

Where to go when home is not possible? Place of care for people under 65 in their last months of life

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Abbreviated abstract: Marie Curie Hospice Glasgow provides specialist inpatient palliative care for symptom control and end of life care. There are a cohort of young patients with a prognosis of weeks to months where return home is not possible due to complex needs or lack of family support. Finding appropriate care for younger people can be challenging. We examined this issue by looking retrospectively at hospice inpatients under 65 years of age in a 12-month period. An alternative model of care is required to support these patients.

Related publications:

Schneider, A. Deprivation and informal care the end of life. Scottish Centre for Administrative Data Research (2019)



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The logo for the SPPC Partnership for Palliative Care, featuring a blue circular icon with a white cross and the text "SPPC Partnership for Palliative Care" below it.

Previous work, challenge, and approach

Background:

- Glasgow has a high level of deprivation and research has shown people are more likely to live alone and have less access to informal carers.
- When hospice inpatients with prognosis weeks to months are unable to return home, transfer to a care home will be explored. Finding a suitable care home for a young person can be challenging, is often met with resistance and can be a source of distress during the remaining portion of a patient's life.
- For the over 65 population in NE Glasgow, patients have access to part HSCP funded complex palliative care beds at Four Hills. There is no equivalent option for younger patients.

Aims

- Describe the characteristics and trajectories of hospice inpatients under 65 years to inform future models of care.

Techniques and Methods

Retrospective electronic case note review (EMIS and Clinical Portal) for patients under 65 admitted to Marie Curie Hospice Glasgow April 2019 to April 2020.

Data collected included demographics, Scottish Index of Multiple Deprivation (SIMD) and length of stay (LOS) with closer review of those patients with a LOS >17 days.

Further qualitative data was gathered for patients with LOS over 50 days.

Age	Sex	Diagnosis	LOS (days)	
64	M	Prostate cancer	81	Single man with spinal cord compression, referred for care home, distressed by this prospect. Deteriorated and died in hospice prior to care home transfer.
64	M	Glioblastoma	41	Admitted with seizures and right sided weakness. His wife was exhausted after caring for him at home for 2 years. Resistant to idea of care home. He deteriorated and died in hospice.
57	F	MND	61	Significant physical, psychological and communication care needs. Large community package (£250k) unable to provide 2 carers overnight so home not feasible. Remained in hospice for end of life care.
46	F	Glioblastoma	98	Single woman whose main carers were elderly parents, repeated falls requiring one to one nursing throughout her inpatient stay. Referred for care home, source of great distress for parents who did not wish her to be moved. She remained in hospice for end of life care.
56	M	Colorectal cancer	84	Spinal cord compression, physical disabilities and significant care needs. He did not wish care home. Discharged home 2 weeks prior to death.
36	F	Glioblastoma	74	Single mum, physical disability and house now unsuitable. Rehoused with her children from hospice.
34	M	Colorectal ca	55	Single man with IT pump and complex pain. Care needs too great to be met at home remained in the hospice for end of life care.
32	F	Metastatic melanoma	56	Single woman from Poland with cerebral metastases, reduced mobility and significant pain. Unable to return home as lived in shared flat and no family in Scotland. Remained in hospice for end of life care.

Results and Conclusions

Results:

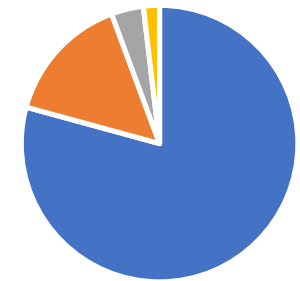
116/ 357 (32%) unique patients admitted 1st April 2019-1st April 2020 were under 65 years. 116 (32%) Female 59% Male 41%.

Average length of stay was 17 days (all ages). For under 65s mean LOS of 35 days and median of 30 days.

Of under 65s with LOS >17 days:

- 58.4% of patients were in top 3 deciles of deprivation (37.7% in most deprived)
- 51/53 patients had diagnosis of malignancy.
- Most of these patients died in the hospice (79%) versus home (15%) and hospital (4%).
- Care home transfer was explored in 5/10 exemplars with LOS >50 days however all deteriorated and died in hospice.

Place of death



■ Hospice ■ Home ■ Hospital ■ N/A

Conclusions:

- Younger patients had a longer length of stay
- Themes of living alone, deprivation and burden of physical and psychological symptoms were barriers to returning home.
- Discussions and processes involved in care home transfer for younger people in last weeks or months of life can be a source of distress and often futile in the context of deteriorating condition.
- Proposal for alternative model of care for younger patients with prognosis of weeks- months
- Dedicated beds for longer term care would enable continuity of care and avoid changes in care setting.