Telehealth at Its Best

Transitioning a comprehensive psychosocial program to a virtual format
Life with Cancer, a program of the Inova Schar Cancer Institute, is a national model for cancer education, psychological health, nutrition, and wellness. Each month, it offers about 200 programs at five locations throughout Northern Virginia. A variety of classes, integrative therapies, wellness programs, individual counseling, and support groups are available to patients (adult and children) who are in treatment or survivorship. Family members and friends of patients are also welcome at many of these programs. Life with Cancer programs are evidence-based and reflect standards set by the American Society of Clinical Oncology, National Institutes of Health, National Comprehensive Cancer Network, Oncology Nursing Society, Society of Integrative Oncology, Oncology Dietitian Practice Group, and the American Institute for Cancer Research. Programs are designed to help individuals and the community understand cancer, its treatment and side effects, how to maintain physical and psychological health, and how to navigate illness and survivorship. Due to generous donations from the community and the commitment of the Inova Schar Cancer Institute that anyone impacted by cancer should have access to the tools they need to live better with cancer, all programs, except for psychiatry, are provided at no cost—regardless of where people receive treatment. For a comprehensive look at the Life with Cancer program, we refer readers to this article in the March/April 2018 Oncology Issues: accc-cancer.org/LifeWithCancer.

Global Pandemic Requires a Call to Action
Due to the COVID-19 pandemic and its associated risks for patients with cancer, all Life with Cancer programming was cancelled on Mar. 12, 2020. Staff, struggling with their own anxiety over personal safety, quickly went into action on how best to continue to meet the psychological and educational needs of patients and families. Although Life with Cancer had offered virtual one-on-one patient sessions for three years through Vidyo, a Health Insurance Portability and Accountability Act-compliant telehealth platform, patient reception had been tepid and services were only used by those who were too ill to travel or those who lived far from a Life with Cancer location. After COVID-19, requests for individual counseling, education, and nutritional consult sessions increased significantly.

Remarkably, between Apr. 1 and Apr. 30, 2020, Life with Cancer successfully transitioned more than 100 classes and groups to a virtual telehealth format, as well as all individual counseling and nutrition and educational consult sessions in which 3,025 patients and family members participated.
Initially, staff was anxious as Life with Cancer made the huge pivot to telehealth and wondered how this new therapeutic realm would affect best practices. Our experienced clinicians use visual cues—body language, breathing, muscle tension, and facial expressions—to direct support and interventions. Many worried how to remain attuned to these important aspects of care through a computer screen.

There was a sense of urgency for clinicians to learn how to navigate the features and functionality of the Zoom platform. Staff was keenly aware of their accountability to patients and families who were experiencing even higher levels of distress during the public health emergency. Our therapists, nurses, and dietitians familiarized themselves with Zoom Pro as quickly as possible, so that they, in turn, could act as Zoom experts for patients and families. Our staff held countless practice sessions to work through any challenges—on both their office and home networks, because most staff were now working off-site. With class location no longer a consideration, schedules were adjusted. For example, five caregiver groups offered throughout the system were condensed to three groups.

Though many team members described themselves as “technologically challenged” long before COVID-19, our clinicians learned from each other, supported each other, and faced fears and technological learning curves together—recognizing that it was all in an effort to continue to provide access and support to patients during this unprecedented time.

Remarkably, between Apr. 1 and Apr. 30, 2020, Life with Cancer successfully transitioned more than 100 classes and groups to a virtual telehealth format, as well as all individual counseling and nutrition and educational consult sessions in which 3,025 patients and family members participated. As of Sept. 1, 2020, in just five months, more than 7,200 individuals had participated in just the fitness classes.

**Lessons Learned**

**Fitness Classes**

Some of the first classes that were made available virtually were fitness related. Prior to going live in this virtual space, Life with Cancer offered more than 100 fitness programs each month ranging from cardio drumming, chair-based exercise, yoga, Tai Chi, Zumba, circuit training, and much more. It was a challenge to understand how these programs would work virtually—especially because the original format offered the in-person experience of improved health through movement and the bond that comes with being in a community of others who have shared experiences.

Because fitness classes were held at five different locations, many offered by contractors, moving these classes online posed several challenges for Life with Cancer.

Susan Gilmore, MS, ACSM-CET, program manager of fitness shared, “The transition from personalized, on-site training to streaming exercise instruction required a technically tricky change-over to re-orient program resources and technology. We moved from fitness training in a controlled environment with music, student cueing, and on-site equipment to instructing our patients in their home environment.”

Our instructors assessed class curriculums to determine how each could be adapted for live streaming, working out challenges with streaming simultaneous music and verbal cuing. Because instructors could no longer see and offer corrections, each class began with written and oral safety reminders and release waivers that participants had to sign prior to class.

Life with Cancer offered 52 virtual fitness classes within the first month. Response to the online format was amazingly favorable. Participation in fitness classes continues to grow as patients welcome the convenience and accessibility of at-home workouts. In fact, Life with Cancer has had almost twice as many students with fewer classes.

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Health System ensured that clinicians had access to the Health Insurance Portability and Accountability Act-compliant telehealth platform, Zoom Pro. One of the first steps was then to determine the state’s Department of Health telehealth regulations. Fortunately, many prior restrictions specific to licensure and accessibility were temporarily lifted due to the pandemic. The next step was to develop a policy for online etiquette that addressed privacy and security concerns for participants. The policy the team developed included the following:

- Participants must enroll for all Life with Cancer classes and programs through the Life with Cancer website registration page.
- Twenty-four hours before a class, registration is closed and a copy of the Zoom invitation is sent to all registrants.
- All curriculum materials are emailed to participants prior to the start of a class.
- To protect the privacy of personal emails (Zoom does not allow for blind-copy sending of a Zoom invitation), program facilitators create, copy, and then send the invitation to participants through their Inova Outlook blind copy function.
- Life with Cancer administrative staff are included in the email, so they can send invitations to accommodate late phone registrations.
- Participants are encouraged to create a Zoom sign-in using only their first name.
- Facilitators use the waiting room option and cross-check names against the list of invitees.
- The class is locked down once the group begins.
- Facilitators disable the screen sharing option for participants.
- For support programs, where information is shared among participants, all participants are asked to activate their cameras, although for several reasons, such as challenges with technology, some participants are unable to comply with this request.
- Participants are asked to ensure that they are in a private space, so no one else can hear or see the session; however, Life with Cancer is clear that privacy cannot be guaranteed.
- Participants are also advised that there is no recording or photos taken of sessions.
- Participant feedback is collected through Survey Monkey after the session ends.
One reason live streaming caught on so quickly and has been so successful has been the ability of our patients and instructors to adapt to the new platform,” shared Gilmore. “The live streaming allows our patients to continue to feel part of the Life with Cancer community. They can reach out to one another after class. Life with Cancer has virtual check-ins to encourage and support students in this ‘new-normal’ environment.”

Perhaps, this comment from one couple sums it all up, “Thank you for all you have done with the fitness program online! The life-affirming connections, the support from you and the teachers, the guided healing, is so greatly appreciated. I’m sure we all share this feeling!”

**Brain Fog Psychoeducational Program**

An education program addressing cancer-related cognitive impairment, also known as brain fog, was scheduled to start the week Life with Cancer was told it could no longer safely hold in-person classes. This four-week program:

- Presents the state of the research on cancer-related cognitive impairment.
- Discusses contributing factors such as anxiety, depression, and insomnia.
- Focuses on evidenced-based strategies to manage the effects of brain fog using compensatory strategies, lifestyle factors (exercise and nutrition), and psychological strategies and contemplative strategies, such as cognitive behavioral therapy and mindfulness.

The program is designed so that each participant completes an individualized brain fog plan at the end of the program. Due to this individualized component and the use of scales as part of the brain fog curriculum, staff required significant time to transition the class to an online format. Typically, one therapist supports the group through all four presentations, but for virtual classes, two therapists were needed to launch the program online.

From a program delivery standpoint, there was also a learning curve. In an in-person group, welcoming participants to the group is easily managed; with the move to Zoom, more attention is required for this once simple task. In the program’s first meeting, an oncology nurse navigator shared background information and the current state of research on cancer-related cognitive impairment. Seven of the 10 registered participants signed on to the Zoom meeting. Some signed on with their name as “iPad” or “iPhone.” For security reasons, the moderator verified participants’ names by offering a private chat with the moderator. Participants who did not respond to these requests were removed from the group. Though this action was intended to safeguard participants’ privacy, the moderator wondered whether removing people from the group might negatively impact the open and inviting environment.

The nurse navigator then delivered her lecture of educationally dense and potentially emotionally charged material. Although she encouraged questions and offered the group a break, more and more participants turned off their cameras as the class went on. This experienced facilitator was concerned about aspects of brain fog that could make virtual learning difficult; for example, executive function changes that affect emotional regulation, concentration, and attention. Was this the right group for this virtual platform? Without participant feedback, it was difficult to come to any conclusions. The navigator also commented that lack of visual cues from participants, which normally helped pace and target her talk, left her feeling exasperated and she only imagined that the participants shared a similar feeling. This first virtual class did not look like a success.

Armed with this information, the oncology clinical therapist who led the second session emailed participants prior to the start of the session and asked them to share their video. This request was an effort to increase social interaction and facilitate concentration, learning, and physiological and emotional regulation based on the polyvagal theory by Stephen Porges.1 Though one group member would not share their video due to security concerns, other group members complied. The facilitator also increased the number of times the group entered discussions, meaning that the slide deck was “closed” and the group returned to a format where all participants were seen on the screen. Although less content was delivered due to this approach, engagement seemed higher. One participant said that after the second session she felt “less defective and understood the brain better, how it was affected by emotions, and what was going on in the body.” Though the facilitator shared that there was still a preference for an in-person group, it was helpful to have participants share their video and have more planned discussions.

**Integrative Psychosocial Oncology Program**

Life with Cancer has developed a novel, four-program curriculum designed to build emotional coping skills and resilience from cognitive, mindfulness-based, and contemplative perspectives called the Integrative Psycho-Oncology Program. Each program...
in the curriculum is five to eight weeks long for a total of roughly eight months. The curriculum focuses on the different strategies of emotional regulation, including cognitive, mindfulness, compassion, and meaning making. One program in the curriculum, “Mind Over Matter,” was developed by Life with Cancer, and the other three, Mindfulness-Based Cancer Recovery, Compassion Cultivation Training, and Meaning-Centered Psychotherapy, were created by institutions such as the University of Calgary, the Stanford Center for Compassion and Altruism Research and Education, and Memorial Sloan Kettering. The programs are designed to be taken in order because the skills learned in earlier programs build a foundation for the experiences and skills learned in the later programs.

At the onset of COVID-related restrictions, one cohort had just finished Compassion Cultivation Training and was scheduled to start Meaning-Centered Psychotherapy. Another cohort had completed the orientation for Mindfulness-Based Cancer Recovery but had not started on program content. Lastly, we offered a monthly drop-in group for anyone who completed the second program in the curriculum, Mindfulness-Based Cancer Recovery. This drop-in group was the easiest to conceptualize in an online format. There were no new skills being introduced, and many of the regular group members knew each other and were familiar with the meditation and mindfulness content. The drop-in group was designed to maintain connection and offer a more formal opportunity to practice. Members of this group shared their appreciation for the opportunity to connect and meditate together, including one participant who said, “I feel that I had special training for this situation.” She shared that the Integrative Psycho-Oncology Program programs, collectively, had taught her
coping skills and that she could trust those skills and her ability to manage uncertainty and fear—the feelings that COVID-19 brought up in her. The drop-in group often closes with a loving kindness meditation and did so in the virtual format as well, promoting shared feelings of connection, gratitude, and satisfaction.

Offering an eight-week experiential program like Mindfulness-Based Cancer Recovery in an online format was more challenging. These groups had met only once in person before making the switch to the virtual environment. Each session had a discussion component, but most session time is spent in meditation or in other mindfulness practices, such as mindful movement, yoga, or walking a labyrinth. The labyrinth is a walking meditation that offers participants more time for silence and to focus on one intention. It is a different form of movement meditation that provides the opportunity for a spiritual connection or connection to an entity larger than the self. How does one walk a labyrinth virtually? Our team members began to explore alternate possibilities. One facilitator gave his participants two different Zoom links for the labyrinth session. One link, he explained, was for the first part of the session—the opening meditation and discussion—and he encouraged patients to use video. The second link was to call in by phone only, so that participants could be mobile and hands free. He invited participants to place the call while outside for a walking meditation in their own outdoor environment. The facilitator was then able to craft the meditation to hold all of the components of the original experience of walking the labyrinth by relying on the exploration of the senses and walking for structure, rather than the structure and intent of walking a labyrinth. Group members shared their enjoyment of this experience and said that they have done similar practices on their own after participating in the group.

Unlike the other Integrative Psycho-Oncology Program classes, the Meaning-Centered Psychotherapy group was intended to be initiated in an online format. Luckily, some participants in the program had also participated in the Mindfulness-Based Cancer Recovery drop-in group. The potential challenge of this group is that the content is often deeply personal and shared very early in the group formation process. Facilitators worked, as usual, to create connection and a sense of safety but felt challenged by the virtual setting. The group is led by two experienced facilitators who noted that they had to work harder to stay connected to each other and to the participants in the group because they realized much of their communication, and therefore coordination, was nonverbal. The first two of the eight Meaning-Centered Psychotherapy sessions were challenging. In the third session, the facilitators focused on their experiences with this group and invited conversation on what was and what was not working. Finally, the group began to coalesce. Many factors may be at work here—a slightly smaller group attended the third session, the content of the session may have been easier to connect to, or, three sessions in, the group was naturally forming.

“I do think participating in a virtual group does change the dynamics. Physical presence allows for more easily shared compassion,” wrote one participant. Another wrote, “Virtual participation also makes it difficult to realize when to speak. When physically present you see others’ expressions and readiness to speak and you can gauge when to jump in.” However, the overall response to the Meaning-Centered Psychotherapy sessions was positive.

Support and Networking Groups
Three Life with Cancer support groups were held virtually even before the pandemic: The Lung Cancer Group, Weight Management for Women Who are Survivors of Breast Cancer, and Young Women with Breast Cancer. Interestingly, the Young Women with Breast Cancer group, which had been held in person at one location for many years, had been cancelled for several months due to low registration numbers. When Life with Cancer offered the support group online, nine women signed up for the first virtual session and requested that the group continue to use this format going forward. Participants shared that their busy schedules and the needs of young children had prevented them from being able to attend an in-person group.

During the first virtual meeting of Weight Management for Women Who are Survivors of Breast Cancer, one participant commented, “It was a bit awkward at first as I was inexperienced with Zoom.” Another wrote, “Conversation lagged initially as there were several new members to the group but got better as the 90 minutes passed. The Life with Cancer staff was very good (as usual!) with providing info and answers to questions. I plan on trying the group again if it’s still online next month. Thank you so much for the continued support!”

The first virtual Lung Cancer Group meeting had 19 participants, who offered many grateful comments. “It was great to be able to connect with everyone in a safe environment. I think the facilitators did a wonderful job of making sure everyone had a chance to share and not talk over others. For a first run, it was fantastic!”

Educational Groups
Life with Cancer offers several pre-surgical classes for patients, as well as rehabilitation classes that focus on survivorship needs. The virtual pre-surgical classes were significantly smaller than the usual in-person group largely due to the number of surgeries scheduled, which decreased due to COVID-19. Patients welcomed the information and interactions. As with other programming, classes worked better when participants left their videos on. Setting this expectation up front and including it in the class description increased patient participation and engagement. The oncology nurse navigator who facilitates the class reported that the level of comfort and engagement among patients was the same as in the in-person classes. Facilitators strove to provide an open atmosphere and found that participants also engaged with each other, which reflected a similar tone to the in-person classes. Some participants mentioned that it was much easier to involve their caregivers in the virtual process because they did not have to coordinate logistics and schedules. A few participants were very appreciative of the virtual pre-surgical class because they...
would not have felt comfortable attending one in person and risking exposure to COVID-19.

The new online format did pose challenges and necessary changes. Traditionally, facilitators distributed informational material during class and offered hands-on demonstrations to participants. As a work-around, facilitators emailed information the day before the class, including PowerPoint slides, a drain record, and other basic information. Sending the information prior to the virtual session allowed facilitators time to help participants who had trouble opening or accessing materials. For information and supplies that were unable to be sent electronically, facilitators created pre-op kits (educational booklets, drain belt, Hibiclens, and/or Ensure) that the patients picked up from their surgeon’s office, the hospital front desk, or by driving up to the front of the Life with Cancer Family Center so the package could be handed off into a car window. It was also important that facilitators had a good grasp of Zoom functions because they needed to switch between sharing PowerPoint slides and full-screen demonstrations of teachings, such as drain or ostomy care, throughout the class.

**Virtual Support of Children and Adolescents Impacted by Cancer**

Life with Cancer’s Child and Adolescent Program offers psycho-education, parent consultations, individual counseling, group therapy, resources, and other programs to support children and adolescents impacted by cancer (e.g., those diagnosed with cancer or whose family members are diagnosed with cancer) and their parents and caregivers. Our licensed clinical oncology therapists provide evidence-based therapies to help with adjustment, anxiety, mood and behavioral changes, grief and loss, and more.

Prior to the COVID-19 pandemic, services were offered in several locations including the outpatient Life with Cancer Family Center, Inova Schar Cancer Institute pediatric oncology clinic, and the Inova Children’s Hospital pediatric oncology inpatient unit. As a result of necessary social distancing regulations, national stay at home orders, and changes to clinic and inpatient policies, Life with Cancer leadership quickly embraced new models of service delivery, like telehealth, to continue providing the highest level of care in this rapidly changing environment.

Converting to telehealth brought unique challenges to our pediatric providers, because virtual formats were not feasible for some of our previous models and modalities of care. For example, we made the difficult decision to suspend our in-person Touchstone Grief Group, a six-week psychoeducational group for children six to twelve years old who have lost a loved one to cancer. There are few evidence-based guidelines for conducting group teletherapy to school-aged children and most of the existing program curriculum involved hands-on activities. As an alternative, Amanda Thompson, PhD, the chief of Pediatric Psychology at Life with Cancer prepared and recorded two educational webinars: 1) the typical emotional and behavioral reactions that are common among grieving children and 2) strategies for supporting children as they grieve. Both videos were immediately made available to parents via the Life with Cancer website. One benefit to this format was that all caregivers of grieving children could access the videos—not just those who had planned to attend the grief group, which typically includes six to eight families. Parents of grieving children are offered individual parent consultation sessions through Zoom, and older children and adolescents can receive one-on-one grief counseling online. This transition has proven successful, as illustrated through the words of a grateful grandmother, who is now the guardian of her 17-year-old grandson after he lost his mother to cervical cancer prior to the pandemic: “He always seems a bit lighter after he speaks with you. He isn’t much of a talker with anyone else, and it’s a challenge for me to gauge how he’s doing. Thank you for finding an alternative way to continue working with him. I always notice a little more pep from him after you meet. He is a difficult one to get to open up at all, so I’m truly grateful for you, especially during this pandemic.”

As with other groups, COVID-19 and the conversion to telehealth required us to alter our approach to individual counseling for children. Dr. Thompson explains, “While adolescents generally have great comfort and familiarity with technology and easily made the transition to the virtual format, we knew it was going to be much more difficult for younger children to stay engaged via telehealth. This is especially true for children who struggle with attention or hyperactivity.”

In addition, child-focused approaches like play therapy do not translate well online, and we do not have sufficient evidence to support its effectiveness in the virtual format. As a result, for our younger children, we have largely switched to offering parental consultations for managing child anxiety, stress, grief, and behavior problems—challenges that have been exacerbated by the required quarantine, school closures and cancellations of major milestones and/or events, and societal focus on illness and collective loss.

“Our goal is to support parents, normalize these challenges, and empower them with evidence-based skills that they can use to coach their children through these difficult times,” Dr. Thompson explains. She describes the success of telehealth in working with the young mother of a five-year-old girl, who lost her father just prior to the pandemic and was struggling with more frequent and intense tantrums and difficulty sleeping alone at night. “After five virtual sessions, where I provided this overwhelmed and grieving (yet very motivated) wife and mother some concrete and evidence-based behavioral management strategies, this young girl is sleeping through the night in her bed and hasn’t had a tantrum in two weeks,” says Dr. Thompson.

Because the children and adolescents we work with are among the most vulnerable, Dr. Thompson notes that there are important considerations for providing telehealth services to children and adolescents, including:

- Thoughtfully considering and/or evaluating whether the child can participate meaningfully in telehealth, which may vary by maturity, presenting issue, physical limitations, attention/concentration, and hyperactivity.
- Ensuring parental presence in the home and/or availability during a session in case of crisis, particularly for adolescents.
who generally choose to meet without a caregiver present.
- Having a clear plan for addressing safety issues that may arise during a session.
- Being flexible (e.g., adjusting your expectations, like the length of sessions if you are having a hard time keeping the child engaged).
- Taking time to build rapport in the virtual environment.

Regarding the latter, Dr. Thompson shares, “Even if you’ve met previously in person, it’s important to take the time to make sure the child feels comfortable in this new environment. Evidence shows that kids who are initially anxious about telehealth tend to feel less distressed after 10 to 15 minutes.”

Oncology therapists have used a number of approaches that take advantage of the virtual platform to promote rapport building, including asking participants to show off their room or preferred toys and belongings, having the child color or draw and then share their picture, using the whiteboard feature of Zoom to play tic-tac-toe or other games, and/or playing virtual Uno while talking.

As the COVID-19 crisis continues, Life with Cancer will look for new ways to support children and families impacted by cancer by leveraging technology and virtual platforms. Therapists are now piloting a support group for parents of pediatric oncology patients and will be launching another support group for adolescents currently in treatment for cancer. The team is learning from their successes, while understanding the limitations within pediatrics, and maintaining a growth mindset to be well positioned to care for children and families in the post-COVID healthcare landscape.

Receiving an email from a patient who has taken the time to craft a heartfelt thank-you that acknowledges the importance of the program and continued connection during what feels like an entirely disconnected time right now validates every effort that was made by Life with Cancer along the way.

Need for Self-Care
Staff quickly determined that though doable, virtual sessions required additional energy and focus and said that they often felt depleted afterwards. The larger virtual groups added additional variables and required steps for both facilitators and participants. Individual virtual counseling required a thoughtfulness toward body language usage because therapists often speak or gesture with their hands and at times hands were below the camera for video visuals. The Life with Cancer team initially scheduled daily meetings to discuss challenges, brainstorm, and problem solve. There was a mutual feeling of “one team,” because all facilitators were learning and implementing virtual programs at the same time. We quickly recognized a continued need for increased patience and flexibility. As a result of all of these new stressors related to virtual programming, it became critical to renew a focus on staff self-care. We heard from some of our clinicians, who are mental health and healthcare experts, that it was hard for them to ask for help. We tried to create intentional spaces through large group and smaller team meetings for Life with Cancer team members to discuss the challenges this new virtual environment brought, in addition to the added stress and fear from the unknowns of the COVID-19 pandemic. We set up a buddy system, pairing staff one on one; organized regular team lunches that are optional; and held after-hours fun, Zoom sessions to play Pictionary and other games. All of these strategies had varying successes. Some of the challenges staff were experiencing (i.e., exhaustion, disconnection, and isolation) are inherent to communicating over video and simply could not be resolved with more video time. We continue to work on supporting our staff as they provide support to patients and families and as we all adjust to this new normal. Given that our traditional ways of coming together as a team in person are not feasible ways to find connections and small successes within work, identifying creative ways outside of work has become even more important.

Looking Toward the Future

Like many organizations, the COVID-19 pandemic forced Life with Cancer into a virtual space much quicker than anticipated. Luckily, our staff have been contemplating this move for several years now. Keenly aware of the therapeutic value of personal connection, closeness, and community building that comes from sharing physical space, the team was surprised to learn the extent to which online programming can meet some of these needs while also eliminating barriers. Given that the pandemic has no end in sight and the immunocompromised nature of oncology patients, it is likely that in-person groups will not be possible for some time and virtual groups will continue to be a viable option to meet the psychological, educational, and physical health needs of patients. For some, offering counseling sessions over Zoom is more favorable than the current in-person alternative where facilitators and patients both don masks, especially when considering the important nuances of body language and facial expressions. The learning curve has been steep and continues to grow at an exponential speed. Fortunately, telehealth can help overcome access issues related to time and travel for staff and patients and other issues, like a limited amount of physical space for classes. As Life with Cancer moves forward, the team will thoughtfully consider what programs can remain online, what new programs are needed, and what challenges will occur when virtual care is transitioned back to in-person care. One thing is certain—Life with Cancer has been changed forever as an organization and will continue to provide programing virtually because it is in the best interest of our patients and families.

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Reference