あるものを理解することができる人」などをあらためてより詳細な項目にして挙げたうえで、「委員会に患者や家族のメンバーがたった一人というのは通常成功しない。委員会の 3 分の 1 から 2 分の 1 を占める位がいい」「患者や家族がアドバイザーになるというのは多くの人にとって新しい役割であることを忘れないこと。多くの支援が必要な患者や家族も出てくる。ただし、誰もが次第に理解し成長してくることを忘れないこと」なども示されている。

「打ち合わせについて」では、「患者や家族に意見を聞いて委員会のメンバーとしての役割が果たせるよう応援してあげること」としつつ、「患者や家族からの後ろ向きな発言で委員会の議論がとまってしまうことがないように、その不幸な体験を理解したことを伝えたうえで、何かできることはないか尋ねてみること。また、防止や改善のためのアイデアがないか聞いてみること」「もし個人的な体験談が非常に長く続くような場合は、話してくれたことを感謝し、理解したこと伝えたうえで、その体験談を活かすもっと別な場があるかもしれないことなどを提案すること」「もし極端に異なる意見が噴出するようなときは、その事案に関するタスクフォースを設定すること。他の委員会の意見を聞くようにすること。その場で結論を出さず次回持ち越しにすること」など、現実的な対応策が示されている。

・「Sharing Your Story: Tips for Patients and Families」「Presentations by Patients and Families: Staff Liaison Coordination and Preparation Roles」について(資料 3-⑥⑦)

PFAC が機能していくためには、患者や家族への支援も必要である。

IFCC は患者・家族向けに、そうした協議会のメンバーとして機能するためにまず必要な技術として「語ることができること」を挙げ、患者や家族向けの toolkit として「あなたの体験を共有するためのヒント」や、受け入れ先向けの toolkit として、患者や家族が上手にプレゼンテーションをできるよう「プレゼンテーションのコーディネート方法」が用意されている。

「あなたの体験を共有するためのヒント」では、「話をする招待を受けたら、何を出席者に伝えたいかをじっくり検討しなさい。」から始まり、「以下があなたの体験を話す際のヒントです」として挙げられている 16 項目のなかには、「出席者はどういう人たちなのかを知って、心に留めておきなさい」といった一般的なヒントから、「あなたの不幸な体験が建設的な学習の機会になるかもしれないことを忘れないこと。効果的ではない怒りは、あなたの話しそのものの力にあまりならない」「あなたの話を聞いて大変心を動かされる人がいるかもしれない。そしてあなた自身も話の途中で感情的になるかもしれないことを心に留めておくこと」と、患者や家族という話し手ならではの視点で挙げている。

・「Patient and Family Leaders in Paid Positions」について(資料 3-⑧)

IFCC のアプローチとして興味深いのは、いわゆるボランティアとして「無償で参加」するだけでなく、「責任のある役割を果たす」という意味において「有償で参加」することを検討していることである。「そればかりか「患者・家族本位の医療の実現のために患者や家族が就くことができる職種が病院にはたくさんある」として、職員として雇用されることを積極的に推進している。

「有償のポジションにおける患者や家族：乗り越えなければならないこととその有効な解決方法」のなかでは、乗り越えなければならないこととして「組織で働くために必要な技術不足」「管理能力不足」「健康状態への配慮」「他の病院職員の抵抗」であり、それぞれの対応方法についてのヒントが示されている。

(表 5)「委員会のメンバーやアドバイザーにはどのような家族や患者を探せばいいか.」

In reviewing possible candidates for advisory positions, look for individuals who:
Share insights and information about their experiences in ways that others can learn from them.
・Show concern for more than one issue or agenda.
・Listen well.
・Respect the perspectives of others.
・Speak comfortably and candidly in a group.
・Interact well with many different kinds of people.
・Work in partnerships with others.
・See beyond their own personal experience.

(表 6)The Institute for Family Centered Care が配信している toolkit

(1)Tools to Foster the Collaboration with Patient and Family Advisors
①Patients and Families as Advisors: A Checklist for Attitudes
②Tips for Group Leaders on Involving Patients and Families on Committees and Task Forces
③Creating Patient and Family Advisory Councils
④Tips for Recruiting Patients and Families to Serve in Advisory Roles
⑤A Patient and Family Advisory Council Workplan: Getting Started
⑥Sharing Your Story: Tips for Patients and Families
⑦Presentations by Patients and Families: Staff Liaison Coordination and Preparation Roles
⑧Patient and Family Leaders in Paid Positions

(2)Other Tools to Foster the Practice of Patient- and Family-Centered Care
①Are Families Considered Visitors in Our Hospital or Unit: A Checklist
②HIPAA - Providing New Opportunities for Collaboration
③Wearing New Glasses
④Sharing Personal and Professional Stories
⑤Magic Wand Exercise
⑥Patient- and Family-Centered Care: What's in it for Me?
⑦Tools to Assist in Designing Supportive Health Care Environments
⑧Patients and Families as Advisors in Design Planning
⑨Design Planning Key Priorities
⑩Conducting Site Visits for Design Planning

⑤「Champion」に向けてた支援活動を行っている

「Champion」というのは、ある取り組みを全体に広げるための突出して優れた取り組みのことである。ある取り組みを全体に広げるための突出して優れた人についても使われる。すでに述べたように、「まずトップが前向きな取り組みを判りやすいかたちで進めること、スタッフがそうした取り組みを理解できるような適切な情報を提供すること、すでにそうした取り組みに興味を持っている人や部署でモデルになるような取り組みを実践すること、スタッフを取り組みに巻き込むこと」といった方法論で進められていくことになる。ポイントは、「すでにそうした取り組みに興味を持っている人や部署を中心としてモデルになるような取り組みを実践する」ことである。したがって「優れたモデル」になりえる確率はもともと高く、「取り組みに興味を持たない人や部署」で同じように成功するかどうかはまた別な問題になる。ただし、そうした優れたモデルが「それまで興味を持っていなかった人や部署に興味を持たせるきかっけ」になることは期待できることになる。

いざ取り組ももうとしても、現場として乗り越えなければならない問題も多い。そこに、このIFCCが具体的な支援をしてくれるのである。MCG Health System（ジョージア州）は、当初の小児の領域（Children' s Medical Center）で始めた患者・家族のアドバイザーとしての参加を成人の領域（Neuroscience Center of Excellence）に広げていった「Champion」として紹介されている。現場にとってありがたい支援であると同時に、IFCCにとっては、単なる成功事例としてのみならず、成功への過程を「変革のプロセス」として、これから同様の取り組みを目指す医療機関にとって貴重な教材となる情報を提供できることになるのである。

資料集

（資料3－①②③④⑤⑥⑦⑧）

「The Institute for Family Centered Care が配信している toolkit」

The Institute for Family-Centered Care,
http://www.familycenterdcare.org

(2)Dana-Faber Cancer Center Institute(DFCI)の取り組み

MCG Health Systemとともに、「患者・家族本位の医療」をめざし、患者・家族の参加を実践している医療機関のひとつがDana-Faber Cancer Center Institute(DFCI)（マサチューセッツ州）である16)。

①Patient and Family Advisory Council について

1998年にスタートしたDFCIのPFACは、現在15人程度の患者・家族（任期は1年から3年）と4人の病院上級管理職によって構成されている。DFCIのPFACは「The Communications Committee（DFCIのPFACの活動を広めるための広報活動）」「The Patients as Educators Committee（医療従事者に患者・家族の立場で体験者の声を聴かせることによる教育活動）」「The Rounding Committee（治療を受けている患者・家族と会いその声を病院に届ける活動）」という3つの委員会を統括している。PFACを「医療の質の改善する」「患者の声を聴く(advocacy)」という二つの活動から育ってきたものだとし、IFCCとも連携しながら進められているDFCIの取り組みは全米のモデルケースともされている。

②Patient Safety Round について

3つの委員会のなかでも特にいま医療安全の視点から新しい取り組みとして力を入れているのが、「The Rounding Committee」が取り組む、患者や家族が患者や家族を対象に行う院内巡回である。近年医療安全の観点から病院の医療安全担当者による現場と職員を対象とする院内巡回（Round）はあちこちでも行われているが、「PFACの取り組みから“患者や家族はまずいことが起きていることやうまくいっていないことを認識している”ことを学んだこと」や「DFCIが培ってきた患者・家族本位の医療を目指す文化に照らし取り組むべきことだと判断するに至ったこと」から、患者・家族（具体的にはトレ

ーニングを受けたDFCIのPFACのメンバー）が院内の患者・家族を対象にインタビューを行うPatient Safety Roundを実践しているのである。「職員が医療安全に熱心に取り組んでおり、なかでも優れた職員（Champion）がいる」部署を選び試行した6ヶ月の結果は、インシデントが劇的に減少するなどの医療安全の視点から大きな成果を得たとして、現在他の部署への展開が検討されているという17)。

③その他の委員会への参加について

また、患者や家族の参加の場はPFACだけではない。PFACが統括する3つの委員会のほかにも、院内の「The Arts and Environment Committee」「The Facilities Planning Committee」といった環境に関するものから「The Inpatient Care Improvement Committee」「The Adult Oncology Clinical Services Quality Assurance Committee」「The Outpatient Care Improvement Committee」といった医療の質に関するものや、患者・家族を支援する「The Patient/Family Education Council」まで、院内のさまざまな委員会に参加しているのである。

④「患者による患者のための広報誌」について

また、DFCIのPFACは「The Communications Committee（PFACの活動を広めるための広報活動）の一環として、「Side by Side」という広報誌を季刊で発行している。「診断や治療の過程で難しい意思決定をしなければならないとき」といった、患者、特にがん患者にとって必要なテーマを患者や家族の視点で取り上げるとともに、Patient and Family Advisory CouncilやPatient Safety Roundといった活動の紹介、そして、活動への参加の勧誘の場としても活用している。

5. おわりに:「医療安全における患者参加の実践プログラムの検討」に向けての課題

本研究の目的は、日本における「患者参加の医療安全」の推進に寄与することを目的とする「医療安全における患者参加の実践プログラムとその効果的教育・研修システムの開発研究」の分担研究として、アメリカにおける取り組みの先進事例や現状から、患者参加の実践プログラムの検討を行うことにある。

平成16年度は、アメリカにおける実践事例としての「Speak Up」や「20 Tips to Help Prevent Medical Errors」といったプログラムや訪問先の病院の取り組みについて報告し、「患者参加の医療安全」の実現に向けての課題として、「患者参加の医療安全の重要性の明確化」「具体的な患者参加のあり方の提示」「インセンティブが働く仕掛け」「患者だけではなくPublicに向けた展開」の4点を挙げた。

平成17年度は、「全体の安全向上への参加」、具体的には「病院全体の安全向上への参加」と「医療全体の安全向上への参加」についてアメリカにおける実践事例を検討するなかから、日本の今後の取り組みに通じる新たな検討課題が見えてきている。

（1）新たな検討課題

①「患者参加の医療安全」のフレームワークの検討

アメリカの実践報告からもわかるように、一言で「患者参加の医療安全」といってもさまざまなかたちがある。「実践プログラム」や「効果的教育・研修システム」を検討していくためには、患者参加の医療安全のフレームワークを整理し、そのうえで、それぞれの取り組みについて検討していく必要がある。

②「参加のかたち」の概念整理

本報告書においてその概念整理を行ったように「参加のかたち」については、「自らの安全確保への参加」と「全体の安全向上への参加」に整理することができる。そして「全体の安全向上への参加」は、その実践の場から「組織全体の安全向上への参加」と「医療全体の安全向上への参加」に整理することができる。本報告書ではふれなかったが、「医療全体の安全向上への参加」については、いわゆる患者団体の、医療の現場や政策決定へのさまざまな参加も進んでいる。日本における今後の参加のかたちとしても検討する必要がある。

③「患者」の概念整理

「患者参加のかたち』の概念整理が必要であるように、「患者」そのものの概念整理も必要である。もちろん狭義に「患者」は「現在診断・治療などの医療サービスを受けている者」ということになるが、医療安全の確保と向上に向けて、「実際に患者になってからの参加では遅いこと」「患者を支援する家族の役割も大きいこと」、そして「患者であれ家族であれ、広くさまざまな資源を活用する必要があること」などを考えれば、狭義の患者のみならず「潜在的な患者」や家族、いうなれば「国民」としての参加の検討が必要になる。

なお、そのなかで「医療事故の被害者」としての参加は、その特別な意義を持つことになる。「患者参加」のなかにどのように位置付けるかの検討が必要である。

④それぞれの取り組みにおいて必要な具体的サポートの検討

IFCCがそのtoolkitのなかでさまざまなサポートを行っているように、実践となれば直面する問題は多い。日本の医療の現場で、患者や家族、そして医療従事者の双方にとって必要なサポートは何か。その検討と、IFCCのtoolkitのような具体的な問題解決のためのヒントの提示が必要である。

先にも述べたが、「医療事故の被害者」としての参加は、一般的な「患者や家族の参加」以上のサポートが必要である。IFCCのtoolkitにおいても、「アドバイザーの役割を果たしてくれる患者や家族の選抜について」として「他の人が学ぶことができるような方法で、自らの体験に関する情報や視点を共有する（共有させる）ことができる人」「自らの個人的な体験の先にあるものを理解することができる人」と示されたり、「あなたの体験を共有するためのヒント」として「あなたの不幸な体験が建設的な学習の機会になるかもしれないことを忘れないこと。効果的ではない怒りは、あなたの話しそのものの力にあまりならない」「あなたの話を聞いて大変心を動かされる人がいるかもしれない。そしてあなた自身も話の途中で感情的になるかもしれないことを心に留めておくこと」と示されたりしている。日本の医療の現場において、どのようなサポートがあれば、「患者参加の医療安全」において、「医療事故の被害者」の参加の障害を取り除き、を「医療事故の被害者」と医療従事者双方にとってより建設的な取り組みにしていくことができるのか、は今後の重要な検討課題である。

(2)今後の検討課題

以上を踏まえ、あらためて、「患者参加の医療安全」の推進に向けた「医療安全における患者参加の実践プログラムとその効果的教育・研修システムの開発」という視点からの今後の検討課題を以下として整理しておきたい。

・患者参加の医療安全の重要性の明確化
・患者参加の医療安全」のフレームワークの検討
・「患者参加のかたち」の概念整理
・「患者」の概念整理
・それぞれの取り組みにおける必要な具体的サポートの検討
・それぞれの取り組みにおいてインセンティブが働く仕掛けの検討
・それぞれの取り組みに向けての具体的な教育・研修プログラムの検討
・Publicに向けた展開の検討

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資料1

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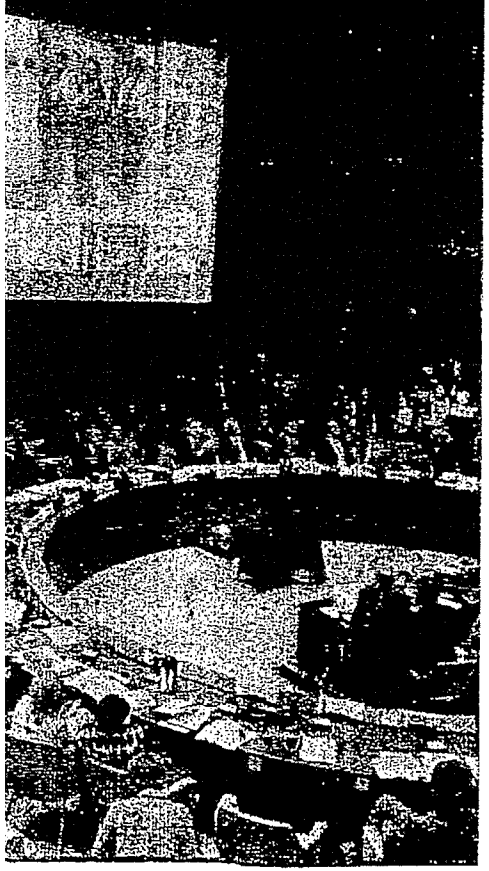


PATIENT SAFETY

A YEAR OF LIVING less DANGEROUSLY

PROGRESS REPORT 2005

World Health Organization

Josie King

Died:
January 2001

Age:
18 months

Place:
Baltimore, MD, USA

Cause of Death:
Severe dehydration and administration of an un-prescribed pain-killing drug during a hospital admission.

CLEAN CARE IS SAFER CARE

A core programme of the World Alliance for Patient Safety, the Global Patient Safety Challenge: A topic that covers a significant aspect of risk to patients around the world and for every WHO Member State is identified for action over two years.

Promoting **Clean Care is Safer Care** is not a choice. It is our duty to patients, their families and health-care workers. Let us move forward together. Each of us can make a small difference, significant improvement requires an effort from all of us.

Didier Pittet
Leader, Global Patient Safety Challenge

The first Global Patient Safety Challenge for 2005-2006 is titled "Clean Care is Safer Care" and focuses on health care-associated infection. Health care-associated infection affects hundreds of millions of people worldwide and complicates the delivery of patient care. These lead to patient disability and deaths and generate significant, additional health-care expenditure.

The vision of the Global Challenge is simple: to catalyse worldwide commitment by policy-makers, experts, clinicians and patients to make "Clean Care is Safer Care" an everyday reality wherever health care is provided.

Professor Didier Pittet, Director, Infection Control Programme, Geneva's University Hospitals, has been an inspirational leader for the development of the Global Patient Safety Challenge.

Serious Harm

ALAN BRANT

Surrey, UK

Alan Brant was 54-years old when in December 2000, he was permanently disabled following the unnecessary removal of part of his oesophagus, incorrectly thought to be cancerous. The biopsy supposedly revealing cancerous oesophageal tissue and leading to the operation, had been contaminated in the lab by a tiny fragment of malignant tumour from a previous test.

A Lifelong Challenge

URIEL AND HIS MOTHER EVANGELINA VÁSQUEZ,

Mexico City, Mexico

Evangelina Vásquez was pregnant with her first child in 1994. Uriel suffered permanent brain damage as a result of fetal distress and neonatal jaundice because:

- Chain of errors related with incorrect testing of her blood type
- Very long labour ending in caesarean section.
- Mother and baby discharged too quickly.

Perspectives in Health, the magazine of the Pan American Health Organization

Serious Harm

IAN KELLY

Surrey, UK

In the year 2000, 41-year old Ian Kelly contracted MRSA following a routine leg operation. Four years later Ian remained ill and agreed to a through-the-knee amputation.

Serious Harm

ALICE KABUSINGYE

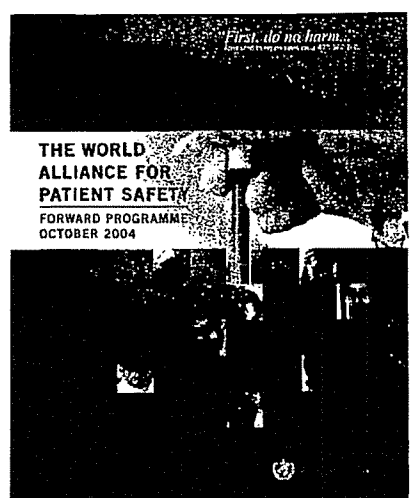
Aged 50 years of Kyabwambe village in Uganda, Alice, had her fingers amputated after a malaria drug was injected into a vein in her arm rather than a muscle.

STRONG FOUNDATIONS FOR SAFER CARE

Reducing accidents and the risk of error in health care requires a significant and sustained response at global, regional and national levels. 2005 was a significant turning point in the world's response to patient safety with the launch of the World Alliance for Patient Safety in late 2004. The Alliance set an ambitious work programme for 2004-2005 calling for accelerated efforts to improve the safety of care

The work of the World Alliance for Patient Safety runs through all levels of WHO. The Alliance Secretariat is based in the Evidence and Information for Policy Cluster, within WHO Headquarters as well as in Regional Offices. The Alliance coordinates the activities between country, regional and headquarters offices, these are critical for the effective development and implementation of plans, strategies, programmes and interventions.

The World Alliance for Patient Safety also depends on the commitment of its partners and technical experts from around the world and other WHO departments, who help extend the capacity of the Alliance Secretariat with operational and technical support



Beyond enabling the core functions of the Alliance, partnerships complement its focus to help improve on a global level one of the basic goals of medical practice **"First do no harm"**

This collaboration often involves the establishment and operation of programme-based working groups or task forces in order to advance efficiently the work in specific areas of common interest.

The Alliance has benefited from the consistent support of the International Hospital Federation, the International Council of Nurses, the International Pharmaceutical Federation, the International Federation of Red Cross and Red Crescent Societies and the World Medical Association

Both developing and developed country non-governmental organizations and agencies participate in the Alliance. Some examples include People's Health Movement, Consumers Advancing Patients Safety, the International Federation for Medical and Biological Engineering and many others

LONDON DECLARATION

Patients for Patient Safety
WHO World Alliance for Patient Safety

We, Patients for Patient Safety, envision a different world in which healthcare errors are not harming people. We are partners in the effort to prevent all avoidable harm in healthcare. Risk and uncertainty are constant companions. So we come together in dialogue, participating in care with providers. We unite our strength as advocates for care without harm in the developing as well as the developed world.

We are committed to spread the word from person to person, town to town, country to country. There is a right to safe healthcare and we will not let the current culture of error and denial, continue. We call for honesty, openness and transparency. We will make the reduction of healthcare errors a basic human right that preserves life around the world.

We, Patients for Patient Safety, will be the voice for all people, but especially those who are now unheard. Together as partners, we will collaborate in:

- Devising and promoting programs for patient safety and patient empowerment.
- Developing and driving a constructive dialogue with all partners concerned with patient safety.
- Establishing systems for reporting and dealing with healthcare harm on a worldwide basis.
- Defining best practices in dealing with healthcare harm of all kinds and promoting those practices throughout the world.

In honor of those who have died, those left disabled, our loved ones today and the world's children yet to be born, we will strive for excellence, so that all involved in healthcare are as safe as possible as soon as possible. This is our pledge of partnership.

March 29, 2006

INSTITUTE FOR FAMILY-CENTERED CARE
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PATIENTS AND FAMILIES AS ADVISORS: A CHECKLIST FOR ATTITUDES

- Do I believe that patients and their family members bring unique expertise to our relationship?
- Do I believe in the importance of patient and family participation in decision making at the program and policy level?
- Do I believe that patient and family perspectives and opinions are as important as professionals'?
- Do I believe that patients and families bring a critical element to the team that no one else can provide?
- Do I consistently let others know that I value the insights of patients and families?
- Do I work to create an environment in which patients and families feel supported and comfortable enough to speak freely?
- Do I listen respectfully to the opinions of patients and their family members?
- Do I believe that patients and families can look beyond their own experiences?
- Do I clearly state what is required and expected of patients and families in their advisory roles?
- Do I help patients and families set clear goals for their role?
- Do I understand that an illness or other family demands may require patients or family members to take time off from advisory responsibilities?
- Do I feel comfortable delegating responsibility to patients and families?

Adapted from Jeppson, E. Thomas, J. (1994). *Essential Allies: Families as Advisors.* Institute for Family-Centered Care, Bethesda, MD.

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Tips for Group Leaders and Facilitators on Involving Patients and Families on Committees and Task Forces

Selecting Patients and Families to Serve as Advisors

- Look for people who are:
  - interested in serving as advisors;
  - comfortable in speaking in a group with candor;
  - able to use their personal experience constructively;
  - able to see beyond their own experience;
  - concerned about more than one issue or agenda;
  - able to listen and hear differing opinions;
  - representative of patients and families served by the hospital.
- Having just one patient or family member on a committee is not usually successful. Strive for patients and family members to be one third to one half of the committee's membership.
- Remember that serving as a patient or family advisor is a new role for many people. Some patients and family members will need more support than others. Recognize that individuals can grow and develop in this role.

Preparation for Meetings

- Consider the convenience and schedules of patients and families as well as staff in planning the times and locations for meetings.
- Send agenda and minutes ahead of time to all committee members, remembering to allow time for material to reach patients and families (they may not have faxes, email etc.).
- Provide a list of committee members with a brief description of who each person is.
- Offer a mentor, an experienced patient or family advisor or another committee member, to serve as support for a new advisor.
- Offer to have someone come to the first meetings with a new member and debrief afterwards.
- Remember that this type of collaboration is new for many people so preparation and orientation is important for staff as well as patients and family members.
- Plan for compensation of time, expertise, and expenses for patients and families.
- Designate one staff member to be responsible for reimbursement and other practical or logistical issues for patient and family advisors.

During Meetings

- Spend extra time on introductions at the beginning of a meeting, especially for a new committee or when there are new members.
- Consider beginning some meetings with a brief story that captures patients' and families' experiences and perceptions of care.
- As the leader or chair, discuss the concept of collaborating with patients and families explicitly, recognizing that it is a process with everyone learning together how to work in new ways. Convey that it will be important for the group to discuss how the process is working from time to time.
- Acknowledge that there will be tensions and differing opinions and perceptions.
- Provide clear information about the purpose of the committee or task force and the roles of individual members.
- Avoid using jargon. Explain technical terms when used.
- Ask for the opinions of patients and families during discussions, encouraging their participation and validating their role as committee members.
- To avoid becoming stuck in the power of a negative situation, acknowledge the negative experience and ask if there was anything supportive, helpful, or positive for the group to learn from the situation. Ask for ideas and suggestions to prevent or improve the situation.
- If a personal story becomes very prolonged, acknowledge the power and importance of the story, suggest that some policy implications can be learned from the story and that there may other more appropriate forums where this story should be shared.
- When there are extreme differences in opinions or perceptions, consider:
  - appointing a task force for further study of the issue;
  - asking the opinion of other groups (e.g., another hospital committee or patient/family advisory group); or
  - delaying a decision and considering at a future meeting.

Anticipate Illness Demands

- Patients and their family members may not be able to attend every meeting. There are other demands on their time and stamina.
- Acknowledge to patients and families themselves and to the committee as a whole that their presence was missed and their participation is valued when they are able to participate. Mailing the minutes and future agendas helps reinforce that their participation is valued.
- Having shared memberships on the committee may help.
- Consider having a "patient and family leave policy" so that consumers can choose an inactive role but maintain their membership should there be circumstances that require some time off.
- Creating a variety of ways for patients and families to participate in the consideration of issues may be useful (e.g., conference calls, written review of materials).

For additional guidance resources available through the Institute for Family-Centered Care: Webster, P. D., & Johnson, B. H. (2000). *Developing and Sustaining a Patient and Family Advisory Council*; Blaylock, B. L., Ahmann, E., & Johnson, B. H. (2002). *Creating Patient and Family Faculty Programs*; Blaylock, B. L., & Johnson, B. H. (2002). *Advancing the practice of patient- and family-centered geriatric care*; Jeppson, E. S., & Thomas, J. (1995). *Essential Allies: Families as Advisors*; and Thomas, J., &. Jeppson, E. S. (1997). *Words of Advice: A Guidebook for Families Serving As Advisors.*

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CREATING PATIENT AND FAMILY ADVISORY COUNCILS

◆ PURPOSE/RESPONSIBILITY OF THE ADVISORY COUNCIL

- Serves as advisory resource to administration and staff of the organization or one of its programs.
- Promotes improved relationships between patients, families, and staff.
- Provides a vehicle for communication between patients/families and staff.
- Provides a venue for patients and families to provide input into policy and program development.
- Provides an opportunity for patients and families to review recommendations referred to the Council by staff or administration.
- Provides an opportunity for patients and families to actively participate in the development of new facilities and programs.
- Channels information, needs, and concerns to staff and administration.
- Actively helps implement changes.
- Provides input into the educational program for staff.
- Collaborates as partners with staff, physicians, and administration in the planning and operation of specific programs.
- Provides opportunities for staff to listen to their customers.
- Provides a safe venue for patients and families to provide input in a setting where they are receiving care.
- Serves as a coordinating mechanism for patients and families.

◆ BENEFITS OF AN ADVISORY COUNCIL

- Provides an effective mechanism for receiving and responding to consumer input.
- Results in more efficient planning to ensure that services really meet consumer needs and priorities.
- Leads to increased understanding and cooperation between patients and families and staff.
- Promotes respectful, effective partnerships between patients and families and professionals.

Developed by Marlene Fondrick and Beverley H. Johnson, Institute for Family-Centered Care, Bethesda, MD, 1998. Revised 2002.

- Offers a forum for developing creative, cost-effective solutions to problems and challenges faced by the program or organization.
- Supplies a link between the program, its surrounding community, and community groups.
- Provides increased emotional support and access to information for patients and families.

Note: The council should not be seen as a place where an individual Council member brings their personal grievances about clinic/hospital experiences to be dealt with and solved. Personal experiences should be used as examples when discussing a program or service. Council members should also bring experiences and perceptions of others families to the discussion. The council should not be seen as a support group. Patients or families who are grieving over a loss should be directed to a support group.

◆ REPRESENTING THE PATIENTS AND FAMILIES SERVED

Seek patients and families who represent a variety of clinical experiences such as type of illness, families, and programs utilized. Include families who have had a broad range of experiences. Include patients and families who have both positive as well as negative perceptions of experiences.

Seek patients and families who reflect the diversity of those served by the hospital or clinic - racial, cultural, religious, socioeconomic, age, educational background, and a variety of family structures.

Identify patients, families, staff, and community organizations that can recommend potential members. Patient representatives, child life personnel, physicians, nurses, managers, and social workers as well as other professionals often are able to recommend candidates.

◆ QUALITIES AND SKILLS OF PATIENT AND FAMILY ADVISORS

Seek individuals and families who are able to:

- Share insights and information about their experiences in ways that others can learn from them.
- See beyond their own personal experiences.
- Show concern for more than one issue or agenda.
- Listen well.
- Respect the perspectives of others.
- Speak comfortably in a group with candor.
- Interact well with many different kinds of people.
- Work in partnership with others.

◆ RECRUITMENT

- Ask staff for suggestions.
- Post and advertise within the units or clinics.
- Put notices in publications.
- Send direct mail to present and former patients.

◆ DEVELOPING THE COUNCIL

Consider developing a patient and family workgroup as a precursor to a more formal Council. The workgroup is a quick way to get family participation in hospital activities. The informal structure of a workgroup may be less threatening to staff. Someone internal or external to the organization can facilitate the workgroup. The latter provides an opportunity for staff and families to become comfortable over time with new ways of working together. The workgroup is a place where both staff and families can learn and practice new collaborative skills and a place to gain confidence in the collaborative process. It provides an opportunity for natural leaders to emerge. The workgroup can provide invaluable information to staff until a permanent council and/or a variety of other collaborative endeavors are established.

◆ COUNCIL STRUCTURE

Determine structure, size, meeting frequency, operating procedures, and bylaws.

SIZE

Smaller groups encourage greater discussion and participation by all members. Most people are more comfortable speaking in a smaller group. It is more challenging to facilitate larger groups and obtain input from everyone. Larger groups will provide a wider range of experiences and input. They also are able to have broader representation of diverse populations. Consider availability of meeting sites to accommodate various sizes of groups. Twelve to eighteen patient and family members is usually considered a manageable size.

STAFF MEMBERSHIP

No more than 3-4 staff should have a permanent place on the council. Other staff can attend depending on topics for discussion. Staff should have easy access to the council. Too many staff will result in patients/families not feeling it is their council.

TERM OF MEMBERSHIP

Consider length of term with rotation being intermittent rather than everyone turning over at once. Suggested term is 2-3 years to maintain some consistency.

COMPENSATION/REIMBURSEMENT

Plan for compensation of time, expertise, and expenses for patients and families. Consider remuneration for patients and families in the form of a small amount to cover travel expenses, baby-sitting, or other costs that might be incurred. Some patients and families may have difficulty joining the Council if they are not given some assistance. Consider providing child care during meetings. If you cannot provide babysitting service, develop a group understanding about whether or not to bring children to the meeting. Designate one staff member from the hospital to be responsible for reimbursement and other practical or logistical issues for family advisors.

OFFICERS

Suggests co-chairs and secretary. If possible provide organization staff such as secretarial support for mailings, etc. Co-chairs could be two patients or family members or a staff person and patient/family member. Suggest selecting one new co-chair each year so there is carryover to the next year.

COMMITTEES

May want to have some permanent committees that could include membership of patients/family members who are not on the council. These might be recruitment, communication, etc. Task forces or ad hoc committees might be identified to work on a specific issue or short-term project. Patients who are not on the council would be encouraged to participate - this will increase the number of patients who participate and provide input.

BY-LAWS

Operating guidelines/by-laws need to be developed by the Council. By-laws are important because they provide the framework for perceived goals and objectives. By-laws also legitimize the group and help promote a feeling of an established, well-organized group. Developing by-laws can be time consuming, however, reviewing bylaws from existing advisory boards can save you time. They can be adapted and amended to suit your group's specific needs.

Select a small core group to develop the bylaws. Among the issues that should be addressed in the by-laws are:

- Purpose of the group
- Goals and responsibilities
- Structure of the group
- Size of the group
- Membership qualifications
- Nominations and elections of members and officers
- Duties of members and officers
- Committees and task forces
- Voting procedures
- Quorum

- Meetings
- Agendas
- Reporting mechanisms
- Guidelines of authority
- Confidentiality
- Amendment procedures

After developing your group's by-laws, present them to the administration for approval. The total membership should review, discuss, and amend if necessary and give final approval.

◆ MEETINGS

SCHEDULE

Frequency - monthly or quarterly is suggested. Monthly is usually adequate. Less frequent - lose momentum and involvement. Too frequent, members will have trouble attending.

Days/times - let the council select but may be dependent on room availability. Consider convenience of both patients/families and staff.

AGENDA

The council should develop a list of issues they wish to deal with and "own" the agenda. Staff or other patients/families can add to the agenda.

MINUTES

Minutes should be kept and distributed widely so the activities of the council are made aware to as much of the organization as possible.

◆ ORIENTATION OF NEW COUNCIL MEMBERS

Orientation should include:

- Introductions and the sharing of personal and family stories;
- The vision and goals of the organization;
- The role of the Council, how its fits within the organization's structure, and how it can assist the organization in achieving its vision and goals;
- The roles and responsibilities of members;
- The roles and responsibilities of officers;
- Meeting attendance expectations of members;
- The roles and responsibilities of staff on the Council;
- How to be an effective Council member;
- How to present issues effectively; and
- How to be most effective in collaborating with hospital/clinic staff and faculty.

◆ MAINTAINING HISTORY

It is important to track accomplishments and publish widely. Track issues the council is working on so they do not get lost.

◆ SUSTAINING THE COUNCIL

- Invest in building leadership skills of members.
- Select patients and families wisely.
- Ensure that the council is representative of families served.
- Maintain balance between new members and committed members with longevity of service.
- Devote time to planning and evaluation of council efforts.
- Set priorities and focus efforts on meaningful collaborative projects.

For additional guidance resources available through the Institute for Family-Centered Care: Webster, P. D., & Johnson, B. H. (2000). *Developing and Sustaining a Patient and Family Advisory Council;* Blaylock, B. L., Ahmann, E., & Johnson, B. H. (2002). *Creating Patient and Family Faculty Programs;* Blaylock, B. L., & Johnson, B. H. (2002). *Advancing the Practice of Patient- and Family-Centered Geriatric Care;* Jeppson, E. S., & Thomas, J. (1995). *Essential Allies: Families as Advisors;* and Thomas, J., &. Jeppson, E. S. (1997). *Words of Advice: A Guidebook for Families Serving As Advisors.*

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TIPS FOR RECRUITING PATIENTS AND FAMILIES TO SERVE IN ADVISORY ROLES

- Ask patients and families who are already involved if they have a friend who might be interested in participating.
- Ask providers to identify patients and families.
- Contact family networks, support groups, or advocacy organizations.
- Post notices in appropriate languages on bulletin boards in waiting areas in clinics and in hospital emergency rooms.
- Post notices in appropriate languages on bulletin boards at educational, recreational, and social service programs, clinics serving patients and families.
- Include information about opportunities for patients and families to participate as advisors in the program's or hospital's consumer satisfaction surveys.
- Ask patients and families who participate in NICU and postpartum reunion gatherings.
- Ask individuals and families who participate in cancer survivor meetings.
- Create a Web page for the Patient and Family Advisory Council and include recruitment information on the site. Link with other relevant Web sites in the community and encourage them to link with the Council site.
- Develop radio and TV public service announcements in the language of the communities you are trying to reach.
- Place a story in community newspapers.
- Use "key informants" — people in the community who are knowledgeable about patients' and families' needs and are a link to other patient and family groups.
- Ask community and church leaders.
- Send notices to social and cultural clubs in the community.
- Place posters in community locations — at large employers, churches, housing projects, clinics, gas stations, social service agencies, and kindergarten registration.
- Send a letter home with school children.

Adapted from Jeppson, E. & Thomas, J. (1994). *Essential Allies: Families as Advisors*. Institute for Family-Centered Care, Bethesda, MD.

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A PATIENT AND FAMILY ADVISORY COUNCIL WORKPLAN: GETTING STARTED

A. Initial Steps for Starting a Council

1. Staff/stakeholders you need to help define the purpose of your advisory council and get support and/or commitment.

a. Physicians

Name	Role	Contact Info

b. Nurses

Name	Role	Contact Info

c. Social Workers

Name	Role	Contact Info

d. Therapists

Name	Role	Contact Info

e. Pharmacists

Name	Role	Contact Info

f. Others

Name	Role	Contact Info

g. One of the factors for ensuring success in an advisory council is support and commitment from senior leaders. Who are the senior leaders from whom you need support and commitment ?

Name	Role	Contact Info

2. Draft a purpose for your advisory council here (These should be your preliminary ideas about a purpose. The council members should be engaged to draft a purpose for the council so they own it):

-
-
-

B. Next Steps for Starting a Council

1. What stakeholders want a patient and family advisory council? Be specific. Those listed are examples.
   a. Board of Directors:
   b. Senior Leaders:
   c. Clinical service leaders:
   d. Staff:
   e. A blend of patients/family members who receive the following types of care:

2. Meeting Logistics
   a. How might the council meetings be structured?
      - Time of Day—ask patients, families, and staff about times that work:

   b. Meeting time—frequency (monthly, quarterly, etc.):

   c. Meeting place—where:

d. Parking:

e. Refreshments:

3. What support does your advisory council need?

a. Staff co-liaison/co-leads (list names):

b. Secretarial—who might provide this:

c. Parking covered by?

d. Budget—consider developing a budget to cover the following:
(list dollar amount estimates, if possible.)

- Food/Beverages
- Printing
- Postage
- Interpreter/translation services
- Parking/Transportation
- Childcare support (if needed)
- Stipends for members (not all councils wish to have stipends)

4. Advisory Council Subcommittees

a. Some councils identify work that could be done by a subgroup of the council. They will do the work and bring their plans to the council for input and sometimes, approval. Are there any subcommittees that you might need or wish to have? Examples are:

		Yes	No
•	Education	Yes	No
•	Communication	Yes	No
•	Membership	Yes	No
•	Facilities	Yes	No
•	Family Support	Yes	No
•	Newsletter	Yes	No

5. Operating guidelines

a. Draft a set of bylaws or operating guidelines might be provided for those putting the council together. They need to be tailored by your advisory council to the needs of the council. (Sample bylaws published in *Developing and Sustaining a Patient and Family Advisory Council*, available from the Institute for Family-Centered Care.)

b. What do you want included in the guidelines?

6. Membership

a. Number of council members

- Patient and family members (suggest 12 - 15)

- Staff members (suggest 3 - 4)

b. Member terms—define the number of years you expect someone to commit as a member (both staff and patient/family members).

- Example: 50/50 mix of 1 year and 2 year terms

c. Attendance expectations—define how often you expect members to attend.

- Example: 75% of meetings or 3 out of 4 meetings

7. Recruitment—Where and how you find members for the advisory council.

a. Where will you maintain the list of potential advisors for the advisory council and other collaborative initiatives? It is wise to maintain a computerized database of names, addresses, interests, etc. so you can easily track additional patients and family members who become involved.

b. Sources/contact persons for the recruitment of patient and family advisors.

Name	Role	Contact Info

c. Patient and Family Advisory Member Application forms. Samples are included in the publication *Developing and Sustaining a Patient and Family Advisory Council*, available from the Institute for Family-Centered Care.

8. Selection of members

a. Selection criteria to consider:

- Able to listen to differing opinions and share different points of view.
- Positive and supportive of the mission of the hospital.
- Share insights and information about their experiences in ways that others can learn from them.
- See beyond their own personal experiences.
- Show concern for more than one issue or agenda.
- Respect the perspectives of others.
- Speak comfortably in a group with candor.
- Interact well with many different kinds of people.
- Work in partnership with others.
- List other criteria you will use:
  - Diagnosis - have a variety of diagnoses dependent on the purpose of the council:
  - What services have the patients and family members used:
  - Diversity of backgrounds:

9. Orientation of Advisory Council Members

Many new members may never have served on a council or participated in collaborative projects with health care staff. Preparation and support are key factors to success.

a. Advisory Council Specific Orientation may include:

- Participant introductions.
- The hospital's history, mission, and values.
- Overview of facilities and services.
- Brief presentations by administrators or other key persons.
- Brief presentations by patient or family leaders who have served as council members or in other advisory roles.
- The role of the council.
- Roles and responsibilities of officers, staff liaison, family members, and staff members.
- Overview of a typical meeting structure — minutes, committee reports, typical agenda.
- Practical details — where to park, what to wear, what to bring to meetings.
- Attendance expectations.
- Additional items:

b. What are the objectives of your orientation?

- To introduce patients/advisory council members.
- To build an understanding of your organization's mission, values, vision, and partnerships.
- To provide photo tour of services or tour of the hospital facilities.
- To have patients/families define clear "purpose" of council.
- To acknowledge that some discussions may create tension or a sense of anxiety and that respectful deliberation is important.

c. What or whom do you want to include as part of your orientation?

- Key leaders of the hospital:
- Key leaders of the services:

C. **Maintaining and ensuring success with your advisory council.**

1. Tracking accomplishments

   a. How will you track your advisory council accomplishments?

      - Specific goals defined and achieved.
      - Minutes.
      - Agenda planning with clear closure and transition at the end of each meeting.
      - Good attendance at meetings.

   b. Celebrating success is a way to sustain a council. List ways you might celebrate successes.

      - Celebratory and acknowledgement activities should be provided with genuine feeling, match accomplishments, and be meaningful to persons involved.
      - Thank you's at meetings when appropriate.
      - Small token gift at the end of a member's term.

2. Planning for barriers and how to overcome them

   a. What barriers do you expect to encounter with establishing and maintaining your advisory council? List barriers and possible strategies to overcome them?

      - Barrier:
      - Barrier:
      - Barrier:
      - Barrier:

3. Agenda ideas for your first 2-3 council meetings.

   -
   -
   -
   -

4. Timeline

Activity	Targeted Completion Date
1. Initial Step for Starting a Council	
2. Next Steps to Starting a Council	
Meeting logistics	
Membership	
Recruitment	
Selection of Members	
Plans Developed for Preparing and Supporting	
New Council Members	
Project Dates for First Council Meeting	
3. Maintaining and Ensuring Success with Your Advisory Council	
Tracking Accomplishments	
Planning for Barriers	