LIVING WITH ILLNESS GROUP – IPOS DATA ANALYSIS
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Background Phyllis Tuckwell Hospice offers a number of group out-patient courses for patients. The Living with Illness group focuses on adjusting to living with an illness, self-management of common symptoms and understanding how illness can affect one’s mood.

Aim To measure the impact of attending the Living with Illness group by assessing patients physical and psychological symptoms at the beginning and end of an 8-week course.

Method The assessment involved 16 patients attending the Living with Illness group.

Tools used were IPOS (Integrated Palliative Care Outcome Scale) tool at the beginning and then repeated 8 weeks later at completion.

AKPS (Australia modified Karnofsky performance scale); to measure overall performance status and ability to perform activities of daily living.

Phase of Illness (POI); to assess whether current care plan was meeting needs.

Results Patients functionally deteriorated (AKPS scores) over the course of the group. Fewer patients were categorised as stable (POI) at the end. Total IPOS scores (high scores indicating more distress) were calculated for 11 patients with two fully completed IPOS’. At the end of the programme the scores/distress were reduced for six patients, stable for two and a minimal increase of one point for one individual. Four patients didn’t complete the programme two were due to worsening health.

Conclusions Despite functional deterioration, IPOS scores improved for most patients attending the group. Some of the greatest improvements were psychological scores; patients feeling more at peace, less depressed or anxious. Of the 11 patients with complete datasets six had a reduction in total IPOS scores equating to reduced over all distress; three had no change or minimal increase of one point. Only two patients had a larger increase in scores. This is despite ongoing deterioration in their health due to their underlying illness.

WHAT ARE THE PSYCHOLOGICAL NEEDS OF CAREGIVERS OF PEOPLE WITH DEMENTIA AT THE END OF LIFE?
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Background The WHO recognises dementia as a global health priority. The incidence and prevalence of dementia is increasing exponentially and neither health nor social care services are able to meet the needs of people with dementia (PWD) at the end of life (EOL) without the help of informal caregivers.

To date, research has demonstrated the high rates of caregiver burden, anxiety and depression but offers little evidence of how best to ameliorate these issues. The aim of this study was to identify the psychological needs of caregivers of PWD at EOL.

Method A systematic review adhering to the Preferred Reporting Items for Systematic Reviews and Meta-Analysis (PRISMA) guidelines and narrative synthesis were conducted. Population: adult (aged >18 years) informal caregivers of a formally-diagnosed PWD. Inclusion: English-language studies of psychological needs of caregivers of PWD at EOL. The electronic databases searched were APA PsycINFO, Ovid AMED, CINAHL by EBSCO, Cochrane Database, Ovid EMBASE, Ovid EMCARE and Ovid MEDLINE.

Results Eleven studies met the inclusion criteria; ten qualitative studies and one mixed-methods study. These studies captured the experiences of 356 caregivers. Data extraction identified 80 findings and data synthesis resulted in 22 categories of psychological needs. A narrative synthesis found six key themes: i) relationship-orientated psychological needs; ii) support needs; iii) information needs to support psychological wellbeing; iv) care of the caregiver and the need to maintain caregiver wellbeing; v) the need for role recognition and an identity outside of the caregiving role and vi) psychological security.

Conclusion(s) Elucidating the psychological needs of caregivers of PWD at EOL is the first-step in being able to improve the quality of life of caregivers of PWD by identifying targets for the help and support they need when providing care for PWD at EOL. Future research should focus on interventions that might address these needs.