Resuscitation' (DNACPR) decision made and recorded prior to their death. The corresponding proportion for all deaths notified to LeDeR in 2019 was 72%.

Perhaps reflective of this is that a third (32%, n=12) of those for whom treatment for COVID19 has been recorded received palliative or end of life care, sometimes apparently without active treatment, in other cases alongside treatment with antibiotics, oxygen or fluids.

Of the 12 deaths for which we do not have information about treatment, just over a half had a DNACPR decision made.

Place of death

The majority of deaths occurred in hospital (88%, n=44), the remaining deaths occurring at the person's usual place of residence.

Circumstances leading to death

The majority of the accounts of the circumstances leading to a person's death indicate a steady deterioration in the person's condition of varying degrees of rapidity. A quarter (26%, n= 13) describe an apparent stabilisation of the person's condition, before a subsequent rapid deterioration.

Of concern is that 20% (n=10) of the reports indicate that the person had been readmitted to hospital in the period before their death. Although these deaths occurred at a time of pressure on hospital beds, in some circumstances the first hospital discharge was clearly unsafe and detrimental to the person concerned. For example, one person had been discharged with a diagnosis of sepsis, only to be readmitted a short while later dehydrated and with end stage renal failure. Another person was discharged home after being treated for acute kidney injury due to dehydration but readmitted the following day in renal failure. Both had tested positive for COVID19.

It may, of course, be the case that the high rate of readmissions was led by people being exposed to COVID19 in the hospital environment at their first admission, and then needing to be readmitted soon afterwards for treatment of COVID19. Of the ten people who had been readmitted to hospital, six were readmitted with symptoms of COVID19 that were different from the reason for their previous admission.

Comments about the quality of care provided

Three-quarters of the 50 completed reviews did not indicate any concerns about the care the person received. However, a quarter (26%, n=13) of the 50 completed reviews did indicate concerns or problems with the person's care, a greater proportion than in previous LeDeR reviews⁷. These were varied in nature. Those specifically in relation to COVID19 included concerns about a lack of Personal Protective Equipment (PPE) used by paid staff, including that paid carers were visiting several vulnerable people in the community each day, using only gloves and a paper mask at most.

In addition, some concerns were raised about decision-making. One carer reported that they thought their relative had been denied active treatment, including escalation to ITU, because of the

⁷ <http://www.bristol.ac.uk/sps/leder/resources/annual-reports/>

way those with COVID19 were being assessed for critical care. Another relative found it distressing that during their relative's admission to hospital, 'at least six doctors' wearing PPE came into his room to tell her that he was not for resuscitation. Her distress was compounded by the number of times the same information was repeated.

Other concerns were in relation to the promptness with which medical attention was provided to a person. Some people had been deemed 'not poorly enough' for a GP visit or hospital admission when family or paid carers had asked for help, but the person had died shortly afterwards. For example, ambulance staff asked a GP to prescribe antibiotics to a person with suspected COVID19 and symptoms of sepsis, but this had apparently been refused on the grounds that antibiotics were contraindicated in COVID19 infection. In another case carers apparently repeatedly tried to get help but were told to care for their relative at home. The person died two days after finally being admitted to hospital.

Conclusions and implications for service improvement

This brief review has highlighted the findings of 50 LeDeR reviews of deaths of people who were suspected to have had COVID19 or who tested positive for the virus. All of the deaths occurred between March and May 2020, but the deaths are not a representative sample – they are simply the first deaths to have reviews completed.

A number of implications can be drawn from this in relation to service provision and improvement, although these findings are presented cautiously given the nature of the sample of reviews.

First is the high proportion of deaths of people with mobility impairments and/or mental health needs that are included in this sample. These are not recognised risk factors for COVID19, but it may indicate that these are people at increased risk because of the regular and sustained contact they require with the people supporting them. However, it may also underpin prejudicial attitudes towards the care and treatment of those with COVID19 and judgements about ceilings of care, and service providers need to be aware of this potential inequity and closely examine the assumptions upon which such decisions are made.

Second is that a third of the sample had epilepsy as an underlying health condition. There is currently no evidence of increased risk of coronavirus infection in people with epilepsy compared to the general population⁸, and this proportion may reduce with a greater number of deaths being reviewed. However, at present and given these findings it would seem appropriate to consider people with learning disabilities and epilepsy as being at increased risk of death from the virus and pay particular attention to protecting them.

Third is that the key symptoms of COVID19 in the general population (fever, new continuous cough, loss of sense of smell or taste) may not be as apparent in people with learning disabilities. Almost all (86%) of the sample had one or more of a fever, cough or difficulty breathing, and these may be better warning signs in this population. Few reported a loss of smell or taste, and there are indications that a loss of appetite may be a better determinant of this. A small number of people

⁸ <https://www.epilepsysociety.org.uk/epilepsy-and-coronavirus-covid-19-faqs#.XvTMikBFw2w>

with learning disabilities were reported to have had no symptoms at all; but it is worthy of note that some had been treated for urine or chest infections in the preceding period.

Fourth, although data about the treatment a person received is patchy, there are indications that the use of DNACPR decisions and the initiation of palliative/end of life care needs monitoring to ensure that this population is not being disadvantaged.

Fifth is that close attention needs to be paid to safe and appropriate hospital discharge planning. One in five of the completed reviews indicated that the person had previously been discharged from hospital, only to be readmitted again soon afterwards. Some of those readmitted may have been exposed to COVID19 during an earlier hospital admission for an unrelated health problem and required readmission to treat the virus. Others appear to have been discharged hastily, without appropriate planning, and this was likely to be detrimental to their health.

Finally, that a quarter of the sample of 50 reviews indicated concerns about the care of treatment of the person must reiterate the urgent need to improve service provision for this population. The 50 deaths occurred at a time of unprecedented demand on health and care services in the most difficult of circumstances. At times such as this, those who are unable to advocate strongly for themselves, who may not communicate in ways that others can readily understand and who are likely to be anxious and distressed without their usual support network require an enhanced level of care, not a diminished one. Additional resourcing for specialist learning disabilities staffing and expertise in primary and secondary care appears to be indicated from the findings of this small study.

Acknowledgements

Thanks to Rachel Calkin and Kamila Gielnik for their assistance in preparing and analysing the data and to Avon Huxor and Paul Hazel for comments of the draft.