

different perspectives in Palestine. This paper reports on the perceptions of the physicians.

Methods This study used an ethnographic qualitative case study approach. It was conducted in one oncology unit in one Palestinian hospital and used two data collection methods: participant observation and semi-structured interviews.

Results The study generated 70 hours of observation and 35 interviews; physicians (n=5), nurses (n=11), children aged 6–18 (n=6), mothers (n=7) and grandmothers (n=6). The findings demonstrated that physicians were reasonably open with parents at the diagnosis stage; however, as the child's condition got worse, they concealed negative information to protect parents from emotional suffering. However, despite their tendency to conceal information, they associated revealing information about the child's deterioration to parents as an important act to protect themselves legally. Furthermore, they generally concealed negative information from children. There seemed to be a close link between the type, intensity and quality of information revealed and the stage of the cancer journey (diagnosis, treatment and prognosis).

Conclusions This study of Arab physicians delivering care to children with cancer and their families are positioned at a point in tension where they are reluctant to reveal information about a child's deterioration and the knowledge that by concealing this information they place themselves in a difficult position. Although concealing information may be explained by cultural context, it does leave a communication gap for children and their parents at a very sensitive time in the child's cancer journey.

5 PUBLIC TRANSPORT AND HOSPICES – DO THEY LINK?

Caroline Hart, Miriam Rigby, WM Cares. *West Midlands Deanery*

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Background Hospitals tend to be in central locations with good links to public transport including dedicated bus stops etc. This is due to very high numbers of both staff and patients needing 24 hour access. Hospices however tend to be less central, in quieter locations, making them less accessible to those who can't drive; be they patients, their relatives or staff. So how easy are they to get to? And how easy is this information to find?

Method For all the hospices within the West Midlands with an inpatient unit (IPU); we looked at the following: what information was available on their website regarding access via public transport; how to access the IPUs via public transport using 'traveline.org' and Google. Finally, we contacted each hospice to ask if they had any written patient/visitor information regarding getting to the hospice.

Results We identified 12 hospices, and 15 IPUs in total. 5 had a link on their homepage indicating 'how to find us', 2 had information about nearest bus routes, 3 had information about the nearest train station. When contacting the hospices directly, only 3 hospices had written information available to give to patients and their relatives. We found that the distance from a bus stop to the hospice varied from a 2 to a 15 min walk, and more than half have no or very limited Sunday service.

Conclusions Most of the hospices in the West Midlands region have no information available regarding accessing the site using public transport, and limited transport services especially off peak.

Does this feed in to the inequalities in access to hospice services already seen across socioeconomic groups? In the first instance we hope this will encourage hospices to provide more travel information for patients, but could this also guide service development and future hospice location planning?

6 THE AGE OF THE CARER HAS AN IMPACT ON THE BURDEN OF CARE EXPERIENCED BY THE CARER

F Mukhtar, U Raja, S Singh, N Lovell, D Yi, JJ Higginson. *King's College London, Cicely Saunders Institute*

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Context Those caring for people with chronic illnesses report high levels of unmet needs. Carers for patients with chronic illnesses must learn how to adapt with the demand of looking after a patient with a deteriorating condition. This can lead to increased stress due to sacrifices such as less time for socialising/financial difficulty.

Objectives To evaluate whether the age of the carer has impact on the burden experienced from caring for patients. Understanding the effect of caring for patients with chronic breathlessness and its burden would help interpret the results drawn from the main analysis of the OPTBreathe study, which investigated the preference for the breathlessness support service.

Methods Answers to the carer burden inventory (CBI), included in the face to face interviews with carers were analysed by carer's age. Categories of age were generated and answers to CBI items were converted into a total burden score. and synthesised by the scoping review of literature on the carers' wellbeing. relationships within the data and relating it to the results of other studies related to the wellbeing of carers. This includes journals and qualitative studies.

Results 65 carers completed 20 items in the CBI, The average age was 65 and 9 of 65 carers were men. 49/65 stated being either comfortable or coping on their current income, whereas only 10/65 stated in financial difficulty. Average burden score was 18.9: 12.5 in age <40; 16.4 in 40–49; 18.3 in 50–59; 20.7 in 60–69; 20.3 in 70–79 and 17.4 in 80+. The graphical illustration showed that there was an increasing trend from the <40 age range.

Conclusions Though the relationship was not linear the results indicate that there is clear larger burden of care on older carers. Suggestions as to why include increased morbidities in older carers and increased financial burden.

7 CARERS' REFLECTIONS ON PROVIDING INFORMAL END OF LIFE CARE AND THE POST-CARE PERIOD: A QUALITATIVE STUDY IN SOUTH GREATER MERSEYSIDE

James Watson, Katherine Jehan. *University of Liverpool*

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Background End of life care need is increasing and will continue to do so. Government policy is for terminal patients to receive care and die in their preferred location. Most terminal patients prefer to receive care and die at home, but lack of palliative care funding places a substantial burden on informal carers. Inequalities exist in end of life care; informal carers

from socioeconomically deprived areas suffer from worse physical and mental health, inequitable service provision and worse service experience, and feel greater financial and social pressures due to caring. Halton and Knowsley – in North West England – are among the most socioeconomically deprived Local Authorities in England.

Method Eight semi-structured individual interviews were conducted with previous informal carers from Halton and Knowsley (caring ended between six months and 12 years prior to interview). Interview recordings were transcribed and analysed inductively, generating themes that arose during interview.

Results Informal carers face numerous challenges during caring and bereavement. Participants were unequivocal in their view that there is not only a pressure, but an expectation that family provide care for terminally ill relatives. Lack of communication from, and between formal care and healthcare professionals left carers feeling isolated and unsupported in providing home end of life care. Patient comorbidities and a system sometimes failing to take responsibility for patient care, impacted on the quality of care received and resulted in carers feeling a loss of control over their situation.

Conclusions This research suggests a more flexible, accountable and better-funded community end of life care system could improve the situation for terminally ill people and informal caregivers. It is also suggested that more research into the costs of providing informal end of life care would illuminate the pressures faced at this highly pressurised time.

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8 ARE PEOPLE WITH DEMENTIA GETTING THE MOST OUT OF OUR HOSPICE SERVICES?

Emily Adam. *Farleigh Hospice, Chelmsford, Essex*

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Background NICE guidance (NG97) recommends we offer early and ongoing opportunities for people living with dementia and their carers to discuss the benefits of planning ahead and preferences regarding their care. A previous hospice audit demonstrated small numbers of referrals for people with dementia. These referrals tended to come late, when disease was advanced. This re-audit aimed to describe how people with dementia are benefitting from our hospice services and identify areas for improvement.

Methods Retrospective review of electronic records for all patients with a dementia diagnosis referred between April 2017 and April 2018.

Results 5% (56/1154) of all referrals were for people with dementia.

66% (37/56) were referred for end of life care.

63% (35/56) were nursing home residents.

None were admitted to the inpatient unit.

None had capacity to discuss Advance Care Planning at time of referral.

41% (23/56) were discharged from services; after either telephone advice 65% (15/23) or a home visit 35% (8/23).

100% had a DNACPR status.

36% (20/56) lacked both documented Preferred Place of Care and Preferred Place of Death.

The median time between referral and death was 13 days.

Conclusions People with dementia make up a small percentage of referrals to our hospice. The referrals are coming late in the course of illness, at a time when patients are approaching death and lack capacity to make decisions about their care. Early involvement of specialist palliative care services could promote opportunities for advance care planning and improved patient care. With our ageing population, focus on integration between services and improving accessibility for non-malignant life limiting illnesses such as dementia is increasingly important. We have recently appointed an 'Admiral Nurse' with the aim of building closer relations with local dementia services.

9 USE OF DEPRIVATION OF LIBERTY SAFEGUARDS

Lady-Namera Ejaimike, Stephanie Adeyemi, Zouina Assassi, Margarita Kousteni. *University College London Hospital, University College London Medical School*

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The Deprivation of Liberty Safeguards (DoLS) are an important safeguarding measure for all patients. It has particular relevance in Elderly Medicine and, increasingly, the Palliative care setting. When patients lack capacity, the use of restrictions and restraints may be authorised, if, in a patient's best interests. Their appropriateness and overlap with end of life care is a complex and ethically challenging area. This piece of legislation has led to an increased workload for healthcare professionals as the number of DoLS applications, and hence paperwork, has spiked in recent years. In an already resource stretched setting, this audit aims to:

1. Assess the current use of DoLS at UCLH including:
2. Clear documentation when patient lacks capacity to consent to staying in hospital.
3. Timely identification of potential deprivation of liberty and therefore DoLS applications.
4. Identify areas for quality improvement.

Method Patients' capacity status was discussed with their consultant. The acid test was applied to determine if a DoLS application was indicated. The medical notes were reviewed to see if this had been completed. Data was collected for 40 patients across two wards.

Results

- 45% of patients lacked capacity and met the acid test criteria meaning a DoLS application is indicated. Only 33% of these patients had evidence in the notes of a completed DoLS application.
- On review of the medical notes, capacity assessments were documented in 1/3 of cases.
- When a DoLS application was indicated, 50% of cases had a form sent on Ward 1 but 0% did on Ward 2.

Our findings show that more work is needed in this safeguarding domain. We recommend identifying ways to improve compliance with this piece of legislation to avoid potential unlawful practice. We will address three areas prior to re-auditing:

- Teaching.
- Increasing awareness of existing resources.
- Simplifying process of completing a DoLS application.