Uncertainty about the future for patients with advanced cancer and their informal caregivers: A qualitative view
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**Background**
- More patients are surviving longer with cancer; both patients and informal caregivers may struggle to adjust to some of the new challenges this brings.
- Being a cancer patient (Pt) or caregiver (Cg) does not make one less of a patient or family member. That's my role, that's my job. "The security of the family is really important. That's my role, that's my job. To think that I might not be there or I might be unable to work and that sort of stuff was really important." Pt1014
- In the Patient Reported Outcomes impact of Age and Carer role demands associated with Treatment (PROACT) study we have developed two scales measuring wide-ranging life impacts of cancer and treatment for Pts and Cgs (see poster board K10 for a full description of the study).
- Some felt it would be easier to have a definite time frame about death and were frustrated that no one could predict what would happen and when.
- For Cgs there was sometimes guilt associated with these feelings although they were recognised by some patients.

**Aims**
- Analysis of over 38 hours of recorded interviews identified 20 major themes and 33 subthemes.
- A predominant theme for both Pts and Cgs was uncertainty for the future. This encompassed issues such as providing for one’s family, employment and finances but also plans for retirement.
- For both Pts and Cgs the uncertainty of the disease trajectory was pervasive. They feel a lack of control and an inability to make plans that resulted in a sense that their lives could only be lived one day at a time.
- Pts were particularly concerned with their family’s future financial and emotional wellbeing.
- Cgs often felt a lack of control over their own future and a sense of life ‘being on hold’.

**Findings**

- 24 patient caregiver dyads
- 9 melanoma
- 9 gynaec
- 6 lung
- Patient age 39-84
- median 65yrs
- Caregivers were partner (N=15), child (N=5), sibling (N=2), friend (N=2)
- Caregiver age 19-85
- median 54yrs

- "I think until we get a good period of time of clear results, no operations and things, I think maybe then we might start to think about moving or a new car but I do feel like we’re just stagnant at the moment" Cg1014
- Some felt it would be easier to have a definite time frame about death and were frustrated that no one could predict what would happen and when.
- For Cgs there was sometimes guilt associated with these feelings although they were recognised by some patients.
- "I think sometimes they’re putting their lives on hold waiting for me to die, but they don’t quite know when that’s going to be and since I don’t know when it’s going to be and nobody else seems to know when it’s going to be it’s a bit awkward" Pt3001
- "It would be easier because you could then, even if it wasn’t a definite, you would roughly have a rough idea and you knew what you were doing" Cg1016
- Age appeared to mediate some uncertainty. In younger participants there were practical concerns around employment, finances and family.
- "I just want them to be happy and safe and stable and at ease with everything. That’s a big concern for me” Pt1016
- Those around retirement age keenly felt the loss of the future they had worked hard to spend together.
- Older participants were less affected by practical concerns. There was also an absence of discussion of unfulfilled life goals interrupted by the cancer.
- Pts and cgs rarely discussed their concerns for the future with each other and more commonly described not talking openly as a means of preservation of self or the other person.

**Summary and Conclusions**
- Patients and their informal caregivers are challenged about coping with death but equally about coping with life and the lack of a defined trajectory.
- Uncertainty impacts many areas including employment, retirement and general planning for the future.
- The range and scale of the ‘impact of uncertainty’ varied however few people were unaffected by the discomfort of ‘not knowing’.
- Dyads seldom discussed these concerns with each other so might benefit from professional help aimed at facilitating open discussion together.

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