Introduction

• The Carers (Scotland) Act (2016) places a duty on local authorities to prepare an Adult Carer Support Plan for all carers.
• There are an estimated 500,000 people caring for someone with a terminal illness in the UK.[1]
• Timely identification, assessment and support can reduce the overwhelming pressure of caregiving, increase competence, confidence, satisfaction and the quality of care given.[2,3]

Aim

To provide evidence on the supportive needs of carers of people with a terminal illness to inform recommendations regarding the optimal timescales for the creation of Adult Carer Support Plans under the Carers (Scotland) Act (2016).

Methods

1. Literature review
   Synthesise qualitative and quantitative research from last 5 years.

2. Secondary qualitative analysis (SA)
   92 transcripts from bereaved carers who cared for people with a range of malignant and non-malignant diagnoses.

3. Focus groups (PFG)
   2 focus groups in 2 Scottish cities with bereaved carers. Thematic analysis and consensus workshop to extract themes across datasets.

4. Stakeholder event
   Health and social care professionals and third sector representatives to discuss and disseminate findings and inform implications.

Results

• Themes included; triggers and barriers to identification, the support needed and received (practical, psychological, respite, information and communication and co-ordination), issues relating to end of life care and the impact of speed of terminal decline.
• Identified needs were diverse and can be divided into those which support the carer to care for the cared-for, and the needs of the carer themselves.[4]

Identification of carers

‘Because for every carer, there’s somebody that isn’t well. So the onus has to go on GPs, receptionist, hospital people.’ [PFG 1].

Support with physical care

‘And OK the medical profession can cope with the, you know, dispensing drugs and all the rest of it, and blah, blah, blah, but I needed to understand what the hell was going on…..’ [SA, Glioma 23].

Psychological support

‘…and I was greeting like a big wean, I must admit, when these guys came round me, and they told you, you know, ‘cause they knew what you were going through…. But I was still emotionally, I don’t know how to put it. I was still fragile…’ [PFG 1].

Respite and replacement care

‘I couldn’t even go to the toilet, when I went to go to the toilet she was screaming. So her and I sat up all night, me in one chair and her in the other.’ [SA, Frailty 2].

Co-ordination of care

‘I think at first you think you can do it all, and then you very quickly realise you can’t.’ [PFG 2].

Speed of terminal decline

‘…she [GP] came in a couple of days after to see how I was coping and she says “we didn’t expect it so quick” so whatever happened in the end I don’t know.’ [SA, Cancer 2].

Conclusions

• Ensuring that those caring for someone in the last six months of life get the support they need as quickly as possible is crucial to reduce the risk of a breakdown in the care provided.
• Health and social care professionals need to take a radical, reactive move to presume that every patient has a carer, and ensure they understand their entitlements.
• It should be the ambition of the Carers (Scotland) Act (2016) that identification happens early in the illness trajectory, before the terminal phase of illness.