COVID-19 deaths in care homes: primary care management study

Clifford Wyn Jones, Liam Taylor, Aimee Clement-Rees

ABSTRACT
Objectives COVID-19 presented a new risk to the care home sector. Primary care adapted their approach to the management of COVID-19 in care homes as the pandemic evolved. Our aim was to evaluate the clinical presentation, management, care planning and clinical decision-making, and after death care of care home residents who died due to COVID-19 in Aneurin Bevan University Health Board in Southeast Wales.
Method Clinical records of 136 in care homes were reviewed by a General Practitioner reviewer using a standardised template. These were then reviewed by a multidisciplinary panel to identify themes.
Results Most individuals presented with ‘typical’ COVID-19 symptoms (cough, fever); however, >50 presented with atypical symptoms. 90% had a record of Do Not Attempt Cardiopulmonary Resuscitation (DNACPR) decision, but only 46% had documented advance care planning (ACP), and only 37% had a clearly documented treatment escalation plan.
Conclusion Care home residents are at risk of sudden clinical deterioration and death. This evaluation demonstrates that although DNACPR is in place for most individuals, holistic planning for end of life (including ACP and clinical care plans covering management of deterioration and escalation of care) is only present for a minority.

INTRODUCTION
COVID-19 is a new disease and it is therefore important that we put in place mechanisms to ensure that we are able to learn quickly from our experience and use all available data to inform the development of effective and safe clinical pathways. People living in care homes (nursing and residential) are a cohort who may be particularly vulnerable to the impact of COVID-19 due to their pre-existing health conditions and the nature of their care setting. Data so far indicate that a significant proportion of deaths in the community setting from suspected or confirmed COVID-19 are accounted for by care home residents.

In Aneurin Bevan University Health Board, by mid-April 2020, health and social care providers were dealing with numerous outbreaks and deaths in care homes. It was assumed that existing advance care planning (ACP) would assist in the management of COVID-19 in care homes.

During the early stages of the COVID-19 pandemic, some specific concerns had been expressed in the media and within the health and social care workforce regarding COVID-19 in care homes.

Particular issues for general practice included the perception that decisions regarding resuscitation and ceilings of care were being made without due consideration or consultation with individuals and their families. Also, changes in legislation and the ‘lockdown’ of care homes created great uncertainty and some confusion regarding death administration, particularly verification and certification of death processes. These changes were taking place rapidly within the first phase of the response as knowledge was emerging about COVID-19.

Key messages
What was already known?
COVID-19 disproportionately affected residents of care homes.
COVID-19 was a real-world test of existing advance care planning (ACP) processes.

What are the new findings?
ACP in care homes may not be applicable to rapidly changing emergency scenarios and did not fully cover the clinical scenarios encountered during COVID-19.

What is their significance?
Clinical
Specific plans for deterioration are required to optimally support care home residents.
Research
Applicability of traditional models of ACP in care homes.
In consultation with local stakeholders, a service evaluation was commissioned to review the response and support provided by primary care to care homes during wave 1 of the COVID-19 pandemic and the effectiveness of existing ACP in the context of COVID-19.

**METHODS**

A decision was made to carry out a mortality review of suspected/confirmed COVID-19 deaths in care homes. The review would cover all deaths due to COVID-19 in March and April 2020. Additionally, nine care homes were identified as having experienced a higher number of deaths (>10 residents or >40% of residents). All deaths in these nine care homes were included in the review. During the review, in the second half of May, an additional residential home experienced a significant outbreak of COVID-19. Previously, only nursing homes had experienced a similar number of deaths, therefore it was decided to include these cases in the wider mortality review.

The scope of the review included:
- Resuscitation (Do not attempt cardiopulmonary resuscitation) decisions, ACP and treatment escalation planning (TEP).
- Clinical presentation.
- Verification of death process and practice.
- Documented cause of death.

Residents of care homes who were admitted to and died in hospital settings were excluded.

The clinical records of suspected/confirmed COVID-19 deaths between 1 March 2020 and 30 April 2020 were reviewed by one of four clinical reviewers using a case review template. These reviews were then collated by the project lead and scrutinised by a multidisciplinary panel to identify themes and issues. (online supplemental file 2)

**RESULTS**

The review (online supplemental file 1) included 136 cases in total and 27 care homes. The key features of the cases reviewed were:
- First presentation was on 5 March 2020 and the first reported death was on 9 March 2020.
- Age ranges from 49 to 102 years, with an average age of 88.4 years.
- During the period of the review, swab (antigen) tests were not routinely performed for suspected COVID-19 cases in care homes, therefore only 16 of the cases were swab positive.

Most cases experienced ‘typical’ COVID-19 symptoms of fever and respiratory symptoms. However, >50 cases experienced presenting symptoms not included in government testing guidance.

In almost all cases, DNACPR was in place prior to death (90%), but only 43% had ACP (or equivalent). There was no clear escalation plan documented in 33% of cases (figure 1).

Professional bodies had issued advice regarding verification of death via video consultation. Formal guidance was issued by the Welsh Government on this issue on 15 May 2020 (https://gov.wales/verifying-death-times-emergency-coronavirus-covid-19). In the vast majority (100 cases), verification of death was carried out in person by out-of-hours clinicians or the registered General Practitioner (GP), with only eight recorded cases of remote verification.

Causes of death entered are a matter of clinical judgement, determined by the patient’s medical history and the circumstances of their death. The rules surrounding the completion of the Medical Certificate of Cause of Death (MCCD) have changed following the Coronavirus Act 2020 (enacted on 25 March 2020). Seventeen cases were identified that may have warranted the inclusion of COVID-19 on the MCCD. Although some of these deaths may have been due to other causes (eg, dementia), in the context of the COVID-19 pandemic, the mode of death was suggestive of COVID-19.

**DISCUSSION**

Practices and care homes had to adapt rapidly in response to changing guidance regarding access to care homes and remote triage and video consulting due to COVID-19.

There were no identified concerns regarding the clinical care and management. There was variation in approaches to carrying out face-to-face reviews in care homes, and the approaches to obtaining clinical information in lieu of physical examination. Reviewers commented on variation in the quality of clinical records and documentation by primary care teams. The level of clinical detail was greater where reviews were conducted by a GP who had an established relationship with care homes through delivery of the Care Homes Enhanced Service. In the context of concerns in the media regarding care homes, the lack of detail regarding physical parameters and rationale for clinical management plans is of concern.

Following the switch to remote consulting, there were concerns that care homes would be pressurised to support remote verification of death. This was not the case in this review. However, verification of death during the out-of-hours period is a significant demand.
We did not identify any significant issues or concerns regarding certification of death and there was evidence of appropriate discussion with the coroner.

Care planning, encompassing DNACPR, ACP and planning for deterioration, remains a significant issue in the care home sector. There remains significant variation in understanding the different types of planning processes, and how they are carried out and communicated. It was evident that although DNACPR processes are widely applied, this does not extend to ACP. DNACPR, ACP and planning for deterioration (eg, TEP) seem to be conducted in parallel, with no cross-referencing. Care home residents (in particular, nursing home residents) will often have multiple complex health issues and are at high risk of deterioration and death from multiple causes; however, there is little evidence that preparations are made for these scenarios (other than DNACPR) until deterioration occurs. Addressing these issues and parallel processes should be a priority for primary care and care homes.

Deaths in care homes increased by 134% during the first wave of the COVID-19 pandemic, the greatest relative increase for any recorded place of death. The rates of ‘typical’ COVID-19 symptoms within our cohort were consistent with other studies. Other studies have highlighted that ACP discussions were disrupted by the COVID-19 pandemic, particularly when discussions needed to involve family and proxy decision-makers. However, our case series highlights issues with pre-existing ACP. A lot of ACP was not robust or applicable when applied to the situation that clinicians and care home staff were presented with, and this was compounded by the impact of lockdown on communication with families and carers when faced with rapidly deteriorating care home residents.

This review has provided near to real-time information on how general practice has responded to COVID-19 in care homes and has enabled a greater understanding of the approach of GPs to clinical management when patients experience rapid deterioration. However, this review was limited to individuals who died in the care homes and does not include individuals who recovered or were admitted to hospital. The features noted in the cases reviewed may not be applicable to all care home residents diagnosed with COVID-19. Due to pressures on care homes at the time of the review, we relied on information contained in GP clinical records. It is possible that additional information regarding ACP and escalation plans may have been present in care home records.

**CONCLUSION**

This evaluation demonstrates that although DNACPR is in place for most individuals, holistic planning for end of life is only present for a minority. We have identified issues regarding applicability of ACP as a result of changes in ways of working and nature of COVID-19. The important next steps are that these are addressed and integrated into wider changes that have been implemented during COVID-19. A clear framework is required to support care home staff during COVID-19 outbreaks, focusing on clinical assessment and care planning.

There remains significant variation in ACP in the care home sector. This evaluation highlights the gaps between ACP and clinical plans for management of deterioration, and the weaknesses in our current approach to end-of-life planning in care homes.

**Twitter** Clifford Wyn Jones @cliffjonesgp

**Contributors** LT commissioned this service evaluation and agreed the protocol. CWJ planned the evaluation, collated the data, oversaw the review process and wrote the final report and this article. AC-R supported the planning and delivery of the service evaluation.

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**Competing interests** CWJ is the end-of-life care lead for RCGP Wales (voluntary, unpaid) and represents RCGP Wales on the Welsh Advance and Future Care Planning Group.

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**ORCID iD**

Clifford Wyn Jones http://orcid.org/0000-0002-7220-0787

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Short report