MERSEYSIDE AND CHESHIRE PALLIATIVE CARE
NETWORK AUDIT GROUP

DEVELOPMENT OF PSYCHOLOGICAL SERVICES IN PALLIATIVE CARE
SUPRA-REGIONAL AUDIT AND GUIDELINES

KATIE EVANS
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The art of medicine
Caregiving as moral experience

Every person who has been in love or built a family knows that there are things, essential things, that money can’t buy. Patients with serious illness and their network of caregivers know this too, because those things that really matter to us are threatened and must be defended. And many clinicians, reflecting on what is at stake in health care not only for patients but for themselves, know the same thing. The market has an important role in health-care financing and health systems reform, but it should not reach into those quintessentials of caregiving that speak to what is most deeply human in medicine and in living. This is the moral limit of an economic paradigm. Or at least it should be.

But we live in a truly confused age. The market model seems to have infiltrated so thoroughly into human lives and medicine that in certain circles—policy making and analysis, hospital and clinic administration, and even clinical work—economic rationality with its imperative of containing costs and maximizing efficiency has come to mute the moral, relational, religious, and aesthetic expressions of patients and caregivers. Most take it for granted and accept its implications. Models from economic psychology, behavioral economics, and business studies, based on the narrowest calculations of what a “rational” person would choose as most cost-effective, are now routinely applied to clinical decision making and the organization of care. They model the choices available to patients and their family members as if they were sufficient for the torturous experience of life at an early age, the routine frustrating pressures that constitute caregiving for neurodegenerative conditions, the adoration of depression that brings disability to the brain and heart disease, and the emotional and economic challenge of serious childhood disabilities. Such models, by the claims of both health policy experts and program administrators, are themselves value laden, and, once introduced, warp the concept of health care—a kind of gravitational field that affects the instrumental and distorts the human.

Professionals and lay people may rally against the allure of the market model in caregiving, and yet in current debate over health care reform in the USA, the UK, China, and many other countries, neither the voices of clinical professionals nor those of family caregivers are invited or adequately heard, let alone equal weight. This is not just an issue of the corrosive effect of unbridled capitalism on human values which is not malign enough in itself, but it is part of something much deeper. It is also a stunning failure of people who have “skin in the game,” which means nearly all of us, to adequately articulate and champion an alternative. In caregiving, I believe there is an alternative that makes the case for the long-term limits of the market and also offers a different vision. Caregiving is one of the foundational moral meanings and practices in human experience everywhere; it defines human value and resist undue reduction to counting and costing.

Consider how central caregiving is in the human function. Caregiving is an inextricable part of relations between caregivers, the raising of children, and the institutionalization of those in the workforce. Caregiving is the very definition of how families and friendship networks cope with the presence of illness and disability among their own. And there is an ancient lineage to caregiving across historical periods and societies. Nursing, medicine, and the allied health disciplines justify their status as healing professions by underlining their professional commitment to caregiving. Religious traditions respond to suffering in rituals that animate caregiving in both social and subjective realms. All cultures have elaborate systems of healing and ideas about illness and its cures and treatments that are enacted in the care of the sick. Of course, the sensitivity of caregiving extends well beyond medicine to stewardship of the environment, support for the welfare of the poor, and to the building of political institutions and programmes that advance basic human interests.

To be sure, the moral distance between stated values and actual practices is substantial. Over the last several years, when I have delivered lectures at medical schools and health science centres, I have explained to the audience that, given how little in the way of financial, time-in-the-curriculum, and other resources most medical schools devote to the principles, values, and practice of caregiving, perhaps we should allow medical schools to remove caregiving as a goal of medical education and restrict the curricula to technical clinical competencies and biomedical knowledge. The response to this suggestion is usually a passionate defence by those in the audience of how important caregiving is to medicine and I adduce to their own sense of purpose and meaning. So in light of this seeming paradox—medicine invests little in caregiving, yet it is core to health professionals’ motivations and identity—how should we think of caregiving?

For family members, close friends, the sufferers themselves, and professionals, caregiving turns on the amelioration of pain and suffering. Practical assistance with activities of daily living—feeding, bathing, ambulating, toileting—is a basic component, as are protection and emotional support. For physicians, in particular, diagnosis, prognosis, treatment, and rehabilitation can be done in ways that emphasise their human as well as their technical aspects, both of which are part of caregiving. But here I wish to emphasise the moral articulate and champion an alternative. In caregiving, I believe there is an alternative that makes the case for the long-term limits of markets and also offers a different vision. Caregiving is one of the foundational moral meanings and practices in human experience everywhere; it defines human value and resists undue reduction to counting and costing.

The Marie Curie Palliative Care Institute
LIVERPOOL

www.themariecure.com Vol 289 November 1, 2012
SCOPE AND PURPOSE OF THESE GUIDELINES

1. The overall objective of the guidance is to provide evidence (or where evidence is lacking, consensus) based requirements for the provision of psychological services to patients and families receiving palliative care.

2. The clinical, healthcare or social question covered by the guidance is: “What is needed to provide an effective psychological service for patients and families?”

3. The target audience to whom this guidance applies is all health, social care and pastoral care workers in specialist palliative care, with particular emphasis on those responsible for the development of psychological services.
CURRENT GUIDELINES - GENERAL PRINCIPLES

- Psychological distress is defined as “a multifactorial unpleasant experience of a psychological (cognitive, behavioural, emotional), social and/or spiritual nature that may interfere with the ability to cope effectively with cancer.”

- Psychological distress is commonly experienced in cancer and palliative care patients.

- The prevalence of conditions such as anxiety and depression are significantly higher in cancer (10-30%) and palliative care patients (45-58%) than in the general population.

- Various types of cancer (e.g. head & neck) and differing stages of disease process (e.g. diagnosis or advanced disease) predispose patients to experience greater distress.

- Psychological distress has been shown to have a significant impact on quality of life, degree of pain, physical functioning and families.
It is suggested that regardless of severity, patients with psychological distress will benefit from appropriate professional support. \(^9\)

At least 10-15% of these patients will warrant specialist psychological or psychiatric intervention. \(^10\)

However in order to access such support, appropriate identification, assessment and referral systems for psychological distress are required.

There are various professional and voluntary services available to assist patients experiencing psychological distress.

Currently there remains a lack of co-ordination and integration of specialised psychological support services with palliative care providers e.g. counselling, clinical psychology, liaison psychiatry. \(^1\)
The National Institute for Health and Clinical Excellence (NICE) Guidance suggests that palliative care service providers in each Integrated Care Network (ICN) should look to develop services in line with a four level model. For further details of this model see Figure 35.1. [Level 4]

There should be support available for all staff who offer psychological support. [Level 4]

There should be access to formal clinical supervision for staff utilising psychological approaches who are working at Levels 3 and 4. [Level 4]
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Specialist palliative care units should provide access to education programmes in psychological care. These programmes should be open to all clinical staff working with palliative care patients and their families. Programmes should include the assessment and management of Level 1 and Level 2 situations (see Figure 35.1).  

Training in communication skills is essential for all clinical staff.  

Training programmes should be developed in accordance with the evidence base and in collaboration with psychological specialists. This training should be updated on a regular basis.
Appropriate facilities/environment for psychological assessment and intervention should be available/identified, providing privacy and comfort for patients and their carers. ¹⁰ [Level 4]

Each palliative care service provider should establish written criteria for the identification and assessment of psychological distress, together with referral criteria to the appropriate professionals providing psychological assessment and intervention at Levels 3 and 4. ¹⁰ [Level 4]
CURRENT STANDARDS

1. Each palliative care service provider should have written referral criteria to guide access to professionals working at Levels 3 and 4. [Grade D]

2. All clinical staff providing palliative care must have access to the referral criteria. [Grade D]

3. There should be a named lead psychiatrist and psychologist identified at Cancer Network level to advise on the provision of specialist care at Levels 3 and 4, including access to emergency psychiatric support. [Grade D]

4. Clinical staff practising at Levels 3 and 4 should have regular clinical supervision. [Grade D]

5. All clinical staff working in specialist palliative care should have had accredited communication skills training and receive regular updates. [Grade D]

6. Managers of staff involved in providing palliative care must ensure that there are procedures in place to provide appropriate support for all staff and that staff are aware of the procedures. [Grade D]
CURRENT REFERENCES

LITERATURE REVIEWS

Psychological Services in Palliative Care

Vicky Hindley

Psychological Services for children and adolescents who have a relative receiving palliative care

Clare Jeffries

Tools used in the assessment of psychological distress in palliative care

Katie Evans
Adult Psychological Services in Palliative Care

Vicky Hindley
DEVELOPMENT OF PSYCHOLOGICAL SERVICES IN PALLIATIVE CARE

LITERATURE REVIEW - VICKY HINDLEY

ADULT PSYCHOLOGICAL SERVICES IN PALLIATIVE CARE

Databases searched: AMED
Embase
Medline
PsychInfo
BNI
CINAHL
Cochrane

Existing guidelines searched: NICE
NCAT

Terms used and combined:
“Palliative”
“care”
“advanc*”
“disease”
“terminal”
“end of life”

“psycho*”
“solution focused therapy”
“cognitive behavioural therapy”
“holistic assessment”
“anxiety management”
“distress”
“depression”
General Background

Psychological distress, anxiety and depression is well documented among cancer patients

Early identification and effective treatment should be considered essential for comprehensive care

Appropriate psychological intervention is required but are often not recognised

Service Provision and Structure

Local arrangements to provide people approaching the end of life with access to psychological support.

Their needs should be met any time of day or night

Supportive environments for managing psychological symptoms which provide privacy and dignity

Staff support available with access to formal supervision (levels 3 & 4)

Cancer patients offered psychological needs assessment throughout illness

Deliver psychological services in line with the four level model

- National Institute for Health and Clinical Excellence CG123. Common mental health disorders full guidelines
Therapies

Cognitive Behavioural Therapy
- Reduces distress (and pain) in patients with breast cancer [LEVEL 1]
- Reduces anxiety and depression in Inpatient and outpatient hospice patients [LEVEL 2]
- CBT may also help distress in patients with advanced cancer [LEVEL 3]

Psychotherapy
- Improve overall coping skills, family dynamics and alleviate suffering [LEVEL 3]

Family Therapy

Solution Focused Therapy [LEVEL 3]

1. Tatrow K, Montgomery GH. Cognitive behavioral therapy techniques for distress and pain in breast cancer patients: a meta-analysis. Journal of Behavioral Medicine, 01 February 2006, vol./is. 29/1(17-27), 01607715

LITERATURE REVIEW - ADULT PSYCHOLOGICAL SERVICES IN PALLIATIVE CARE

There should be a **Network Psychological Support Group (NPSG)** which is recognised as the network's primary source of opinion on issues relating to patients' and carers' psychological support and for co-ordination and consistency across the network on such issues.

Named consultant psychiatrist/psychologist as Lead and Chair

**Minimum membership**
Representative of each localities (Level 2 or above)
User representatives x 2
Named secretarial/administrative support

- NHS National Cancer Action Team. National Cancer Peer Review Programme
The Network Psychological Support Group (NPSG) is responsible for:

- Agreeing the training programme, trainers and assessors for Level 2 practitioners
- Ensuring there are personnel available to give support to practitioners in MDTs
- Agreeing the induction programme for Level 3 and 4 practitioners and their ongoing support
- Agreeing and distributing a policy on screening for patients' and carers' needs for psychological support
- Agreeing and distributing guidelines for referral of patients and carers for psychological support;
- Producing a baseline and mapping of the networks current service provision;
- Producing a current service specification;
- Producing a current service needs assessment
- Producing a service development strategy;
- Producing a training and education strategy;
- Providing information for the cancer services directory.
Psychological support for children with a relative receiving palliative care

Clare Jeffries
LITERATURE REVIEW - PSYCHOLOGICAL SUPPORT FOR CHILDREN WITH A RELATIVE RECEIVING PALLIATIVE CARE

Databases searched:
- AMED (1985 to Jan 2104)
- EMBASE (1980 to Jan 2104)
- Medline (1946 to Jan 2104)
- PsychInfo (1806 to Jan 2104)
- BNI (1992 to Jan 2104)
- CINAHL (1981 to Jan 2104)
- Cochrane
- NICE

Search Terms:
- Palliat* OR “end of life” OR “life limiting” OR “terminal Illness” AND
- Child* OR teenage* OR adolescen* OR “young person” AND
- “Pre-bereavement” OR “bereavement” AND
- Psych* OR support OR Counsel* AND
- Service*

Further searches of databases of first and last name authors and references from above articles. Total = 376 Included 47, Excluded 329
(327 - Not applicable – children with palliative condition/adult children and 2 Non-English articles)
EVIDENCE

- of *impact of illness and death* of a parent/carer on children and adolescents

- for *factors that influence* how children and adolescents *cope* with the illness and death of a parent/carer

- for *interventions that improve* how children and adolescents *cope* with the illness and death of a parent/carer
2 years after death of parent 1/3 children may have enduring emotional and behavioural problems to merit counselling. (Harvard Bereavement Study 1996)¹

Parentally bereaved children have higher risk of: ²,³,⁴
- depression
- anxiety
- delayed emotional development
- low self esteem
- sleep disturbance
- post traumatic stress disorder
- social exclusion
- traumatic grief
- reduced school performance

Risk of negative outcomes is magnified in children already vulnerable or disadvantaged. ⁵

Significant levels of stress during palliative phase of illness²,⁶

Higher levels of depression and anxiety than after death. ³

Children’s well-being is especially vulnerable at the time of the diagnosis and when the illness situation changes. ⁷

6. Beale EA. Sivesind D And Bruera E. Parents Dying Of Cancer And Their Children Palliative And Supportive Care. 2004.2; 387–393
DEVELOPMENT OF PSYCHOLOGICAL SERVICES IN PALLIATIVE CARE
LITERATURE REVIEW – EVIDENCE FOR FACTORS THAT INFLUENCE HOW CHILDREN & ADOLESCENTS COPE WITH ILLNESS AND DEATH OF A SIGNIFICANT ADULT

Risk Factors

Negative/non-supporting relationship with surviving caregiver
Poor relationship with parent who died
Low self esteem and external locus of control
Concurrent stressful life events
Pre-existing mental health in adolescent/surviving caregiver
Circumstances of death (e.g. traumatic)

Protective Factors

Open, warm, positive relationship with surviving caregiver
Surviving caregiver competent parent
Accepted by peers and adults
Opportunity to express feelings about patient and have these feelings validated
Sharing information about parents illness and death
Higher socioeconomic status
Internal locus of control
Religiosity
Intellectual and social competence

Children have **distinct developmental stages** that influence

what they **understand**,  
how they **behave**,  
how they **mourn**  
and how **information can be tailored** to their needs.

Literature Review – Evidence for interventions that improve how children & adolescents cope with the illness and death of a significant adult

Family based approaches/groups of peers

Pre-bereavement intervention studies.

All showed improvement in outcome.

1 Long term RCT study (10 years on) continued improvement

Skilled short term work pre-bereavement can benefit child and family and encourage resilience.

Long term counselling can reduce family coping skills.

Ending long term counselling can be another loss.

Audit Results

Emma Longford
New Guidelines and Standards

Clare Finneghan
NEW GUIDELINES - GENERAL PRINCIPLES

- Psychological distress is defined as “a multifactorial unpleasant experience of a psychological (cognitive, behavioural, emotional), social and/or spiritual nature that may interfere with the ability to cope effectively with cancer.”

- Psychological distress is commonly experienced in cancer and palliative care patients.

- The prevalence of conditions such as anxiety and depression are significantly higher in cancer (10-30%) and palliative care patients (45-58%) than in the general population.

- Various types of cancer (e.g. head & neck) and differing stages of disease process (e.g. diagnosis or advanced disease) predispose patients to experience greater distress.

- Psychological distress has been shown to have a significant impact on quality of life, degree of pain, physical functioning and families.
NEW GUIDELINES - GENERAL PRINCIPLES

- The illness and death of a parent or other significant adult can impact on children and adolescents in the immediate, short and long term. Children and adolescents' well-being is especially vulnerable at the time of diagnosis and when the illness situation changes. Levels of depression and anxiety can be higher during the palliative phase of the illness than after death. Bereaved children may show reduced school performance, self-esteem, social exclusion and delayed emotional development when compared to non-bereaved children. The risk of negative outcomes is magnified in children who are already vulnerable or disadvantaged.

- Patients with children often feel that they are not supported in communicating with their children about their illness and research has shown that a significant number of children reported not being warned about the expected death of their parent. Provision of psychological support for children is sometimes limited.

- There are factors that influence how children and adolescents cope with the illness and death of a parent/significant adult. Research has shown that children and adolescents have distinct developmental stages that influence what they understand, how they behave, how they mourn and how information can be tailored to their needs. Skilled short term pre-bereavement work can benefit the child and family and encourage resilience. Long term counselling can reduce family coping skills and should be avoided if possible. Ending long term counselling can be another loss.
It is suggested that regardless of severity, patients with psychological distress will benefit from appropriate professional support.  

At least 10-15% of these patients will warrant specialist psychological or psychiatric intervention.

However in order to access such support, appropriate identification, assessment and referral systems for psychological distress are required.

There are various professional and voluntary services available to assist patients, carers, families and children experiencing psychological distress.

Currently there remains a lack of co-ordination and integration of specialised psychological support services with palliative care providers e.g. counselling, clinical psychology, liaison psychiatry.

The co-ordination and integration of specialised psychological support services, general professional psychological support and voluntary services with palliative care providers is essential to the provision of good psychological care.
NEW GUIDELINES - SERVICE PROVISION

- The National Institute for Health and Clinical Excellence (NICE) Guidance suggests that palliative care service providers in each Integrated Care Network (ICN) should look to develop services in line with a four level model. For further details of this model see Figure 35.1. [Level 4]

- There should be a Network Psychological Support Group (NPSG) which is recognised as the network's primary source of opinion on issues relating to patients' and carers' psychological support and for co-ordination and consistency across the network on such issues. For further details of NPSG see Fig 35.2.

- There should be support available for all staff who offer psychological support. [Level 4]

- There should be access to formal clinical supervision for staff utilising psychological approaches who are working at Levels 3 and 4. [Level 4]
### Figure 35.1  Suggested four level model for the provision of psychological support

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The Network Psychological Support Group (NPSG)\textsuperscript{23} is responsible for:

- Agreeing the training programme, trainers and assessors for Level 2 practitioners
- Ensuring there are personnel available to give support to practitioners in MDTs
- Agreeing the induction programme for Level 3 and 4 practitioners and their ongoing support
- Agreeing and distributing a policy on screening for patients' and carers' needs for psychological support
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- Producing a training and education strategy;
- Providing information for the cancer services directory.
DEVELOPMENT OF PSYCHOLOGICAL SERVICES IN PALLIATIVE CARE

NEW GUIDELINES – EDUCATION AND TRAINING

- Specialist palliative care units should provide access to education programmes in psychological care. These programmes should be open to all clinical staff working with palliative care patients and their families. Programmes should include the assessment and management of Level 1 and Level 2 situations (see Figure 35.1). ¹⁰ [Level 4]

- The NPSG is responsible for agreeing the training programme, the trainers and assessors for Level 2 practitioners. These programmes should be open to all clinical staff working with palliative care patients and their families. Programmes should include the screening of patients and carers for their need of psychological support and basic psychological support intervention techniques ²³[Level 4]

- Training in communication skills is essential for all clinical staff. ⁹,²³[Level 4] Basic or Intermediate communication skills training should be undertaken by all palliative care staff providing Level 1 psychological support. Advanced communication skills training should be undertaken by all staff providing Level 2 psychological support and above. ²³[Level 4]

- Training programmes should be developed by the NPSG in accordance with the evidence base and in collaboration with psychological specialists. This training should be updated on a regular basis. ¹⁰[Level 4]
NEW GUIDELINES - SERVICE DELIVERY

➢ Appropriate facilities/environment for psychological assessment and intervention should be available/identified, providing privacy and comfort for patients, and their carers and children. 9 [Level 4]

➢ Each palliative care service provider should establish written criteria for the identification and assessment of psychological distress for patients, carers and children, together with referral criteria to the appropriate professionals providing psychological assessment and intervention at Levels 3 and 4. 9,23,24 [Level 4]
During the initial assessment, patients should be asked if there are any related children. This information should be documented together with any concerns regarding communication, existing or potential distress. [Level 4]

Children’s psychological needs should be assessed and documented regularly to ensure problems are identified and addressed early. [Level 3]

Resources for adults on how to talk to children in an age/development appropriate manner should be readily accessible in addition to face to face support for parents, guardians and other relatives. [Level 4]

Parents, guardians and relatives should be signposted to additional local and national resources as required. [Level 4]

Provision for Level 3 and 4 psychological support for the child/adolescent and family should be available. [Level 1]

Where consent is gained, it may be helpful to share information with other organisations involved in the child’s life (e.g. school, college, nurseries, GP, health visitor, social services, psychological services). Where the professional has concerns about the safety of the child, they must follow child protection legislation and organisational guidelines. [Level 4]

Practical and psychological support should be offered to the well parent/carer. [Level 2]
NEW STANDARDS

1. Each palliative care service provider should have written referral criteria to guide access to professionals working at Levels 3 and 4. [Grade D]

2. All clinical staff providing palliative care must have access to the referral criteria. [Grade D]

1. Written referral criteria for psychological support must be available to all clinical staff providing palliative care, to guide access to professionals working at Levels 3 and 4. [Grade D]

3. There should be a named lead psychiatrist and psychologist identified at Cancer Network level to advise on the provision of specialist care at Levels 3 and including access to emergency psychiatric support. [Grade D]

2. There should be a named lead consultant psychiatrist and named lead consultant psychologist identified at Cancer Network level. In conjunction with the NPSG, they will advise on the development and provision of psychological support at all levels across the network. [Grade D]

6. Managers of staff involved in providing palliative care must ensure that there are procedures in place to provide appropriate support for all staff and that staff are aware of the procedures. [Grade D]

4. Clinical staff practising at Levels 3 and 4 should have regular clinical supervision. [Grade D]

3. Service managers of staff involved in providing palliative care must ensure that there are written procedures in place to provide appropriate support for all staff and staff should be aware of these procedures. [Grade D]. Clinical staff practising at Levels 3 and 4 should have regular clinical supervision as per professional guidelines. [Grade D]
NEW STANDARDS

5. All clinical staff working in specialist palliative care should have had accredited communication skills training and receive regular updates. [Grade D]

4. All clinical staff working in specialist palliative care should participate in level appropriate training in communication; psychological assessment and management skills as outlined by NPSG [Grade D]

6. Each service should have procedures in place to ensure that initial and ongoing psychological assessment of patients are undertaken and documented. [Grade D]

7. Each service should have procedures in place to ensure that initial and ongoing psychological assessment of primary carers are undertaken and documented. [Grade D]

8. Each service should ensure that children/dependents of patients are identified and their needs regularly assessed and documented. [Grade C]

9. Patients or relatives with concerns about children should be offered support and guidance and signposted to other resources or referred for Level 3 and 4 support if required. [Grade A]
NEW REFERENCES

NEW REFERENCES

14 Sandler et al. Six-Year Follow-up of a Preventive Intervention for Parentally-Bereaved Youth: A Randomized Controlled Trial Arch Pediatr Adolesc Med 2010 164(10) 907-14
17 Turner J. Development of a resource for parents with advanced cancer: What do parents want? Palliative and Supportive Care 2007. 5, 135–145. 2
18 Cranwell B. Bereaved children’s perspectives on what helps and hinders their grieving. CBUK 2008.
19 Bugge KE and Helseth S. Children’s experiences of participation in a family support program when their parent has incurable cancer. Cancer Nursing 2008.31(6);426-434
22. Merseyside and Cheshire Palliative Care Network Supra-Regional Audit of Psychological Services Data 2013
External Expert Review

Dr Jan Abblett
MERSEYSIDE AND CHESHIRE PALLIATIVE CARE NETWORK AUDIT GROUP

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