Optimizing quality of life through palliative care for adults and children affected by cancer

Implementation of 24 hour Home Palliative Care - From theory to practice

Nicolas Philippou

105M-T3

Track 3 - Improving patient and family experiences

Disclosure of interest: Nothing to disclose
Agenda

1. PASYKAF - Who we are
2. Palliative Care in Cyprus
3. PASYKAF Palliative Care Services
4. Implementing the 24hour Service
5. Results and Conclusions
6. Making a Difference
We are
The Cyprus Association of Cancer Patients and Friends (PASYKAF) - Registered Charity no. 525

Established in 1986 by 21 patients with cancer, relatives and friends

We developed into a specialist organization that now numbers thousand of members, volunteers, sponsors, friends

We aim:
• to provide supportive, palliative care and rehabilitation services
• to educate on cancer prevention and early detection
• to struggle for the improvement of cancer diagnostic treatment services
**Main Activities**

- **Governance/Management**
  - Run and Governed by Patients
  - Managed Professionally – 65 full time employees and 20 associates
  - Organized in 5 districts around Cyprus

- **Services and Programs**
  - Palliative Care Services
  - Rehabilitation Center
  - Psychosocial Support
  - Physiotherapy / Lymphoedema
  - Social Welfare
  - Day Care Centers
  - Free Transportation
  - Programs for Awareness on Prevention and Early Detection

- **Advocacy**
  - WG Rare Cancers ECPC
  - PSWG of ECL
  - Cyprus National Cancer Control Plan Committee
  - Cyprus Patients’ Federation and EPF

- **Volunteering**
  - Board of Directors, majority cancer patients
  - Local District Committees
  - Official Groups - fundraising
  - Coffee Morning Groups
  - Volunteer work
  - Support to cancer patients
  - Work to our Charity Shops

- **Financial Control**
  - 2.5 million euros budget
  - Fundraising activities 90%
  - EU Funded Projects and Government Funding 10%
  - External & Internal Audit Functions

- **Connected**
  - UICC, ECPC, ECL, EAPC, IPOS, EONS, ECCA, Europa Colon
  - Board of Directors of Cyprus Oncology Center
  - Ministries, Universities, etc.
We care

PASYKAF Services

1986 – 1990: Study and research

1990: Psychosocial Support Service

1992: A multi-disciplinary Home Care Service Team

1995: Physiotherapy Service

1996: Bank of Cyprus Oncology Centre

1998: The Day Care Centres

1999: The Lymphoedema Service

2015: 24-hour service coverage of home palliative care in Limassol and Nicosia

2017: First Rehabilitation Center

FREE PASYKAF SERVICES

5000+ cancer patients and their relatives receive care and services from PASYKAF per year

A total offer of €2.5 million
PASYKAF Services – Programs on Public Awareness

Healthy Eating and Exercise

Smoke-free environment for all

Cervical Cancer

Men and women cancers

European Week

Melanoma
Palliative Care in Cyprus

Cyprus Facts

- Cyprus Population 850,000
- 30,000 estimated registered cancer patients
- Incidence 3,500 / Morality 1,250
- Free treatment for all cancer patients
- No Cancer Control Action Plan
- Hospice and palliative care services are pioneered and provided by the voluntary sector only
Palliative Care in Cyprus

Key Points

- Home Care Teams provide supportive and palliative care
- Day Centres provide complementary therapies
- Only one Hospice with 15 beds in Nicosia and another under development
- No dedicated beds for palliative care in any of the government hospitals
- Drug Availability
- No policy on paediatric palliative care
- No official numbers on place of death. Estimates: Home 25%, Hospice 20%, BOCOC 45%, General Hospital 5%, other 5%
- Lack of awareness, knowledge and information about palliative care
PASYKAF Palliative Care Services

PASYKAF Homecare Teams

MDT divided into the 5 districts of the Republic of Cyprus and provide supportive/palliative care.

3 Doctors
22 Nurses (4 part time)
9 Physiotherapists
12 Psychologists/Psychotherapists
4 Social Workers
6 Administrative Staff
3 Drivers
PASYKAF Palliative Care Services

Services

- Referrals to PASYKAF (Oncologist and self referrals at any stage of the disease)
- Supportive and Palliative Care Services (relieve pain and other distressing symptoms)
- Home Nursing Care and Medical Support
- Loan of Practical Aids: Wheelchairs, pressure relieving mattresses, oxygen cylinders
- Support and educate the patient and the care givers
- Assist the patient to achieve his goals
- Empower the caregivers

2014: 2000 patients through 25000 home visits
PASYKAF 24hours Service
Responding to Patients Needs

• National Council for Palliative Care (NCPC) and Public Health England Report published on 3rd June 2014
  – nearly half the people receiving specialist palliative care in the community (46.2%) died in their own home – the place where most people say they want to die.
  – This compares with just over 1 in 5 (21.8%) nationally.

• At PASYKAF in 2014 island wide we had 32% of deaths at home

• Increase our Service from 10 hours a day to 24hrs
PASYKAF 24hours Service
Responding to Patients Needs

May of 2014 – Secured funding from EEA Grants
Implement a pilot 24 hours service in Nicosia and Limassol beyond our existing office hours aiming:

• Reduction of patient and caregiver anxiety (support and educate)
• Reduction in the number of unnecessary hospital admissions, especially at EOL
• Reduction of burden on hospital beds – overcrowded Hospice and Oncology Centres
• On going support for patients and their families
• Encourage more patients to receive home care
Implementing the 24hour Service
Work Packages – 12 months implementation

Our aims:

• To improve our offered health care services
• Improve the capacity or our nursing staff
• Upgrade our Patient Management System DITIS – HoCNet
• Transfer the existing knowledge from our partners, the Norwegian Cancer Society and Turkish Cypriot Cancer Association and
• Publicize our new service and make people to feel comfortable to have home treatment
• Implementing this service across Cyprus
Implementing the 24hour Service
Work Packages – 12 months implementation

The project:
WP1: Project Management
WP2: Dissemination
WP3: Training
WP4: 24h home care implementation
WP5: Project evaluation
Implementing the 24hour Service
Project Management: Visit to Norway – June 2015

Norwegian Cancer Society
Visit to Louisenborg Hospice
Palliative Care Team
at The Akershus University Hospital
Saint Francis Home Palliative Care Team
Implementing the 24hour Service Dissemination & Training

3 Workshops in Cyprus during the project implementation

"Introducing a 24/7 Home Care Palliative Service"

Authors: Nicola Filippou / Sextus Mariska / Chandan Katling
The Cyprus Association of Cancer Patients and Friends (PASYKAF), Ag. Chrysochous 525

Project Overview

Introduce a pilot 24 hours service in Nicosia and Limassol. COPYS ACROSS beyond our existing office hours from cancer care patients.

Milestones & Targets

- AMEND our existing palliative care service to suit our new needs
- Implement our new system
- Train staff in 3 workshops in Cyprus
- Establish a new service in the field of palliative care
- Improve the quality of the service and the communication with the patient and the family
- Integrate the service in the hospital
- Establish a new service in the field of palliative care
- Improve the quality of the service and the communication with the patient and the family
- Integrate the service in the hospital

Initial Results and Statistics

Deaths at Home (in 2015)

<table>
<thead>
<tr>
<th>Death by Reason</th>
<th>Number of Deaths</th>
</tr>
</thead>
<tbody>
<tr>
<td>Cancer</td>
<td>40</td>
</tr>
<tr>
<td>Heart Disease</td>
<td>35</td>
</tr>
<tr>
<td>Stroke</td>
<td>15</td>
</tr>
<tr>
<td>Diabetes</td>
<td>10</td>
</tr>
<tr>
<td>CVA</td>
<td>20</td>
</tr>
<tr>
<td>Other</td>
<td>10</td>
</tr>
</tbody>
</table>

Suggestions

- Have emergency admissions during the night been reduced?
- How many of the patients who died at home would have been admitted in hospital?
- How many of the patients who died at home were given pain relief?
- How has the decision to change been made?
Implementing the 24hour Service

Implementation

- Educate staff and involve in design and implementation
- Increased our team 3 new full time nurses and 3 new part-timers
- Agreed on the on-call subsidy for all nurses and per visit subsidy for out of hours
- Hired 3 Part time Doctors all trained in Palliative Care – on call support & visits
- Acquired new Equipment:
  - Patient Controlled Analgesia Pumps plus reservoir cassettes
  - Ultra sound machines
  - Folding frames, wheelchairs and cushions
  - Suction machines
  - Oxygen concentrators
  - Air mattresses
  - Additional Electric Beds
Implementing the 24hour Service

Implementation

• Software upgrade – to web based application (developed with support of the University of Cyprus and Predu Consulting)

• Promotion (ABL & BTL):
  – Audiovisial
  – Media Coverage
  – Publications
  – Dissemination

• Project Evaluation:
  – Impact on Caregivers evaluation
  – Burden on Personnel
  – Impact on Emergency visits to hospital at end of life
  – Home deaths analysis

• Project Management:
  – Communication Book
  – MDT approach
  – Staff support
  – Monthly debriefing

• Service Policies:
  – Policy – Out of ours Service
  – Policy on Referrals
  – Policy on Visiting Patients
  – Discharge planning
Implementing the 24hour Service
Challenges and Lessons Learned

Setting up Boundaries
No new admissions out of hours
Bloods out of hours – only if family can take to private lab or deliver to Nicosia
No visits alone to risky situations
Safeguards regarding controlled medication
Educating patients and caregivers

Difficulties
Policing ourselves
Waking up/visiting at night
Visits alone to risky situations
Problem solving
Telemedicine/Telenursing
When should I call the Dr?
When should I visit?
Have I made the right call?

The Way Forward
Guidelines and Policies – fine tune
Regular evaluation of our services
Full scale educational program
24 hour service all Cyprus
Improvement in discharge planning
Better communication
Pediatric Services
Psychiatrist, dietician, speech and occupational therapists
Complimentary Alternative Medicine
Rehabilitation Services

Things to think about
Safety - patient/caregivers and healthcare professional
Anticipatory prescribing and care
Equipment availability
Emergency Drug Boxes
Discharge planning
Support for Staff
Involve all MDT 24/7
How to measure employee moral and possible burnout

Challenges
Importance of accurate input of information
Importance of death certificates on System
Source of referrals?
Results and Conclusions

Project Evaluation

Majority of all calls and visits made OOH before 10pm

- Patients who feel safe are less likely to panic
- Good symptom control
- Good anticipatory care
- Patients and families worries about disturbing us late at night (despite our encouragement and reassurance)

Emergency admissions during the night have been reduced

<table>
<thead>
<tr>
<th>24hours patient contact</th>
<th>Limassol</th>
<th>Nicosia</th>
</tr>
</thead>
<tbody>
<tr>
<td>Total out of hours Visits</td>
<td>82</td>
<td>52</td>
</tr>
<tr>
<td>EOL*</td>
<td>44</td>
<td>27</td>
</tr>
<tr>
<td>Before 10pm</td>
<td>68</td>
<td>44</td>
</tr>
<tr>
<td>After 10pm</td>
<td>14</td>
<td>8</td>
</tr>
<tr>
<td>Total out of hours Calls</td>
<td>604</td>
<td>473</td>
</tr>
<tr>
<td>EOL*</td>
<td>178</td>
<td>103</td>
</tr>
<tr>
<td>Before 10pm</td>
<td>516</td>
<td>426</td>
</tr>
<tr>
<td>After 10pm</td>
<td>88</td>
<td>47</td>
</tr>
</tbody>
</table>

Codes: V1/T1 – EOL (D), symptom control
V2/T2 – Psychological Support
V3/T3 – Calls that ought to have been made during working hours.
First Results and Conclusions

Project Evaluation

- Increase of PASYKAF patients who died at home
First Results and Conclusions
Are we optimizing quality of life?

• Evaluate the service, as received by patients and their caregivers.

• Qualitative study in the form of individual and paired interviews was conducted in Nicosia and Limassol.

• All interviews were conducted between the 20-21 July 2015

Key Benefits of 24hr Service

1. Psychological support of the patient
2. Moral support and encouragement of the caregiver
3. Provision of equipment
4. Training caregivers
5. Advice on how to ensure children in the house deal with the changes
6. Advice on how to prepare for the death
7. Financially not imposing
Making a Difference

• Reduction of patient and caregiver anxiety:

“We went home, but we did not have any idea what to expect. The doctor told us about PASYKAF, and they contacted us. Thank God!” – Nicosia

“They arrived just after 4 pm – I remember it was a Friday afternoon, and I had thought they would be in a rush to get away for the weekend. But it was like they had all the time in the world. As though we were the only ones who mattered. And for the first time in weeks I could just feel myself breathe, and be calm. I knew that they would look after us.......”

“I was able to contact them any time of the day or night any day of the week.....”

“We were able to do everything we could – just the same way mum did everything for us. And PASYKAF allowed us to do that.” – Nicosia
Making a Difference

- Reduction in the number of unnecessary hospital admissions especially at EOL:

  “Without this support PASYKAF provided us we would probably have ended up taking my mum to hospital every time we became worried.” Limassol

  “Thanks to PASKYKAF, my mother-in-law had the most beautiful death. Her son was holding one hand and her daughter in law on the other.” Nicosia

  “We were all able to say goodbye properly and to tell her that we loved her. Even her siblings were able to do so.” Nicosia
Making a Difference

• Encourage more patients to receive home care:

“We were all able to say goodbye properly and to tell her that we loved her. Even her siblings were able to do so.” Nicosia

“Thanks to PASKYKAF, my mother-in-law had the most beautiful death. Her son was holding one hand and her daughter in law on the other.” Nicosia

“The nurses of PASYKAF gave me the strength to be able to care for mum. I was trained to be a nurse for mum and PASYKAF supported me so that I could.” Nicosia

“We are indebted to PASYKAF, without them we would not have been able to honour mums wish that she dies at home.” Nicosia
What really matters is......

“...she was so excited on the day she returned home she even walked by herself to the sofa, she was able to see her dogs, her granddaughter, we painted her nails and made her feel nice, we gave her massages and she watched tv, she watched us take care of her, she watched us study for an exam and became excited when we got a good score, we made her feel proud, she didn’t loose her dignity like she did whilst she was in hospital...”

Kind Regards

Andrea Theocli
Thank You!

PASYKAF Limassol Team

PASYKAF Nicosia Team

Team Work

Board of Directors, Management Team including the PASYKAF Services Coordinators, the Doctors and Nurses, Psychologist, Social Workers, Administrative and Fundraising Staff, Drivers, PASYKAF Volunteers, Patients and Relatives
Thank You!

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