



Introduction and approach to advocacy

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DISCLOSURE

➤ NONE





Advocacy - a human behavior

- Basic concepts of advocacy including identification and evaluation of better options, discussion and opinion making, convincing or lobbying and making joint efforts for a cause have been there since early days of humankind.
- Advocacy is a special ability of human mankind largely utilized in politics, sociology, law making and legal affairs and administration for centuries.



Healthcare advocacy

- Structured advocacy is a relatively new concept in health care.
- Important advocacy land marks may include patients' rights, physician's responsibilities, role of society and governments in health care.
- Health is a basic human right as per United Nations declaration. It took years of advocacy to make health as part of this declaration.
- In reality, most people living in the world do not have access to this right.
- Large scale, long term, sustainable advocacy efforts are needed at global level for provision of this right for all human beings.



Health advocacy as a tool

- Advocacy as a tool has been applied for centuries for development and growth of societies and countries. Law making is an outcome of extensive advocacy practices. The same is true for formation of all democracies, civil society organizations and function of governments.
- Structured health advocacy is a tool that converts human behavior into a strong, useful force to bring upon changes in society, system and infrastructure for the sake of patients.
- Eradication of chicken pox and almost complete eradication of polio from world map are prime examples of positive advocacy outcomes.



Neurology advocacy

- The burden of Neurological diseases is probably one of the highest in world but awareness among public and health care authorities is probably one of the lowest.
- Purpose of neurology advocacy is to improve patient care related to neurological diseases. Improved patient care is an outcome which needs improvement in many domains across all regions of world.
- These domains may include awareness, financing, perceptions, training of health care personnel's and regulations etc.
- Neurology advocacy is a structured effort in all these domains



Doctors as advocates

- During last two to three decades advocacy has evolved as an important area among health care professionals especially doctors.
- Doctors have realized that their job is not confined to write prescriptions or perform procedures only, but they could play an effective role in modification, evolution and development of the health care system.
- This realization, led to development of health care advocacy as a specialized area for doctors. Many fields especially pediatrics have done a great job in training pediatricians to become great doctors and advocates. This is a new and emerging role of doctors.
- As advocates, doctors become stakeholders of the whole health care system. They could be advocating for their patients, other doctors and other health care providers. It is important for doctors to learn advocacy skills early in their course of training.



Approach to advocacy

- Identify an issue
 - Objectives of advocacy
 - Advocacy message
 - Action planning
 - Advocacy leadership training
 - Outcome of advocacy
 - Counter advocacy
- 



Identify an advocacy issue

- What challenge or problem do you, your patients, and/or their caregivers face
 - Which of these issues can you personally have a role in changing
 - Which of these issues do you feel strongest about
 - This will keep you motivated!
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Objectives of advocacy

- Outcome of any advocacy project is highly dependent on its objectives. It is essential that objectives are well thought of, well discussed and well written and transparent for all participants.
- All objectives should be divided into short term and long term goals, also defined in primary and secondary goals.
- Advocacy projects could be of short duration and equipped with quickly achievable objectives but their impact lasts much longer.
- Short term objectives should outline outcome at the end of advocacy project while long term objectives should cover expected outcome after one or more years.



Advocacy message

- Whole advocacy campaign actually relies on a message. It should be positive, explicit and target oriented. Language must be understandable and target lay people.
- Negative or complicated message is one of the most important factors for a failed advocacy campaign.
- Outcome of an advocacy campaign relies upon the message. As much as possible help from media and communication experts, marketing and advertising personnel's should be sought before finalizing a message.
- Methods of delivery of message are as important as message itself.

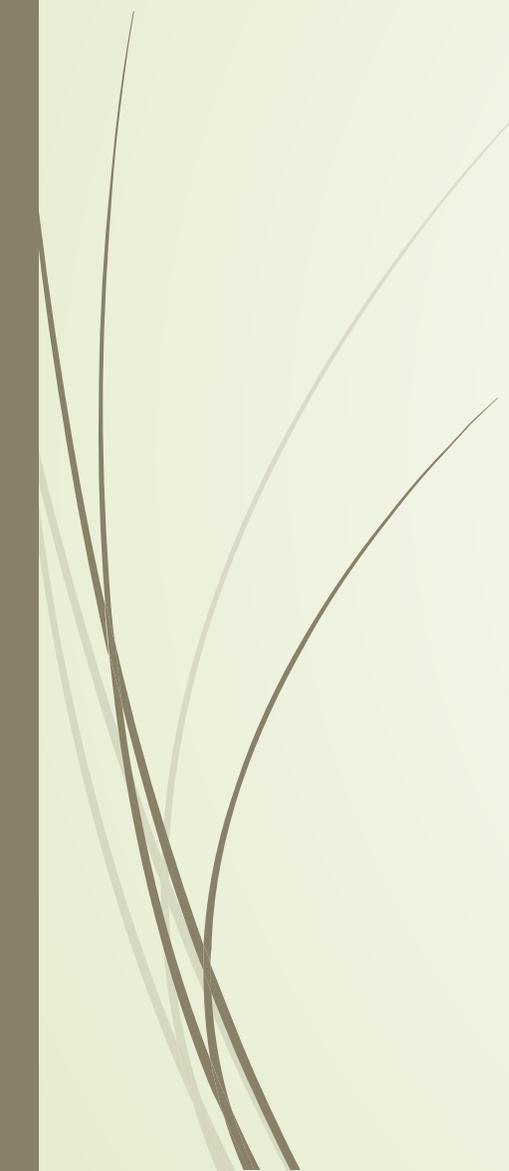


Action planning

- Identify all the Actions you will need to take to accomplish your Objective
- Identify the Target Audience for each Action
- Determine what Resources you will need to accomplish your Action
- Decide which measures will determine Success for your Action
- Set Target Dates for completion of each Action



Advocacy leadership training

- Structured
 - Action planning and execution
 - Team building
 - Media training
 - Communication with legislators
 - Financial management
 - Collaboration
 - Outcome assessment
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Outcome of advocacy

- ▶ Outcome is highly dependent on objectives. SMART Objectives have a high chance of being successful. There are many secondary objectives in addition to one or two primary objectives. Even if an advocacy project is unable to achieve primary objectives but there is always some success in achieving secondary objectives.
- ▶ There is no failure in advocacy campaign. In my opinion there is no bad outcome of an advocacy campaign if the objectives are directed toward welfare of patient's objectives and society. Starting an advocacy campaign or process in itself is great but positive outcomes of an advocacy project have a huge potential for society.



Outcome of advocacy

- Often it is hard to fully imagine overall outcome of an advocacy campaign. It is like a small seed which grows slowly and could become a fully grown tree over many years.
- “Seeds not only grow outwards in form of tree but they continue to grow inward after even after decades. “
- This growing capacity of a small seed is similar to an advocacy project. It continues to grow even after years.”
- Actually it is the long term results which will decide good or bad outcome of an advocacy campaign. A five year or longer follow up plan may be helpful in determining the outcome. Whenever starting an advocacy campaign, long term (five year or ten year) outcome should be a part of discussion even your campaign is only for three to six months.



Counter advocacy

- ▶ Impact of advocacy is multidirectional and may affect other stakeholders or persons/groups.
- ▶ As an advocate you have to be prepared to handle and address counter advocacy campaigns. While planning an advocacy campaign it should be worked out that what stake holders are going to be affected and if there is a counter advocacy campaign how it will be handled.
- ▶ Most of counter advocacy campaigns represent interests of a small group. Sometimes it could be stronger than advocacy campaign itself.
- ▶ It may be helpful to discuss issues and plans with other stake holders especially if they are going to be directly affected with your advocacy campaign.
- ▶ Your messages and campaign should not be directed towards another stake holder. Controversy may be helpful for media coverage but at the end advocacy goals are hard to achieve amid lots of controversies.

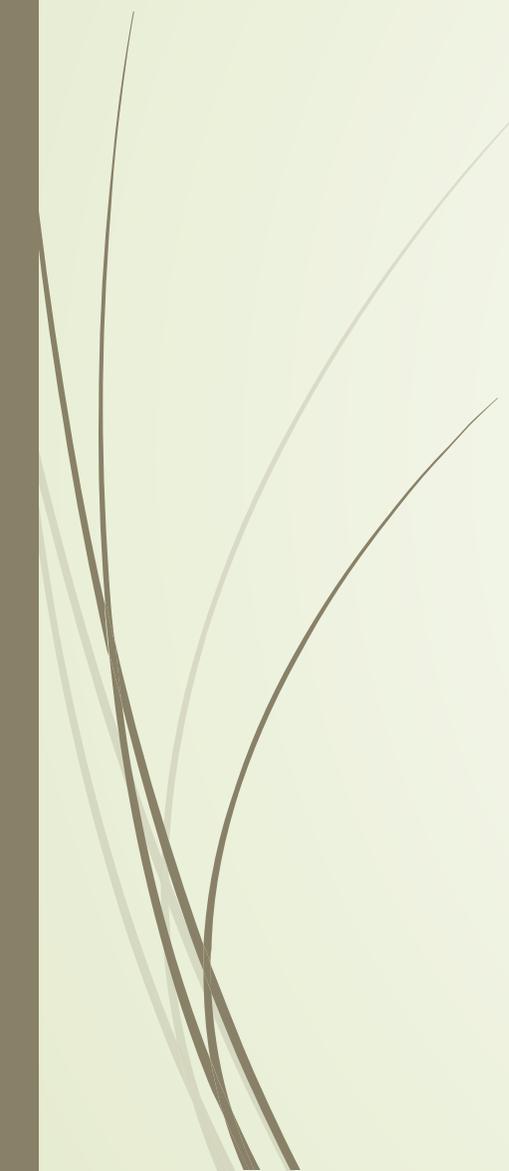


Doctors role in health advocacy

- Multidisciplinary care model
 - Role of advocacy in managed care
 - Social health care system
 - Doctors as leaders of health care system
 - Role of doctors in patient support groups
 - Professional organizations and health care advocacy
 - Doctors training in structured advocacy
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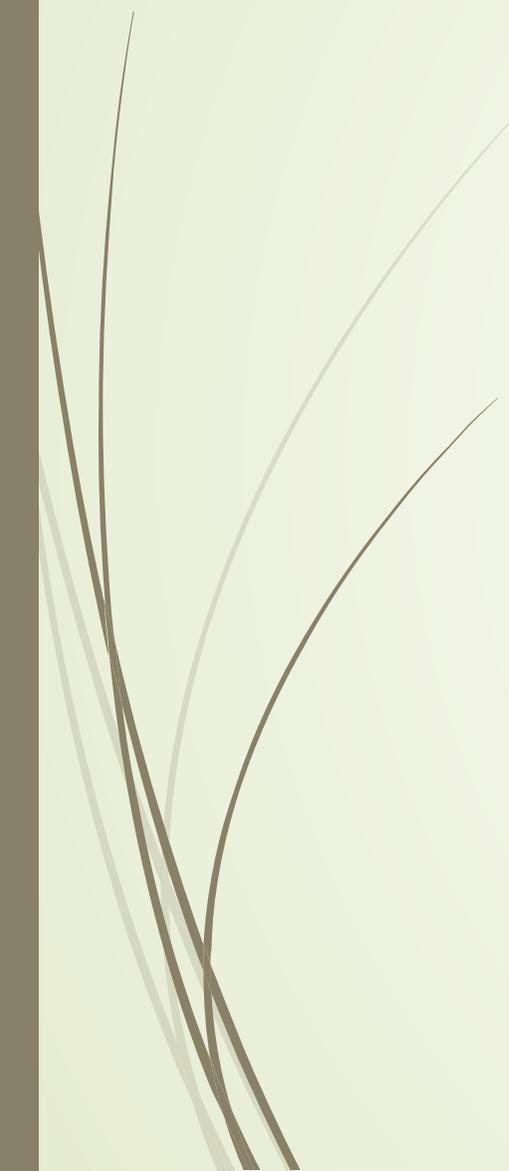


Multidisciplinary care model

- Multidisciplinary care means a patient will be seen by many specialists with diverse expertise. These may include nurses, physiotherapists, rehabilitation experts, nutritionists, financial counselors and social workers etc. There may be multiple doctors involved in care of a patient.
 - This model has modified doctor's role to a great extent. In most cases, doctors still have a role in diagnostic and therapeutic planning and execution but they are not the only one providing care. Care has shifted to a team approach in this model.
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Multidisciplinary care model

- Interaction between various care providers is mandatory. It takes more time and communication on part of physicians. Number of doctors in United States and Europe has delegated care responsibility to nurses, nurse practitioners or physician's Assistants especially in areas requiring multi-dimensional care.
 - Advocacy is challenging in this kind of business model but advantages include improved care quality, increased ability to influence processes and outcomes and overall better outcomes of advocacy activities
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Role of advocacy in managed care

- ▶ Health care has become a successful business model in many parts of world especially in United States. These health care models are run by business and financial experts with very little role of doctors. Many governments with huge health budgets are outsourcing part of their delivery to these managed care organizations. These companies may make millions of dollars as revenue or profit.
- ▶ Both doctors and patients have little say in this model and have to comply with rules and regulations made by this third party business organizations. ¹Primary objective of these organizations is to maximize profits, with quality of care as second or third priority. In this model, a large share of health care cost is not directly spent on patient care but towards management.



Role of advocacy in managed care

- This model could be improved by increasing role of patients and doctors both in decision making process related to diagnostic work up, therapeutic interventions and cost and availability of medication etc.
- Regulations and monitoring of this health care system is utmost important by local and national health care authorities. This may be an important area where advocacy can be very effective in bringing changes in managed care models



Social health care systems

- ▶ This is a popular model in European countries where 10-20 percent of budget is allocated for health and government is responsible to provide complete health care including prevention, home care, and social- support related to health care and even long term care including rehabilitation. These systems are run by government organizations like NHS in United Kingdom. Social health care systems are largely funded by tax payer's money and monitored by publicly elected officials.
- ▶ Doctor's role in this system is advisory. Sometimes doctors are part of management in this system and they have a stronger say as compared to managed care models.
- ▶ Advocacy could be effective in these systems with help of civil society, media and other stake holders



Doctors as leaders of health care system

- ▶ Most of world health experts are still doctors. Leadership of health care systems at large is provided by business professionals.
- ▶ Leadership training, advocacy, financial management and business solutions are unfamiliar topics at medical schools. Most doctors do not get any training related to understanding and managing businesses. Health care technology is another important area where doctor's role is largely limited to users of these technologies.
- ▶ These areas especially economics, regulations, lobbying and management are becoming more and more important for doctors especially if they want to have a leadership role in future health care model. These could be labeled as Social science of medicine. Adding social sciences in medical school's curriculum will redefine role of doctors in society.

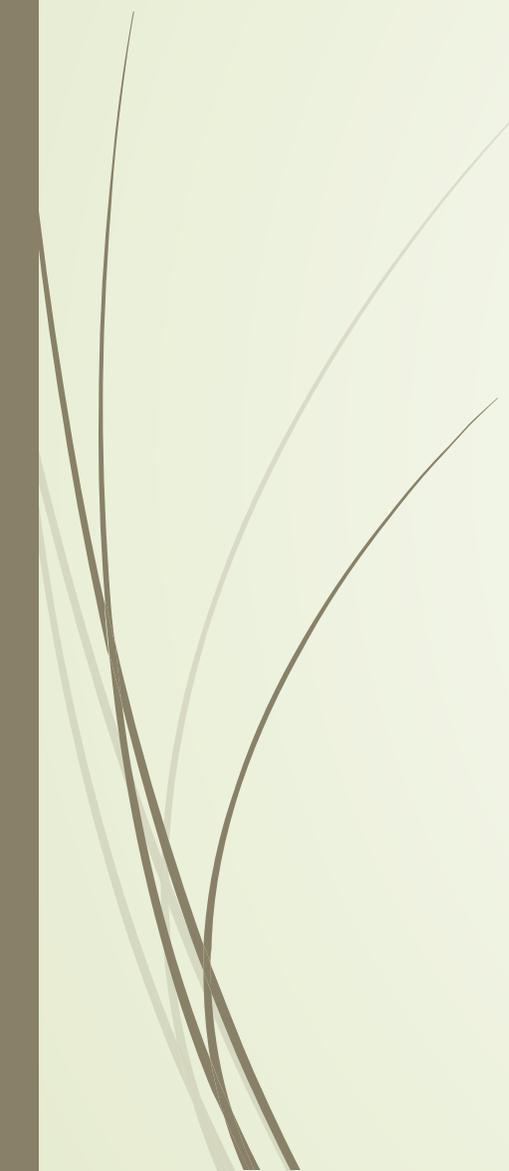


Role of doctors in patient support groups

- ▶ Patient support groups are a new dimension in health care advocacy. These groups are usually formed by patients and their family members. These groups could be highly effective and influential in advocacy. Doctors may play an extremely important role in establishing and guiding these groups and advising. These groups can play role in awareness, lobbying and media management for any advocacy project.
 - ▶ Patients are obviously most important stake holder in any health care system. These groups may define their role in future health care models. Patients support groups may be able to lobby and negotiate for better care with managed care authorities or even government authorities.
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Role of doctors in patient support groups

- In future, doctors could team up with patients support groups for many quality care initiatives. Professional societies should have a close communication with patients support groups. World Stroke Organization has adopted a model to have patients support organizations as directors for WSO.
 - Doctors could initiate, motivate and guide patients to start these groups or become supporters for active groups.
 - WHO has prepared a data base and guide for doctors for this support groups.
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Professional organizations and health care advocacy

- ▶ Many professional organizations have started advocacy as one of their main activity throughout year in addition to scientific teachings and trainings. American Academy of Neurology is a notable example. AAN started advocacy training (Palatucci program) more than a decade ago and has trained more than 300 neurologists as advocates. AAN started public policy and advocacy fellowship and AAN on hill program, when number of neurologists visit congressmen and senators offices for lobbying and advocacy on a pre-specified day.⁷⁻⁸
- ▶ World Federation of Neurology was effective in publishing of World Brain Atlas by WHO. WFN is working with WHO to define stroke as a brain disease. International league against epilepsy and International Beauru of epilepsy have been successful in developing WHO resolution for epilepsy. Many national societies are actively working with health authorities and governments for improved care for their patients.⁹ World Federation of Neurology also has an effective advocacy program including World Brain day and advocacy training workshops at World Congress of Neurology. Some of professional organizations especially nurse's organizations have transformed into strong advocacy groups.

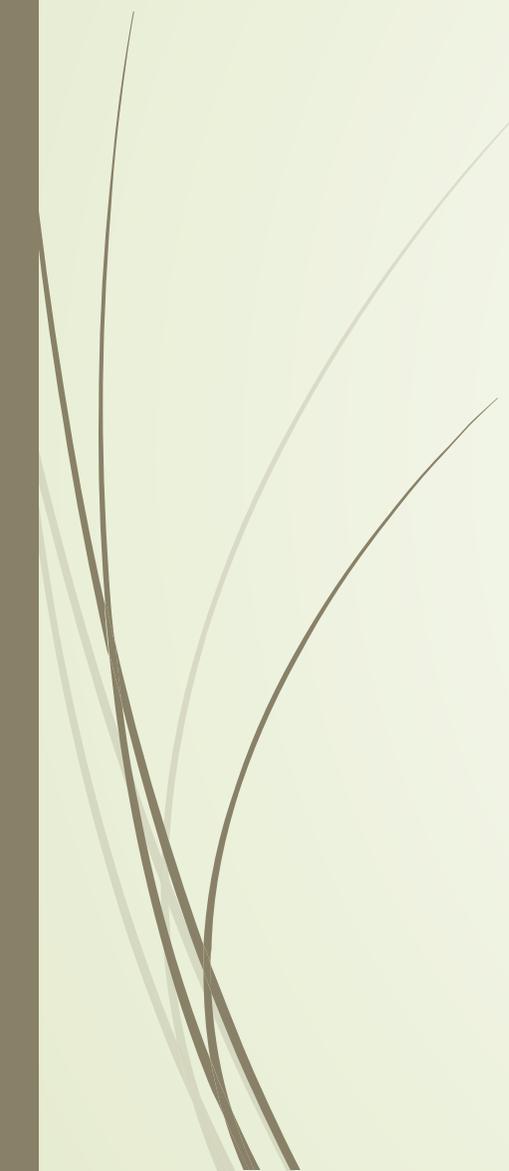


Doctors training in structured advocacy

- Advocacy is a skill. These skills could be developed by teaching, training, practice and mentoring. We have suggested that advocacy training should be a part of residency training programs especially Neurology residency programs. An introduction to Health care advocacy should be taught as a subject in medical schools and universities.
- Residency training programs are more suitable to incorporate advocacy leadership training. All residents should go through a 12-15 hours' workshop learning basic concepts and skills. This could be done through an online course. After workshop each trainee should start and accomplish an advocacy project under mentorship of a trained advocate. This could be added as module or project in a residency program. Same could be done for young neurologist and junior faculty members. AAN Palatucci advocacy leaders program is a good model for high impact short training workshop. Mentoring is extremely important for long term growth of these trainees.



Conclusion

- Advocacy is a skill
 - Doctors could play an important role in health care systems and health outcomes with this skill
 - Professional organizations and patients support groups have a strong role in advocacy
 - Advocacy outcomes could be long term
 - Structured advocacy training and mentoring improves outcomes of advocacy campaigns
 - We must have more and more neurologists involved in advocacy
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Advocacy in Neurology

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