Research provides a valuable opportunity to progress the evidence base for the care that is offered. Palliative patients and carers may discuss concerns about involvement in clinical research with their community pharmacist.

Palliative Care Research
The evidence base developed from non-palliative patients is often difficult to interpret in our complex patient population. Clinicians, researchers and government agencies have a responsibility to further develop and interpret the evidence base in the palliative care context.

Vulnerable patient groups are often excluded from pre-marketing research by pharmaceutical industry: the focus is on short-term safety and efficacy outcomes in comparatively healthy patients.

The palliative patient is typically vulnerable due to increasing frailty, cachexia, varying stages of organ dysfunction and the need to manage new symptoms while concurrently managing long-term comorbidities. To complicate issues further, poly-pharmacy is often necessary with a considerable focus on off-label use of medicines. Consequently there is much to learn about the management of this complex population through involvement with rigorous trials.

Exclusion of palliative patients from post-marketing research is unwarranted: unwrapping the complexity helps to develop more efficient approach to management of this vulnerable population.

Research can take place in a variety of settings allowing patients based in hospital as well as those within a community environment an opportunity to participate.

Patients with a palliative diagnosis are generally keen to participate in clinical research as it has a potential to improve the quality of care for them as well as others at the end of life. In fact, trial participants in general do better than non-trial patients even when assigned the control arm. This is because they are observed more closely than usual – so monitoring and compliance with treatments improves. In addition, participants describe the social benefits of having contact with a research unit.

Future research opportunities will concentrate on:

> Verification of new indications for well-established medicines: Do SSRIs have a role in the management of dyspnoea;
> Discontinuation of medicines at the end of life: When do the risks outweighs the benefits of cholesterol lowering agents;
> Examining the consequences of iatrogenic harm resulting from a prescribing cascade
> Building more efficient processes for managing care in the community: What are the barriers to timely access to medicines for community based patients. There is still a lot to discover and fine-tune in the specialty of palliative care. Without the united support of clinicians, researchers and government agencies, the road forward will be slow and inefficient.

Useful resources


For more information
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